

CARE MATTERS

A guide to the Carers
(Equal Opportunities)
Act 2004

Philippa Russell

For The Elizabeth
Nuffield Educational Fund

May 2007



The
Nuffield
Foundation

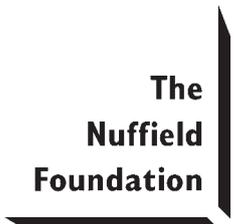
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Contents

Foreword	2
Introduction	3
1. The Carers (Equal Opportunities) Act 2004 in context	5
2. The Carers (Equal Opportunities) Act 2004 in detail	11
3. The Carers (Equal Opportunities) Act 2004 – key duties	13
4. Family carers	15
5. Finance and implementation	27
6. The Mental Capacity Act 2005	35
7. The Disability Discrimination Acts 1995 and 2005	37
8. The Human Rights Act 1998	47
9. Welfare Reform Legislation	49
10. Looking to the future	53
11. Appendices	
11.1 Carers' assessments – what's in it for you?	55
11.2 A checklist for positive practice	60
11.3 Paying for care	62
11.4 Further information	64
12. Notes	68

Foreword

The publication of the ENEF guide for adult learners with caring responsibilities raised awareness of the continuing challenges facing adult learners who are caring for a disabled child or other relative. The publication of the guide highlighted the 'postal lottery' of support for adult learners and carers. It also coincided with the implementation of the Carers (Equal Opportunities) Act 2004, which belatedly raised the profile of family carers as adult learners and for the first time required local authorities to include and respect family carers' wishes to learn or work within the Carer's Assessment process.

In the light of an identified policy gap (but also new opportunities), ENEF agreed to support a new project in order to raise awareness of the duties set out in the Carers (Equal Opportunities) Act 2004 and related legislation and guidance (in particular proposals around welfare reform set out within the Welfare Reform Bill and the Childcare Act 2006).¹ In developing this guide, we have worked with partner local authorities and organisations of family carers or parents of disabled children with a view to producing a practical guide which is 'fit for purpose' and will enable local services to respond more proactively and strategically to the changing needs of family carers who wish to work or study. In particular we wished to raise the profile of adult learners with caring responsibilities across local government and in further and adult education. Many family carers told us in the course of our work that they felt marginalised and socially excluded. They wanted practical support with their caring roles but they importantly also wanted practical support for their own professional development and role as active citizens.

The Government has recently launched a review of Independent Living, as part of the work-plan for the new Office of Disability Issues. As one mother of an adult disabled son explained:

The Government's proposals for welfare reform set out education, training and employment as the cornerstones of successful adult life. I didn't want respite for my son, he didn't want to be 'looked after'. We both wanted a life. We wanted to make a

contribution. In helping me (and my son!) to train and work, the Government has in turn made us me less reliant on expensive social services. But we wish it had not been such a challenge to get the lives we wanted!

The Carers (Equal Opportunities) Act 2004 reflects the Government commitment to independent living and maximising potential. It is integral to wider proposals for the reform of health and social care. But it poses challenges and will require active strategic partnerships between local authorities, family carers and the people they support. This guide considers the Act and its implications with specific reference to improving life chances (rather than providing traditional models of care). It also explores positive strategies for the achievement of equality of opportunity and sets out the relationship between (and contributions from) other relevant legislation and policy development.

A key element in this project has been raising awareness of duties under the Disability Discrimination Acts 1995 and 2005, in particular of the Disability Equality Duty which was implemented in December 2006. The end product is a guide, which provides a framework for local action around the Carers (Equal Opportunities) Act 2004 and related legislation.

Recognising the importance of a multi-agency approach, the guide also seeks to raise the profile of adult learners with caring responsibilities within the local authorities' wider duties, eg, development of Children's Centres, 'Extended Schools', accessible leisure services, use of the Carers' Grant and related Carers' Strategy. It also addresses the interface between local authority delivery of social care and the local Children's Information Services, Job Centre Plus and FE and adult education providers in order to improve local options for childcare and family support and to promote support for learning as an integral component in wider policies and planning for children's services and carers' strategies.

Introduction

The Carers (Equal Opportunities) Act 2004 marks a new approach to support for family carers in England and Wales.

When the Minister with responsibility for Social Care addressed the House of Commons Standing Committee on what would become the Carers (Equal Opportunities) Act 2004, he was underlining a major challenge for social care as then organised:

We want carers who wish to work to have the right to work. For those carers who wish to take part in education, we want that to be built into the care plans that are put together for the person for whom they are caring. We want carers to have the opportunity to engage in leisure activities (including adult education and learning) ... the fundamental life expectations that all members of the Committee would expect for ourselves and for our families are often denied to carers because of their responsibilities and duties.²

A House of Commons Research Paper commissioned to inform the new legislation³ had noted with some surprise that ‘the assumption was often made [under previous carers’ legislation] that there was no choice but that the carer should give up all prospects of education, training or work’. With the implementation of the Carers (Equal Opportunities) Act 2004, this automatic assumption that family carers would opt out of employment (and any related education or training) was no longer lawful.

The importance of carers being encouraged into work (or remaining in work) and participating in education and training is central to the Government’s proposals for welfare reform. Therefore the Carers (Equal Opportunities) Act breaks new ground in requiring local authorities, when carrying out a Carer’s Assessment, to consider the family carer’s need to engage in education, training and employment, as well as having access to leisure and short break activities.

As Luke Clements⁴ commented, when reviewing the range of legislation relating to family carers:

This new Act, for the first time, marks a major cultural shift in the way in which carers are viewed. It marks a shift in seeing carers not so much as unpaid providers of care services for disabled people but rather as people in their own right, with the right to study and work like everyone else. Carers have too often been socially excluded and (like the disabled people for whom they care) denied the life chances that are offered to other people ... we now have the opportunity to change lives and let carers have the ambitions they deserve.

The publication of the ENEF guide for adult learners⁵ with caring responsibilities raised awareness of the continuing challenges facing adult learners who are caring for a disabled child or other relative. The publication of the guide highlighted the ‘postal lottery’ of support for adult learners and carers. It also coincided with the implementation of the Carers (Equal Opportunities) Act 2004, which belatedly raised the profile of family carers as adult learners and for the first time required local authorities to include and respect family carers’ wishes to learn or work within the Carer’s Assessment process.

In the light of an identified policy gap (but also new opportunities), ENEF agreed to support a new project in order to:

- Raise awareness of the duties set out in the Carers (Equal Opportunities) Act 2004 and related legislation and guidance (in particular the Childcare Act 2006).⁶
- Work in partnership with carers’ and disability organisations and interested local authorities in raising awareness of the legislation, its implications for family carers and to develop a strategic plan for its delivery.
- In doing so, to raise the profile of adult learners with caring responsibilities within the local authorities’ wider duties, eg, development of Children’s Centres, ‘Extended Schools’, accessible leisure services, use of the Carers’ Grant and related Carers’ Strategy.

- To take account of major changes in support for family carers wishing to study and work proposed within the Government's 'Welfare to Work' reforms. These will have considerable implications for local authorities and family carers and should improve both local options for childcare and family support and actively promote support for learning as an integral component in wider policies and planning for children's services and carers' strategies.
- To assist local authorities with regard to their disability equality duties under the DDA 2005 and to produce accessibility strategies to progressively improve the range of options for disabled family members.
- To produce a practical guide for local authorities and the voluntary sector (and relevant partners) with regard to the implementation of the Carers (Equal Opportunities) Act 2004.

We are grateful to the local authorities, the education and training providers and the family carers' and disability organisations at local and national level – in particular the national umbrella organisation, the National Network of Family Carers, which contributed to this guide. In particular we welcome a new and dynamic approach to support for carers. The Carers (Equal Opportunities) Act 2004, the related disability legislation (in particular the Disability Equality Duty in the Disability Discrimination Act 2005) and the proposed reforms of both welfare and social care transform expectations of carers. They acknowledge that many family carers wish to continue in education, training and employment and that, as one Family Carers Support Group commented in our survey:

Historically being a carer was seen as the end of an active independent life. It was a valued role but one which involved sacrifice and often poverty. Family care was a private activity – often inadequate and frequently provided in an 'ad hoc' way. But we are seeing changing expectations. Caring is now compatible with 'having a life'. Caring is enhanced not diminished when the family carer can continue with study, work, leisure activities. The 'cared for' person values a lively carer – and families usually need the income generated by employment! Most importantly we see the Carers (Equal Opportunities) Act as bringing family care into the 21st century. It is what the Prime Minister would describe as 'improving life chances' – and it is what our members would call 'the right to full citizenship'.

1 The Carers (Equal Opportunities) Act 2004 in context

Who cares? Some statistical evidence on family carers in the UK⁸

Evidence from the 2001 Census gives powerful messages about the situation of family carers.

The Census shows us that:

- Across England and Wales, 10% of the population (around 5.2 million people) are carers looking after relatives, friends or neighbours on a regular but unpaid basis. 3.9 million of these carers are men and women of working age. There are higher concentrations of carers in some parts of the UK, in particular parts of the North East and North West, Cornwall, Wales and Yorkshire.
- Caring occurs at all ages, but is most common amongst women and men aged 45–64 years of age. Almost a quarter of women in their 50s are carers.
- Children (perhaps surprisingly!) are the fastest growing group of disabled people because of improved health care and survival rates. Disabled children are now likely to remain in the family home through childhood into adult life and thereby have considerable impact on parents' ability to work. Research indicates that 55% of families with a disabled child live in, or have lived at, the margins of poverty.⁹
- There is a marked relationship between poor health and substantial amounts of caring across all groups.
- With reference to employment, 1.5 million carers are in full-time employment, with nearly 700,000 carers in part-time employment. Women carers have much higher rates of part-time employment than men.
- Particularly high rates of caring are found amongst younger people of working age from the Pakistani and Bangladeshi communities. 1 in 8 young Pakistani and Bangladeshi women are carers.
- Working carers are more likely to be unqualified and less likely to have university degrees than other employed people.

- Working carers of both sexes are more likely to be clustered in lower level jobs than other workers and appear to have less access to higher level positions or opportunities to train or qualify for them.
- Working carers (especially women) are more likely than other workers to work from or near home.

The Census data gives clear messages about the need to actively include carers within Government and other strategies to raise expectations, create opportunities for further education and training and to support career development rather than random work placements. As Carers UK notes:

This data (within the 2001 Census) suggests that carers need to be specially targeted in skills policy development, as a group whose access to skills and qualifications may have been neglected in the past. We should be seriously concerned that women (and some men) with heavy caring responsibilities should be clustered in lower level jobs which do not necessarily match either their skill level or their aspirations.

Messages from the ENEF Surveys

As the data from the 2001 National Census reminds us, providing substantial amounts of care can have a detrimental impact upon training and employment opportunities. In practice, family carers of a disabled relative (whether child or adult) have very similar information needs when looking for childcare or other support to enable them to study, work or enjoy leisure activities. Two surveys carried out in 2005 and 2006 on behalf of the Elizabeth Nuffield Education Fund found that family carers continued to experience major barriers in accessing learning, training and employment, largely because of the lack of appropriate accessible and affordable care.

The surveys identified a number of particular challenges for family carers, including:

1. **Getting the appropriate level of DLA, or other benefits or tax credits intended to underpin the costs of care.** Some families of disabled children still do not understand the Tax Credit system. Families felt that ‘being poor before you start learning’ discouraged them from finding out what would support adult learning.
2. **Mothers (and some fathers) told us that they had to change careers because of their relative’s care needs.** In most cases, this involved additional study and qualifications. A major barrier was persuading local authorities to give discretionary funding for courses (in particular distance learning). Another potential barrier to study was the timescale for grants and support (including financial support through Job Centre Plus and other initiatives to support employment) because the family carers had to take longer over the study period and did not qualify or complete the course within the prescribed period.
3. **Understanding entitlements to Carers’ Assessments and Direct Payments/Carers’ Grants.** Families repeatedly said that their local authority would not see support for learning as an appropriate service. Direct payments were not generally available and there were wide variations in eligibility criteria between local authorities.
4. **Having accurate information on arrangements to support childcare and learning.** Most families with disabled children felt that information on childcare to support employment was getting better. But there was a dearth of information on support for learning. One mother complained bitterly that her local authority would provide short breaks for ‘respite’ but absolutely refused to provide cover for her OU residential week in the summer holiday period. Parents were ‘cautiously optimistic about the long-term implications of the Childcare Act for improving childcare options for disabled children’.
5. **Finding accurate information on what one mother called ‘the whole of the education system if you are an adult learner’**, eg, Learning Direct, purchasing a computer, studying part-time, getting funding for distance learning. One group described adult learners with caring responsibilities as:

constantly excluded, with none of the flexibility offered to families wishing to enter or retain employment.

Some carers felt that:

our relatives’ need for education or training was recognised – at least to a limited extent – by some local authorities and by Job Centre Plus. But our parallel needs as carers were not so recognised. We were constantly told such care ‘would be too expensive’. We felt we were being encouraged to stay on benefits because it would be cheaper.

6. **Reluctant providers of childcare or family care:** although some families reported very helpful colleges and universities (and the local childcare sector), others found on-site provision reluctant to include disabled children. The most satisfied women used NHS on-site childcare (usually to support training as a nurse or related health professions whilst working in the NHS facility). Some families felt that though the education system is now covered by the DDA, the focus was on disabled learners and not on the disabled children and young people using the child-care or leisure facilities on-site. A number of family carers in the 2006 survey felt that:

the best care for our relatives would be parallel opportunities for adult education or leisure learning. But we have found that many of the more suitable courses have been withdrawn because of changing policies on funding ‘non-accredited training’.

7. **Families found it particularly difficult to juggle the costs of different forms of childcare or support when used simultaneously.** One mother noted that although the university nursery did admit her disabled child, she had to pay fees throughout the year – but in the previous 12 months, her son had needed two periods of 6 weeks out of the nursery because of orthopaedic surgery. To keep up with her course, she had to ‘pay double’, employing a childminder locally to care for her son. In the 2006 survey, a number of families were using the Working Tax Credit component of Child Tax Credits in order to fund

support for work and study. However, they noted that the tax credits assumed full-time or significant levels of part-time work throughout the year. One parent noted that:

unless our employer is willing to employ us and give study leave, we cannot cover our work-related training or study through tax credits. Therefore we cannot afford the level of childcare necessary for a disabled child and we cannot support our study.

8. **Family carers with adult children or other relatives reported the greatest difficulty in finding information and support**, although there was evidence that some Carers' Groups provided a lot of help. They noted the:

real problem when your child is too old for child tax credits, when you leave the children's services department which gave direct payments for childcare and when it is so much harder (and so much more expensive) to find good private care.

In the 2006 survey, 80% of respondents wished to continue to work or study after their children moved to adult services. 60% felt that they would need to change their employment and wished to study both for leisure and also to enhance skills and employability. 45% felt that they must move towards a greater degree of home-working or self-employment, but wanted the skills necessary – as one mother put it:

to become totally self-servicing, I could move to consultancy but I will have to service myself and I am not sure I have all the IT skills to do this effectively.

9. **Families from minority ethnic groups (including asylum seekers) had very varying experiences.** Information on options was seen as a key concern. Purchasing equipment, books and covering travel costs were seen as major barriers. Two local support groups for black and ethnic minority families with disabled children stressed the importance of:

avoiding assumptions about what we want. Social services often think that black and minority ethnic group families

don't want day services, short breaks, childcare to support employment. They assume that our families always 'do it'. But we are like everyone else. We want good objective information. We want services which are culturally appropriate but we also want services which enable us to train, to access education. To think about careers.

Carers felt that basic information was essential, one co-ordinator of a community group commenting that:

Many BME families simply don't know about or understand things that would help them – like getting DLA. They don't know about services. We have to raise expectations – and that means working with community leaders, who will know where these families actually are.

10. **Older family carers had a wide range of views on education and training.** Some wanted to use adult education to improve existing skills (not necessarily in order to gain employment). Some wanted additional qualifications and intended to work. One woman, who had cared for a severely disabled son (injured in a road traffic accident at 6 and now 35) wanted to do a post-graduate course, which would enable her to teach. She felt 'that her life had been put on hold' until better information on financial support through her Carers' Group enabled her to access direct payments and the Independent Living Fund and provide proper support for her son. She felt carers needed to understand that 'getting better services for their relative in his own right could enable the carer to have a better life too'. One Carers' Support Group told us about three family carers who had retired early to support disabled partners. All three were doing degree courses, one man telling us that:

I never had the chance to go to university when I was younger. I was surprised that I could still get a grant, even though I was retired! I am taking my degree over a longer period than my very young fellow-students. But I am doing a law degree and I don't think it is a waste of money. I will put it to good use helping carers like myself – and I feel so energised. My wife

has benefited too as I am no longer depressed. I couldn't have done this without my local Carers' Centre – and I didn't go near them for two years because I frankly thought they were not for people like me!

11. **Older family carers were the most likely to feel that education and training were neglected in information about local services.** A number felt that they needed to 'restore their confidence' (there was praise for Learn Direct, NIACE, the National Extension College and local 'taster' courses). Carers' Centres were usually well informed but, as noted above, some family carers did not know about or choose to use their local centres. Two local branches of MENCAP admitted that:

We don't know much about career development for family carers – we are much better informed about study and career options for people with a learning disability. However, we are aware of a growing number of people with a learning disability who are also family carers and who want to 'have a life'. We will be talking to our local carers' networks to see how we can work better together.

The major challenges

Family carers (of all ages) felt that adult learners suffered from the financial costs of caring, low expectations (surprise in many instances that they should wish to study or work) and poor information on financial support and care options. Families also identified some additional costs, which would not necessarily apply to other adult learners, namely:

- **The cost of care/cover for learning** (with carers having to purchase such care or cover when other families could rely on friends or families or their relative's increasing independence).
- **Travel costs:** the majority of family carers noted that they had to pay for travel costs to and from care facilities (often not local) and their relatives were frequently unable to travel on their own.
- **Costs associated with learning:** families with a disabled relative are frequently unable to purchase the equipment, which is 'normal' to

many families' lives. Many of the families consulted did not have a computer or else had older equipment, which was unreliable. They did not necessarily have access to the internet and a laptop was seen as a priority for many of the adult learners. Local policies on the purchase of books are variable. One mother described her delight when her LEA decided to give her a 'book grant' of £200 a year. She pointed out that she could not get to the university library easily because of her caring responsibilities and her local library was usually shut and had no section with scientific textbooks. Some carers said they had difficulties in covering care costs and fees for 'summer schools', which they saw as essential to their courses.

However, the major barrier was seen as information. One mother said that advice from Contact a Family had enabled her to receive the highest rates of DLA for her son. This in turn affected other benefits and the family's income had been sufficiently boosted for her to contemplate returning to education. Other family carers commented on advice and support from Carers UK and the National Union of Students. But as one carer commented,

Being a family carer is being part of a vicious circle. You don't have enough money and you are so tired that you just manage somehow. You don't know where or how to find out what's available. You want to get a better life for all the family – it's not only about money, it's having purpose. I got back to education and now to employment because somebody gave me the information I needed. I feel like a different person – but why can't local authorities realise that learning benefits everyone? I was made to feel selfish and a freak when I asked for short breaks to go on a summer school. I had to pretend to be near suicide to get what I wanted! But it's all right now ... we have got our lives back. [Personal communication]

The local authority challenge

Three local authorities agreed that the Carers (Equal Opportunities) Act presented major challenges with regard to support for family carers wishing to study or work. They all noted:

Pressure on resources, changing populations of family carers with an increase in disabled

people with complex disabilities living in community provision and higher expectations in families of 'ordinary lives'.

However, they all identified positive steps for the future, including:

- **Stronger partnerships with the local community**, in particular the engagement of local family support groups, voluntary organisations and community leaders in identifying priorities for carers and in planning short, medium and longer term to improve the range and quality of local provision.
- **Using the Carers' Grant more strategically**, not only to provide direct care but to fund what one local authority described as 'improving life chances', eg,

Looking more creatively at the capacity of Carers' Centres to support learning and skills development – we installed computers, with 'smart cards' for internet access to support one group of carers who were interested in Open University courses.

Another local authority said that it:

reviewed our policy on short breaks and 'respite care' in conjunction with local carers. We found that some carers wanted time out to study more than a holiday – so we included 'study time' within our new policy.

- **Using Direct Payments:** Two local authorities responded to requests from family carers and were using Direct Payments more flexibly to cover transport, home care and activities for the disabled family member, which permitted the carer to study. One authority commented that:

... making Direct Payments more generally available has proved a good investment. Many family carers only require modest levels of additional support in order to meet their needs, for example to go to the local college. Before they were often asking for short breaks or regular all-day day-care because there was no other way of getting cover. Now we can be flexible, which is what everybody wants.

- **Positive and effective information strategies:** All local authorities who contributed to the survey or commented at a later stage recognised the importance of information for family carers. Three were working in active partnerships with the local LSC (Learning and Skills Council), the voluntary and community sector and Job Centre Plus in order to help carers use multiple sources of help where appropriate. One local authority, which organised regular welfare rights sessions at a local Carers' Centre, estimated that up to 50% of Centre users were able to claim additional allowances, benefits or tax credits because of improved information. With regard to children, Children's Information Services were seen as key in ensuring that parents of disabled children had the best possible advice on finding and funding childcare – whether for work or study. However, all local authorities acknowledged the challenge of reaching 'hard to reach' family carers of all ages, who were not known to services and did not join or use local carer or family groups.
- **Responding to more diverse communities:** Families from black and minority ethnic communities were recognised as being particularly at risk of being poor, socially excluded and unaware of local support services which might assist them. Some local authorities were appointing specific development or link workers to encourage participation in planning and using local services.
- **Changing needs:** Most local authorities acknowledged the challenge of providing more individualised services and balancing the potential tension in social care between 'respite' and support for ordinary lives. Some local authorities were concerned at balancing financial pressures and an increase in children and adults with complex disabilities and health conditions, requiring high levels of practical support, with the desire of some family carers for support for employment or training. Such support might take a family out of poverty and provide a rich range of opportunities for the disabled person, but was seen as competing with what one authority described as 'life and death care, with a family virtually breaking down under the daily regime of personal and nursing care'. However, a number of authorities

noted that they needed better partnerships with other agencies, such as Job Centre Plus and anticipated developing these new relationships through the Carers (Equal Opportunities) Act.

- **Planning for the future:** The reorganisation of social care, in particular the creation of integrated Directorates for Children's and Adult Services, was seen as positive in terms of integrating a wider range of services (with special reference to social care). But problems were also identified, in particular the:

gradual erosion of FE and adult education courses below Level 2 Qualifications. For people with learning disabilities and their family carers, these are often lifelines in terms of personal development and social care. Of course education is not, and should not be, seen as 'care'. But it often performs two functions (for children and adults!). We need a wider debate at national level about the role and value of these courses and of course, from the point of view of family carers, about their significance in permitting different family members to study together.

The same local authority underlined the opportunities (and challenges) in enabling both disabled people and family carers to improve their life chances through education, training and employment and the need for better strategic partnerships with employment and education services. It also anticipated:

Using the DDA 2005 Disability Equality Scheme to get whole authority approaches to improving the life-chances of disabled people and family carers. The refocusing on outcomes rather than short-term interventions in children's services is very positive – but we need the same approach for family carers. The Carers (Equal Opportunities) Act enables us to take this longer-term view and we will use the Disability Equality Scheme to underpin our three-year action plan – for disabled people and for their family carers. That way, we can invest as well as react, and hopefully change the culture of our social care services.

2 The Carers (Equal Opportunities) Act 2004 in detail

The Carers (Equal Opportunities) Act 2004 builds upon:

- The Carers (Recognition and Services Act) 1995
- The Carers and Disabled Children Act 2000

It inter-relates with the Disability Discrimination Acts 1995 and 2005 (with reference to the disabled person rather than the carer, unless the carer is also a disabled person).

It also relates to children's legislation (in particular the Children Acts 1989 and 2004, the Childcare Act 2006 and related assessment arrangements).

What does the Carers (Equal Opportunities) Act 2004 say?

The purpose of the Carers (Equal Opportunities) Act 2004 is to give carers more choice and opportunities in order to lead a more fulfilling life. It does this through:

- Making sure that carers get the right information in order to make informed choices about their lives.
- Making sure that their assessments consider leisure, education, training and work opportunities.
- Gives local authorities stronger powers to enlist the help of housing, education, health and employment services in supporting carers.¹⁰

Why did we need this new Act?

It is estimated that there are over 6 million family carers in the UK. The majority of family carers are women, but there are growing numbers of young carers and of disabled people who are carers in their own right. 80% of family carers are of working age, but 60% have given up paid work in order to care. A study from the Department of Work and Pensions¹¹ and the University of York found that most family carers wished to remain in work, but found it very difficult to do so because of lack of information, poor support from social services and difficulties in accessing training or education in order to

change careers if appropriate. 'Jenny', the mother of 'Peter', a twenty-year-old son with a spinal injury following a road traffic accident, described her Job Centre Plus adviser as giving her:

excellent advice on re-training, qualifying as an EFL teacher would give me flexible working hours and use my skills and experience. But as soon as I explained my son's age and disability, her attitude changed. She thought that the level of support would be 'too expensive' and I would be better on benefits and making my new career that of a carer. I was so disappointed that she didn't see the value of investing in me. I told her that the additional support while I trained would be paid back amply in tax and national insurance when I was working – in a year. I don't think she understood the issue. She was kind but she didn't really listen. And when I went to social services, they didn't see it as their role to help me get into training and work. I was offered two weeks respite in the summer – but we didn't need 'respite'; my son and I wanted to get a life.

In the end, Jenny was able to access her course, because her son asked for a Direct Payment in his own right to attend some local leisure services. Peter said that:

It felt as if I was looking for childcare – for myself, and I'm a man! But I knew my mum needed to work and to go to college so I asked social services about something for myself. I enjoy the leisure centre and the art course. I am going to college and Mum knows I'm safe. But I feel guilty too because it's all so difficult.

How will the Carers (Equal Opportunities) Act 2004 make a difference?

The principal aims of the Carers (Equal Opportunities) Act 2004 are to:

- Make sure that family carers are given information on their rights and the full range of options open to them.
- Make certain that work, life-long learning and leisure are considered when a family carer is assessed.
- Give local authorities new powers to ask for assistance from the housing, health, education and other local authorities in providing support to family carers.

3 The Carers (Equal Opportunities) Act 2004 – key duties

Section 1 of the Carers (Equal Opportunities) Act 2004

Section 1 amends the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000. Section 1 now expects that:

- When a local authority is assessing a disabled child or a disabled adult, they must inform the family carer of their right to a carer's assessment if it appears that they might be entitled to such an assessment.
- If the local authority thinks that it would have a legal duty to carry out a carer's assessment (ie, that a request to do so would be 'reasonable'), then it must inform the family carers about their rights.
- The local authority must carry out a carer's assessment, unless it would be 'unreasonable' so to do.

The provision of information on the right to a carer's assessment is widely regarded as crucial to improving the lives of family carers. Every year, over 2 million adults become family carers. According to Carers UK, almost half of carers who have not had a carers' assessment do not know that they are entitled to one.¹² Only half of family carers were told about their own rights to assessment and assistance when the person they were caring for was assessed.¹³

It is important to remember that Section 1 applies to family carers of all ages, including children and young people under 18, provided that they are caring for an adult who is assessed under section 47(1) of the NHS and Community Care Act 1990. This section also amends the Carers and Disabled Children Act 2000, with reference to young people 16–17 caring for adults.

Section 2 of the Carers (Equal Opportunities) Act 2004

Section 2 of the Act amends both the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000 by ensuring that carers' assessments must include consideration of whether the carer:

- Works or wishes to work
- Is undertaking or wishes to undertake education, training or any leisure activity.

Section 2 also covers children under the age of 16 with caring responsibilities. But it is expected that assessments of children with caring responsibilities should routinely be assessed under the Framework for the Assessment of Children in Need (ie, under children's rather than carers' legislation).

Section 2 breaks new ground by requiring local authorities to amend their assessment arrangements in order to incorporate any issues relating to work, life-long learning or training. Carers UK firmly believes that:

Section 2 of the Act could help signpost carers to new training and learning courses, help them on the pathway back into work or remain in work.

Section 2 also breaks new ground because previous laws focused on family carers' ongoing ability to provide and continue to provide care. Now the new emphasis is not only on supporting family care, but also upon ensuring that family carers have the 'right to a life' and to the things which most people take for granted – leisure, work, education and learning opportunities.

Section 2 matters because:

- 80% of family carers are of working age, but every year 2.3 million carers stop working. With appropriate information and support, they could move to new opportunities in education, training and employment.
- 7 out of 10 family carers find themselves financially worse off when they have to give up work. A recent TUC report argues that in order to achieve full employment and economic growth, the Government's Comprehensive Spending Review and its proposals for welfare reform should focus on getting the half a million people with caring and family responsibilities into work. The TUC stresses the importance of making adult education, training

and life-long learning accessible to family carers in order that they can ‘have careers, fully engage in their local communities and enjoy an ordinary life’.¹⁴

Section 2 of the Act has the potential to change lives! If family carers have better information about training and employment opportunities, there will be positive economic benefits. Carers who are able to participate in life-long learning (whether for leisure or for accredited qualifications for future employment) will avoid social exclusion. They are more likely to feel that they have a valued role in family and community. Importantly, they will contribute directly to the nation’s economy through taxation and earning capacity. One mother commented that:

When my local authority assessed my needs as a carer, I was astonished to be asked if I wanted to work, perhaps to change career. I said I did want a life of my own – though I wanted to be a good carer too. As part of my assessment, my social worker got me information on local college courses. She suggested that my husband also studied whilst I did my course. He now spends one morning a week in adult education. A very modest direct payment covers the taxi to and from the college, as I could not manage his wheelchair on public transport. The college is fully accessible and my husband as a disabled student is protected by the DDA!¹⁵ The college has to make ‘reasonable adjustments’ and it works really well. It was the first time that I felt ‘John’ and I were both people with rights and responsibilities. It’s made such a difference to our lives.

Section 3 of the Carers (Equal Opportunities Act 2004

Under Section 3 of the Act, the local authority can request any local authority, local education authority, housing or health authority to assist it in planning carers’ services. Section 3 says that if the local authority requests such assistance ‘in planning the provision of services ... the authority must give due consideration to the request’.

The local authority can also ask another authority to provide services if the carers’ ability to provide care would be enhanced by such services.

This section is important because many disabled

people need support from a number of agencies. Many family carers complain of the fragmentation of services between different agencies and the problems, which this causes.

Section 3 might be used in a number of ways, for example in the provision of equipment, transport or staff training.

Naria is an asylum seeker, who has just received confirmation of her refugee status. She was a nurse in her own country and is desperate to qualify in order to practice in the UK. Her brother Sahid is 22 years old and has mild cerebral palsy and severe mental health problems relating to abuse prior to their arrival in the UK. Naria identifies two courses, one on access to learning for adult learners, the other an intensive English course for newly arrived asylum seekers and refugees. She feels that her brother’s health depends upon her ability to communicate in English and she is desperate to make friends in the local community. The local authority carries out a carers’ assessment and identifies a community group which will pay the (modest) fees. On Naria’s behalf, it requests assistance from the local Community Mental Health Trust (CMHT) in order to help Sahid and provide some support. Sahid is currently refusing to leave the house. The Team agrees to carry out an assessment and offer Sahid the chance to attend a local drop-in centre for people with mental health problems. It offers a range of leisure activities and identifies volunteers who are able to act as escorts to and from the centre. Sahid is also offered a support group for asylum seekers with mental health problems, but he has difficulty getting out of the flat. Naria and Sahid have been offered a ground floor flat because of his mobility problems. But there is a six-month delay before a ramp can be installed from the front door to the pavement.

The Carer’s Assessment includes an interim assessment from the local occupational therapy service, which loans a portable ramp pending the permanent installation. The Integrated Community Equipment Service provides Sahid with a ‘rollator’ (walking aid) so that he can move about outside the home. Sahid accepts the help and Naria goes to college. She expects to start formal training to qualify to practice in the UK in the new academic year.

4 Family carers

Who is a 'carer'?

It is estimated that over 6 million people in the UK now provide care for a relative, friend or neighbour who is in need of support. There is no separate definition of what constitutes a 'carer' in UK legislation. In general, a carer (often called a family carer) is defined as someone who provides unpaid care to another person who is in need of support because of:

- Mental or physical illness
- Old age
- Disability.

Family carers can be of any age and can include parents caring for a disabled child and young carers (ie, children and young people usually supporting a sick or disabled parent). An increasing number of disabled people are also carers (eg, a parent with a learning disability or a disabled parent).

This definition excludes paid carers and volunteers who may also provide unpaid care (usually on behalf of a community or other voluntary organisation).

For the purposes of this guide, the term 'family carer' is used in order to distinguish between carers providing unpaid and voluntary support and carers who may be employed by the local authority or by individual families, or who may be volunteers working under the direction of a voluntary organisation or charity.

Listening to family carers

All assessments carried out under health, social care or education legislation may take the views of family carers into account. But the entitlement to a carer's assessment (which may in turn lead to additional support) is dependent upon agreement that:

they are carers who provide or intend to provide a substantial amount of care on a regular basis.

There is no single definition of 'substantial or regular' care, but the definition can include general

supervision as well as direct hands-on personal care. Carers who meet this definition have a statutory right to a 'carer's assessment' and in certain circumstances to support services provided through the relevant social services department.

Local authorities have a general duty to take the views of family carers into account when considering how best to make provision for a disabled person.

When considering whether to make provision for a disabled person, the social services department can consider whether support to the family carer should be integrated within any agreed 'care package' for the disabled person in question.

Family carers: basic rights

All family carers have basic rights (largely the right to have their views taken into account by a local authority when it is considering how best to make provision for a disabled person).

- In most cases, the local authority social services departments will consider the role and view of a family carer of a disabled adult, when it is undertaking an assessment of a disabled person. In the case of a parent of a disabled child, the local authority must consult and involve the parents in any assessment arrangements.
- Family carers who provide, or intend to provide a 'substantial amount of care on a regular basis' have additional rights, in that they are entitled to have a separate 'carer's assessment'.
- When undertaking a community care assessment, social services departments must 'take all reasonable steps to reach agreement with the person and, where they think it appropriate, any carers of that person, on the community care services which they are considering providing to meet his needs.'
- A disabled person can refuse to accept a service offered to provide support for the family carer. However, in instances where the disabled person is not able to give informed consent

(perhaps because of Alzheimer's Disease or a similar condition), then the local authority and family carer may use new arrangements under the Mental Capacity Act 2005 to determine whether agreement has been given.

- Parents of disabled children must be involved in any assessment of their children's needs. They may also ask the local authority for additional support with childcare, short breaks and a range of family support services set out in Section 17 of the Children Act 1989. The Childcare Act 2006 strengthens parents' rights to childcare for disabled children up to the age of 18.

However, in none of the above circumstances is there automatic entitlement to services. Local authorities can set their own eligibility criteria for access to services. In the case of adults, these are published locally under *Fair Access to Care*.¹⁶

Local authorities have powers to consider the financial situation of both disabled people and family carers and may charge for (ie, recoup some of the costs of) community care services.

What is a Carer's Assessment?

Certain family carers have the right to request a Carer's Assessment. The local authority cannot 'unreasonably' refuse this request. The right to a Carer's Assessment is related to three different Acts, namely:

- The Carers (Recognition and Services) Act 1995
- The Carers and Disabled Children Act 2000
- The Carers (Equal Opportunities) Act 2004.

The three Acts inter-relate. The Carers (Recognition and Services) Act 1995 introduces the concept of the 'Carer's Assessment'. The Carers and Disabled Children Act 2000 extends the rights of carers, giving them:

- The right to support services, following assessment.
- The right for these services to be offered as Direct Payments or through vouchers.

The Carers (Equal Opportunities) Act 2004 extends the existing rights with regard to assessment and provision of services. As noted below, it:

- Gives local authorities a statutory duty to inform family carers (of children or adults) about their rights and
- Requires Carers' Assessments to consider whether the family carer is working or wishes to continue to work, and is undertaking or wishes to undertake, any education, training or leisure activities.

The separate Carer's Assessment is directed at family carers who provide (or intend to provide) 'a substantial amount of care on a regular basis'. The interpretation of 'substantial' will vary on an individual basis. The guidance¹⁷ notes that:

The term 'substantial' and 'regular' is not defined in this guidance. In any given situation, the test that a practitioner should apply will relate to the impact of the caring role on the individual carer. In particular, the practitioner will need to address the following questions:

- ***Is the caring role sustainable without additional support?***
- ***How great is the risk of the caring role becoming unsustainable?***

In deciding whether a family carer can continue caring without additional support (and in assessing the risk of a break-down), the assessor is expected to consider 'the carer's experience' in terms of:

- His/her personal autonomy
- Health and safety
- Managing daily routines
- The needs of other members of the family
- The level of support required on a regular basis.

Developing positive policy and practice around the implementation of the Carers (Equal Opportunities) Act 2004 into action

The Act places new and proactive duties on local authorities to ensure that family carers are informed of their right to a Carer's Assessment. The local authority must:

- Make an effort to identify family carers (who may not be known to social services departments and are often called ‘hidden carers’) and:
- Make sure that information is available and accessible to all family carers.

Heron,¹⁸ consulting a wide range of family carer groups, underlines the need for an information strategy to make sure that there is local agreement on:

- What information is needed.
- Who is responsible for collecting information locally.
- Designing and planning the information resource.
- Disseminating the information.

Heron’s views mirror the carers’ groups consulted as part of this guide. They stressed the importance of:

- Developing a local information strategy for family carers. This should be developed in partnership between the voluntary and statutory sectors and should set clear targets, with regular review.
- Making information a key component in the local Carers’ Strategy.
- Providing comprehensive information for family carers – covering the full age range (from young carers to older people).
- Providing information, which is relevant, jargon-free and available in a variety of formats.
- Addressing the needs of the local community and acknowledging cultural and social diversity. Some local authorities are using local radio stations (often a reliable way of reaching minority ethnic groups).
- Recognising the challenge of reaching ‘hidden carers’ and disseminating information through multiple sources.

Family carers stressed the importance of being open and honest about all local options. One mother commented that:

It was useful for family carers from across the sector to meet with the local authority. I think we all started by feeling that some people got a much better deal than others and the system was unfair!

Another family carer noted that:

We also realised that social services can be very worried that it won’t be able to meet demands if they talk about Carers’ Assessments and all that. But really information is not only power, it’s a way of using existing resources better. When we really mapped out all the local services and options for family carers, some families realised they could get help without going through the local authority.

A third family also observed that:

Some families had never heard of the Carers’ Centre or of Carers’ organisations, which might help. Others had never heard of Direct Payments – they wanted just a little bit of help in order to study or work but they were chasing after expensive residential respite care and all that because they did not understand the alternatives. We even got honest over budgets – not easy, but when we all worked together, we agreed our priorities. I think we’ve made a difference. And I think we and the local authority now know we can work together for the future.

One family carers’ support group described a joint review of local arrangements for carers’ assessments.

In our authority, a consortium of local parent and carer support groups decided to review the Carer's Assessment. We felt that it needed to be more person-centred and to encourage family carers to talk about their real lives and what support they needed. We agreed that in our authority the assessment was too often geared to what was already available – for services for which there was a long waiting list.

We also found that our Councillors did not really understand why support for learning or work should be seen as a service. They felt they were 'drowning under crisis after crisis' and that support for study and work were somehow a bit of a luxury compared to the other things they were dealing with on a daily basis. We had a very open discussion, we consulted local families and the local authority (including elected members) and we all realised that actually helping people into education, training or work is an investment for the future. If we help more family carers to be independent, then we free up the specialist services for those who need them most.

But best of all, we realised that the main barrier to working better together (and looking at the 'new generation of family carers') was the lack of a real

strategy. Now we have a local Carers' Forum, where representatives of the local voluntary sector, the Carers' Centre, and the Learning Disability Partnership Board meet with elected members, the 'lead' for the Carers' Strategy, representatives of health, education and social care. We found the biggest barrier was information – or the lack of it – so we now have a regular newsletter and a link on the local authority's website.

We realised we needed everyone to work together. We're also working with organisations of disabled people – if we make the DDA work properly, then more disabled people can use ordinary services and family carers need less support! And we've set up a data-base of carers as well – they get the regular newsletter and we hope that many of them will never need a carer's assessment because they'll be getting all the help they need by themselves. The trouble with caring is that you are often part of a hidden army. When things break down, you get awkward and expensive, but given some sensible advice a bit earlier and maybe some support, well, then we can help ourselves (and the local authority budget!).

The family carers contributing to this guide agreed that:

- **Information matters** – information for family carers, but also information about family carers for commissioners and providers of services.
- **Partnership matters** – local carer groups and organisations of and for disabled people need to work together. Local forums or consultative meetings are important.
- **There are many 'hidden' family carers.** Many family carers (and disabled people) welcome web-based information, which is instantly accessible and easily updated. But others may have limited access to the internet and prefer paper or personal information exchange. Some family carers will come from minority ethnic groups and may have real problems in accessing information. Some will enjoy sociable events where they meet other people and can share ideas and issues with each other. Others will prefer web-based information.
- **Assessment of any kind can be alarming to family carers and disabled people.** Some families will be reluctant to seek an assessment without active encouragement. Young carers may think assessment of their parent's needs may lead to the family breaking up and the young person going 'into care'. Some family carers may not believe that there are local services to help them. In some cases the disabled person is reluctant to comply with any assessment or outcome. Therefore, it is essential to produce practical local information about what a Carer's Assessment means.
- **No presumptions should be made about carers' support.** A family support group for carers from the Asian community reported that families were frequently assumed to 'look after our own, although such support is frequently not available'. The same group also noted that many Asian families have more than one disabled family member and women (and sometimes men) have multiple care responsibilities. They noted one local authority

which employed an Asian link worker to develop services for family carers from that community and her success in identifying a range of issues (and practical solutions) to carer problems and the creation of culturally appropriate services.

- **Needs change:** Family carers identified certain key areas for development. These included managing transitions (from school to adult services, from work to unemployment or from 'relative good health to quite the opposite').
- **Emergency care was seen as a priority.** A number of carers said that they used services which were often unnecessary, but which they needed to keep on a retainer basis in case of emergencies. Some local authorities were developing new schemes (including vouchers to use with a designated care agency, peripatetic domestic help and flexible use of Direct Payments in some cases for carers to pay for their own support). 'Being ill' was constantly reflected in consultation with family carers as one of the biggest anxieties because of its unpredictability.

Megan describes how she and her local Carers' Group decided to work with their local authority to produce a *Guide to the Carer's Assessment*. She says that:

Our Carers' Forum set up a special working group. We worked hard to help family carers be open and honest about their lives and what would make a difference. The group produced 'a day in the life of ...', with key questions about everyday life, any education, training or employment, other family members. The leaflet was translated into the main community languages and distributed through local community groups. The local authority felt that the leaflet 'demystified assessment' and enabled everybody 'to be both ambitious and realistic'.

One immediate outcome of the project was a much greater awareness by the local authority of the importance of education and training. In consequence, the same group is working with the local authority around developing their local Childcare Strategy and the new duties to provide childcare for disabled children and young people up to age 18 under the Childcare Act 2006. Similarly a grant to a local voluntary organisation has enabled the local FE College to provide some leisure activity for adults with learning disabilities whilst their relatives study.

John (supporting a wife with multiple sclerosis) described how his local Carers' Strategy includes formal links with the local Learning and Skills Council and Job Centre Plus. Both were surprised at the large number of family carers who were unaware of allowances and support available through these routes. He spoke with delight of the information he received through a local Carers' Network about training and job opportunities through local New Deal initiatives. Both he and the local authority in which he lived admitted that:

We had not thought of support for employment – or training – as a service for carers. In fact we were terrified of escalating demand for scarce respite care and traditional day services. We had not thought before we started working together that helping carers back into work or education would help them to help themselves. Now Job Centre Plus advisers are regular visitors at our Carers' Forum. It is indeed a 'New Deal' for many people who basically thought their ordinary life was over.

It was very clear from our survey responses that family carers want personalised and sometimes very different practical support for their caring role. 'Substantial and regular care' can mean different things to different family carers. For example:

Vivian is supporting her husband, who has developed early-onset Parkinson's Disease and has had to give up work because of his health problems. He is very depressed and resents his wife going to her part-time job and studying part-time for a Master's Degree in Education. Vivian feels that her employment is essential to maintain the family home and her two daughters. Her employer is sympathetic and permits her to work flexible hours. But she cannot easily adjust her academic studies. She requests a Carer's Assessment, in order to get a Direct Payment. She wants to employ a support worker to spend three hours, three times a week with her husband to cover the late afternoon period when she is on her course. She argues that she is providing substantial and regular care, even though her husband's main care need at present is some interest and occupation to address his depression. Her preferred support worker is a local early retired man who shares her husband's passion for chess and is able to go out with him for a drink or short walk rather than carrying out traditional 'care tasks'. She is clear that she does not want 'respite care' (which her husband probably would refuse) but needs a relatively modest amount of help in order for the family to remain independent.

Nargis's son has Down's Syndrome and cardiac problems. He requires regular supervision and because of his health needs, cannot currently attend the after-school club run by his school along with his two younger siblings. Nargis worked as an (unqualified) nurse in Central Africa for some years but will need to re-qualify in order to practise in the UK. She has decided to change career direction because of the difficulty of working shifts as a nurse. She is currently studying on two access courses (one in English, one on computer studies) and expects to start a full-time social work course in the next academic year. However, she cannot consider the course without additional support for her son. Following a Carer's Assessment, her local authority agrees to provide a Direct Payment. This will cover the cost of some additional support in her son's after-school club and to bring him home when the club is over. The local authority also agrees to fund John on a summer holiday playscheme to enable his mother and siblings to have a break. Nargis is also given useful information on other services which may be able to help her, including advice on disability allowances and child tax credits, information on local parent support groups and advice on covering the additional costs of her course (eg, books, her own computer, etc.).

Both Vivian and Nargis demonstrate the importance of flexible approaches to carer support. They also illustrate the importance of good quality local information on all available options. A number of local authorities referred to the importance of Children's Information Services and other services which cater for the whole community but do not necessarily have the best information on carer support unless they are part of an authority-wide strategic approach.

What happens if the person being cared for is under 18?

It is important to remember that the new requirements apply to family carers with responsibilities for other adults or for children and young people under 18. However, if the person cared for is under 18, then assessment of families' care needs should be carried out in accordance with the statutory guidance set out in the *Framework for the Assessment of Children in Need and their Families*.¹⁹ This guidance emphasises the importance of holistic assessment of family needs and avoiding piecemeal, repetitive or parallel assessments. Following the passage of the 2004 Act, the Carer's Assessment must also take account of the parent's ability to care for, or continue to care for, the child and to take into consideration whether they work (or wish

to work) or to undertake any education, training or leisure activity or wish to do so. This means that local authorities now have a duty to ask family carers about these activities and take their wishes into account in drawing together any care package. Support services for families with disabled children are provided under Section 17 of the Children Act 1989, as amended by the Children Act 2004.

Local authorities must also take into account any assessments carried out under Section 6 of the Carers and Disabled Children Act 2002 and the Carers (Equal Opportunities) Act 2004. Disabled children and their families should have access to the full range of childcare options open to other families. *Choice for Parents, the Best Start for Children* (2005) sets out the Government's commitment to improve childcare for disabled children through the national Childcare Strategy and the Childcare Act 2006.

The Childcare Strategy is particularly important for parents with disabled children, as lack of affordable and accessible childcare is frequently cited as a reason why such parents are unable to study, train or enter employment. Historically many local authorities have regarded provision to help parents study or work as outside the requirements of Section 17 of the Children Act 1989 (ie, as services outside the general requirement to make provision for 'children in need'). However, the Government is clear that, subject to assessed need, local authorities can and should provide support to families who wish to study, train, enter or remain in employment. Policy guidance on the Carers and Disabled Children Act 2000 and the Carers (Equal Opportunities) Act 2004²⁰ notes that:

When assessing the needs of disabled children and their families, social care staff should now be aware of the range of options to enable those parents who wish to participate in the workforce to do so, and of the potential financial, emotional and social benefits to parents of working. Support to parents to help them to work (including support for education and training) could be an effective way of safeguarding and promoting the welfare of the child.

The Childcare Act 2006 requires local authorities for the first time to plan in order to provide 'affordable and appropriate childcare' for parents of disabled children and young people up to the age of 18. It is assumed that such childcare will largely be provided through the proposed expansion of Children's Centres and Extended Schools and that families will cover the costs of childcare through child tax credits. In the case of some disabled children, the working tax element of the child tax credits may be insufficient to provide sufficient affordable childcare in order for parents to study or work. Local authorities still have powers under Section 17 of the Children Act 1989 to provide financial support for childcare but are also empowered to charge for such services, subject to assessment.

Childcare for disabled children should be a priority both within the local Children and Young People's Plan and the relevant Carers' Strategy. Survey responses from parents indicated that many were unaware of the possibility of applying for enhanced rates of child tax credits because they had a disabled child. They were also unaware that it is now possible to use child tax credits to fund home-based care as well as centre-based provision.

The new duty to provide childcare to support employment will apply to all children and young people up to the age of 14, but up to 18 if a child or young person is disabled.

The Carers (Equal Opportunities) Act 2004 – what about young carers?

Young carers are also protected under the Carers (Equal Opportunities) Act 2004. Young carers are described as:

Children and young people under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks.²¹

It is estimated that there are around 175,000 children and young people in the UK who could be identified as young carers. The average age of young carers known to projects in the UK is 12 years old. The Princess Royal Trust for Carers²² suggest that 84% of young carers provide 1–19 hours a week, 9% provide 20–49 hours a week and 7% provide over 50

hours. In many cases, young carers are reluctant to reveal the level of support provided, often fearing that they (or their relative) will be moved from the family home if the situation becomes known to social services. In practice, children and young people have always helped other family members and have welcomed the opportunity to do so. But problems can arise if care responsibilities interfere with education or the health and well-being of the young person. SCIE (2006) notes that:

Problems arise when the level of responsibility taken on by the young person is inappropriate for their age or maturity. Practitioners should be aware that young carers, having taken on roles beyond their years, can present as more mature than they really are. The impact of caring on the young person is an important consideration and could be influenced by a number of factors such as family circumstances, the age of the young carer, the amount and type of care given and crucially whether the cared-for person has adequate statutory or other sources of help.²³

Families consulted in the Nuffield survey (2006) revealed that children and young people frequently helped the main carer, often preparing meals, providing support in between the parent or main carer leaving the house and the paid carer arriving or generally 'helping out' around the home. Many of the respondents noted that siblings (under-reported in the majority of carers' surveys) had an important role in enabling their parents to work or study (particularly when courses took place in the evening or at 'twilight' hour sessions outside the usual care agencies' schedule).

Some family carers praised local Children's Services for:

- **Developing a multi-agency strategy for carers**, which included joint working between adult and children's services.
- **Carrying out holistic assessments under the Framework for the Assessment of Children in Need** which recognised the young people's need for support in appropriate caring roles and tailored family support and practical assistance with housework, etc. to fit in with the young person's lifestyle and education.

- **Running and supporting Young Carers' Groups** and providing a range of activities (including emotional support).
- **Recognising that family carers need support**, not only in their primary care roles but also in a parenting capacity.

One Young Carers' Group suggested that:

- **Carers' Assessments should always include the views of children and young people in the family** – but they need to be positive. Many young carers are terrified of the family being broken up!
- **Caring can be frightening** (particularly if the parent or other relative has a degenerative condition) – young carers need someone to talk to. Young Carers' Groups are great – but you can't go if you are caring for someone!
- **Young carers should be happy with what they are asked to do.** We shouldn't be asked too often to cover for emergencies and do very personal things for adults in the family!
- **We have our own needs as young people** – some local authorities give young carers priority for after-school or holiday schemes, pay for school trips and generally make sure we get an ordinary life. We want to care; we're part of a family – but we need our lives too.
- **Schools could do more!** It's hard to be criticised for not doing your homework when you have been trying to look after your autistic brother. Adult services assessing our relatives' care needs should take account of our special homework time – and they should never make us late for school!
- **Access to further and higher education.** Young carers can miss out on education if they have a major caring role. One Young Carers' Group had, at the request of its young members, asked the Education Authority to provide 'Learning Mentors' to give practical advice and support in accessing continuing education. Many young carers feel a high degree of anxiety about leaving the family home to develop their own career, but are also ambitious for what one young woman

described as a 'real adult life, doing something worthwhile and being able to go to university to prepare for it'!

This Young Carers' Group noted that members were frequently late for school because the paid care staff did not turn up on time. One young man felt particularly incensed that his father (the primary carer for his mother who had multiple sclerosis) had examinations for his teaching course on the same day as his son's GCSE exams and no special arrangement was made to allow both to leave home on time, secure that the carer had arrived. But importantly, the same group noted that:

Young carers have to speak up too. If I had told my mum's social worker about the exams, I guess we might have been covered. But we didn't – and the new carer was late. Somehow we didn't think exams were social services' business. But of course they are, when it comes to caring!

Young Carer's Group thought that accessible websites were invaluable ('the thing about caring is that you just don't get out and about much') and particularly praised the Princess Royal Trust for Carers' Young Carers website for practical advice and links to other young carers.

Family carers also expressed concern about the non-disabled children or young people in the family. One mother commented that:

My daughter (with cerebral palsy) was assessed and we get some help with a direct payment. But I have two other children who often help me and I think their needs get missed. I'd like a lighter touch assessment to make sure they're not forgotten. They do too much since we became a single parent family. I'd like to redress the balance.

Young carers should be helped by the introduction of the Government's Common Assessment Framework. The Common Assessment Framework is a 'first stage' multi-agency assessment which can be initiated by relevant professionals, the parents or the young person himself. The emphasis is on the early identification of any particular problem or additional need and a rapid response to addressing it. Information on the Common Assessment Framework is available locally or on

the Every Child Matters website²⁴. The assessment can lead to a more detailed statutory assessment, referral to a relevant local authority department (eg, housing) or the immediate provision of appropriate support. Parents, children and young people are fully involved and already some pilot local authorities are indicating that assessments are addressing issues about caring and associated support.²⁴

Family Carers – accessing education and learning

The Carers (Equal Opportunities) Act 2004, as noted elsewhere, breaks new ground by requiring local authorities to consider the wishes and needs of family carers with reference to education, training, employment or leisure. Assessment arrangements must take account of the family carer's wish to participate in education, training, employment or leisure as well as the current undertaking of any employment.

Historically many local authorities have hesitated to provide support for working family carers (or indeed to support education and training), feeling that such support was not a usual use of social care. The new legislation clarifies the duties and powers of local authorities to have regard to family carers' own aspirations and lifestyles and in effect to consider the longer-term outcomes of any intervention or support service. This broader objective parallels a similar commitment to 'improving life chances' of disabled people and placing any support services within a broader and more strategic approach to assessment and care management.

Local authorities are not obliged to provide or fund direct education services under the Carers (Equal Opportunities) Act 2004. However, they can:

- Provide information on relevant educational opportunities (including information on sources of funding) as part of a multi-agency Carers' Strategy.
- Provide practical support with caring in order to permit the carer to study. This support can include day care, taxi fares, access to leisure or other day-time activities or domiciliary home services.

- With regard to school-age children (in particular disabled children), provide information and support with accessing childcare – including after-school and holiday programmes.
- When carrying out a carer's assessment, ensure that it takes account of the family carer's wish to study or train and considers how best to support these aspirations.
- When carrying out an assessment of a disabled child under the *Framework for the Assessment of Children in Need*, ensure that the family's need for support with education, training or employment are fully reflected in any outcomes.
- Recognise the potential of Direct Payments to provide flexible support for education or training and give family carers information on both assessment for Direct Payments and on options for their deployment.

Family carers who are disabled people or who have disabled relatives should remember that all educational establishments (from pre-schools to universities) have duties under the Disability Discrimination Act 1995 and SEN and Disability Act 2001²⁵ to make 'reasonable adjustments' to accommodate disabled people and to plan progressively to improve accessibility over time through the Accessibility Planning Duty. 'Reasonable adjustments' can include:

- Access to the curriculum (ie, use of different materials, communication aids, etc.)
- Improvements in the physical environment
- Accessible information.

Even if the family carer is not disabled, improved accessibility can enable the person cared for to attend another course as part of a leisure or independent living programme. Our respondents told us that they often found it convenient for their relative to enjoy a leisure or similar course on the same premises while they studied. Similarly, many colleges and universities offer a childcare service or crèche. This service must now make reasonable adjustments in order to include disabled children.

Respondents to our survey identified a number of positive responses by local authorities to family

carers who wished to study or train. These included:

- **Information** (including information on support for training and employment from the local Job Centre office).
- **Information on support for learning** through the local education authority (including advice on fees for courses, purchase of computers and other equipment, any special grants for books, etc. and information on relevant organisations for further assistance – for example the National Union of Students and the National Institute for Continuing Adult Education).
- **Assistance with the costs of childcare** (both through information on application for Child Tax and Working Tax Credits and through the use of direct payments to purchase local support).
- **Advice for disabled adult learners** (including referral to the Disability Rights Commission and relevant organisations such as SKILL).
- **Direct payments to adult carers**, to cover leisure or social care activities for their relative whilst they studied and also to cover taxis and other reasonable expenses. One local authority purchased a microwave oven so that a disabled partner could prepare his own hot drinks and food safely when his wife was studying.
- **Working in partnership with the local Learning and Skills Council and Education Authority** to identify any problems for carers in accessing education and training and how best to address it.
- **Providing emergency cover** – identified as an issue for one Carers' Support Group, whose members wanted 'cast iron' cover at times of examinations or key interviews.

As one parent carer commented:

The most important thing about my carer's assessment was that it saw me as a person with ambitions as well as responsibilities. My social worker put me in touch with the right adviser at Job Centre Plus and she was very helpful. The college was helpful too – they suggested a course for my [adult] son, which he

really enjoys. We have a quite modest Direct Payment for the taxi, which takes us both there and for the course fees. Importantly my social worker knew which of the two local colleges had really taken the DDA seriously and had some additional staff available to provide personal support. I didn't know much about local services but there's a really good local carers' support group and through them I and other 'mature students' are having some input into our local carers' strategy. What's struck me is how modest most of our requests are – but we just were not listened to. Even my GP helps now as patients are asked if they have any special needs as carers. I am now promised an early morning appointment for myself or 'John' if we need it – less time off work, less hassle and one thing less to worry about!

Another carer said that her carer's assessment led to:

agreement that I could have two weeks 'respite' for my mother while I went on an Open University Summer School. Actually my mother would never have agreed to go to 'respite', but she did agree to go on a special holiday down on the South Coast.

One carer, a former asylum seeker with formal refugee status, described her carer's assessment as:

So positive. I was scared, I thought they will think me a nuisance. I knew I wanted to work in the UK, to make a real contribution. But my English was poor and I needed good English and more training to be a nurse again. I was told about a wonderful 'Access to Learning' course. That gave me confidence, put me in the right direction. But I couldn't have gone and left my husband. He has mental health problems, he is scared to be alone. But I was put in touch with a mental health support group, they introduced us to someone who has become a friend. My husband finds it hard but he can let me go to my course. Next month I start a nurse training course to update me and enable me to work in the UK. I have a Direct Payment so that I can ask the person we met at the support group to give my husband some extra support. They will start going to a course too. I feel really good now, I think we have a future.

The role of the health services in supporting family carers

Good health matters. Carers UK estimate that 65% of family carers with health problems do not currently receive an increase in services following a carers' assessment.²⁶ They found high rates of depression, anxiety and stress associated with becoming a family carer. Some carers pointed out that Health and Safety arrangements protected the health and safety of paid staff, who were expected to move and lift disabled people.

Carers UK noted that:

Lack of support services may be unlawfully putting carers' health at serious risk and severely compromising the safety and well-being of the person they care for.

Family carers did not get the same protection. However, some carers' assessments did adopt a holistic approach towards the needs of family carers and one mother noted that:

I had developed back problems through lifting my daughter (who has multiple disabilities). When she was at school, it was all right because she was out of the house all day. I did the lifting in the morning and evening and I had some help in school holidays. Now she is an adult, with only two short sessions in day care, I am lifting all the time. I was studying to become an accountant and working part-time. That worked with reliable support at school. When she left school, everything changed. I didn't expect the carers' assessment to bring about much change. But it did. The assessment considered my physical and mental health and now I have help in getting Melanie up and showered in the morning and in putting her to bed. Melanie also has a Direct Payment to pay for time at the local leisure centre. They say assessments cost money – but actually my assessment will save money as I am now on a waiting list for some home adaptations. With the right shower and a good home hoist, I won't need so much from the paid carers. I still have to cover my work and my study, but I've been given information about help that might be available through my local Job Centre. At least I haven't been told that I'll just have to stay at home!

Melanie's mother benefited from local agreement between social services and the primary care trust to 'pool budgets' to pay for some equipment and support for family carers. But she also commented that:

When you ask for a carer's assessment, you have to think what evidence you can provide. My GP was very willing to support my need for extra help and to say that my own health needs were being damaged by constant lifting. Melanie's physiotherapist provided information about a suitable shower, hoist and some minor adaptations to our house. I realised that part of the problem rested with the lack of training on safe lifting for care staff. I talked to my local carers' support group and they are now working with the primary care trust to set up some training on safe moving. We were able to convince them that if they didn't do this, then carers would break down and we'd be looking at expensive residential care homes!

Primary Care Trusts have a duty to consult with their local community with regard to priorities for primary care services in the area. The Government proposes to bring health and social care more firmly together at local level, with more Primary Care Trusts moving into 'practice based commissioning', which can include a number of care services. *Your Health, Your Care, Your Say*²⁷ anticipates greater involvement of service users (including family carers) in developing policy and practice at local level. At the same time, The Prime Minister's Strategy Unit (2005)²⁸ emphasises the Government's commitment to more individualised care services, building on current work around Direct Payments and moving towards 'Individualised Budgets' which in many cases will be managed directly by disabled people or family carers themselves. Individualised Budgets are currently being piloted for disabled adults and for disabled children.

5 Finance and implementation

The right to individual and personalised care – Direct Payments and Individualised Budgets

The introduction of 'Direct Payments' has radically changed the way in which social services departments provide services. The Direct Payments Act 2000 introduced Direct Payments for disabled people who had been assessed as requiring a service from the local authority. A 'Direct Payment' is a cash payment paid in lieu of a service provided directly by social services. It is paid to, or on behalf of, the disabled person (with the exception of parents of disabled children under 16) and can be used flexibly to pay for personal care, transport, access to leisure, etc. The disabled person, or his representative, is accountable for the use of the Direct Payment and the money can only be allocated following a local authority assessment.

Direct Payments were initially only available to adult disabled people. However, the Carers and Disabled Children Act 2002 extended the scheme to parents of disabled children under 16 and to young disabled people 16–17. The flexibility and personalisation of the scheme has been widely welcomed, although there are local variations in the level and availability of Direct Payments and the arrangements to support them.

The introduction of Individual Budgets

The Government is currently piloting an extension of Direct Payments, namely the introduction of Individual Budgets. Like Direct Payments, Individual Budgets will offer disabled people or family carers the right to purchase their own personalised package of care, subject to assessment by the local authority. Individual Budgets may bring together funding from health, housing, social care and (in certain circumstances for adults only) education and training. If the pilots are successful, Individual Budgets will be generally introduced in 2007.

In certain circumstances family carers may also receive additional individualised support with the costs of care in order to study, train or work through the Department of Work and Pensions' various schemes to encourage unemployed people into employment. The Government is currently reviewing these procedures²⁹ through a major programme of welfare reform. The Welfare Reform Bill introduces a new Personal Capacity

Assessment, linked to better supported Pathways to Work. It is anticipated that there will be enhanced support in order to enable disabled people, family carers and the long-term unemployed to enter, re-enter or remain in employment and, if necessary, to have access to appropriate training and professional development in order to work. Historically there have been limited partnerships between local authorities and Job Centre Plus. These are likely to be further developed in the future.

But the introduction of Individualised Budgets and increase in Direct Payments also poses challenges. The Disability Rights Commission,³⁰ exploring health inequalities in access to primary care, had strong messages from family carers about:

- **'Poor information'** – people discharged from hospital with no discharge plan, no information on their support needs and, worst of all, often no real communication because of issues of confidentiality and consent.
- **'The cost of caring'** – the considerable cost of visits to hospital or community health appointments, the purchase or maintenance of equipment and loss of earnings to cover periods of intensive care.
- **'Carers' own health'** – the Disability Rights Commission heard about family carers who had refused treatment (including treatment for cancer or other potentially life-threatening conditions) because they had no reliable cover for their relative.
- **'Checking the little things that make a big difference!'** – a carer's assessment should include attention to any unmet needs for health care – including information on the local chiropody service, details of local pharmacists who offer a 'collect and deliver' service for prescriptions, local dentists with accessible premises and experience in working with patients with learning or other disabilities who may need additional attention. Some family doctors offer a counselling service or access to support groups around particular conditions such as diabetes. One local

authority is introducing a 'Health Passport',³¹ prepared in partnership with the local primary care trust and setting out the range of support which family carers can expect from across the local authority and relevant health services.

- **'Health care at the wrong time'** – family carers who wished to work or study talked about waiting for the district nurse or doctor to arrive, inconvenient appointments, delays in delivery of essential items such as incontinence pads, and non-available transport.

However, the Disability Rights Commission also found positive examples of family carers developing packages of support in partnership with their local social services department and primary care trust in order to support employment or study.

Elinor was a full-time mature student at a northern university when her single parent mother died suddenly in an accident. Elinor's brother Steve had severe learning disabilities, was aged twenty-five and living at home at the time of his mother's death. Elinor returned home for a year, deferring her final degree year, to sort out Steve's care arrangements. Steve had severe epilepsy, was on regular medication and occasionally needed the administration of rectal diazepam. He needed some assistance with mobility and with feeding. Elinor identified a day service near her university which Steve would be happy to attend. However, the staff were unhappy about the prospect of administering rectal diazepam and assisting Steve with feeding 'in case he choked'. They felt that Steve needed additional support which they were unable to provide. Elinor asked for a carer's assessment and for input from the Primary Care Trust. Her agreed care package included a Direct Payment for support for Steve first thing in the morning and on his journey to the day centre. The package also covered the cost of a taxi to and from the centre. The primary care trust agreed to train both the early morning support worker and the centre staff in the safe administration of medication and in safe feeding techniques. The majority of the day service staff agreed to be trained when they realised that they were being offered accredited training which in turn would enhance their CVs. Elinor has completed her degree (with a two-week holiday for Steve funded over her examination period).

The Disability Rights Commission recommends that disabled people and family carers should jointly agree where possible:

- **What support their relative needs from local health services** (this can include training, provision of equipment, help with transport, advice for families and for any other services used).
- **What support the family carer needs from local health services** (this can include support for their own health needs, provision of support in caring, provision of information, and recognising the increasing debate about confidentiality and consent).
- **What professional advice or support might help** – for example an assessment of the family home by an occupational therapist, referral to a specialist rehabilitation or other centre for advice on equipment.
- **Clarification about any support services provided through the primary care trust or other relevant health services** – for example, information on any drop-in or other centres for people with mental health problems, domiciliary services for chiropody, etc.

The majority of carers' services are provided through the local authority. However, information and advice from local health services may be essential in helping family carers make use of them. In particular, primary care trusts can provide risk assessment, relevant training and advice for carers employed through direct payments or for staff working in day services. It is important that care support groups work closely with their primary care trusts to make sure that family carers are on the agenda and that they are consulted on any changes in policy or services.

The introduction of the Disability Equality Duty (Disability Discrimination Act 2005) (see page 39) means that family carers and disabled people of all ages will have a real opportunity to contribute to the development of local Disability Equality Schemes. As noted elsewhere, these schemes must be based on a review of local provision, undertake real consultation with the local community and make practical proposals in a three-year action plan to improve access and equality in the public service concerned. The Disability Rights

Commission is producing practical guidelines for local service users, to ensure that they improve the quality and accessibility of local services.

What works for family carers

Consultation with carers and local authorities identified a number of practical actions to underpin a proactive approach to supporting carers and implementing the Carers (Equal Opportunities) Act. These included:

- **Producing local guides ('A-Zs')** of local support services for family carers. Many family carers are not aware of local or national voluntary organisations which might help them.
- **Going on line:** developing or expanding websites which can be easily updated.
- **Family Carer Forums:** ensuring that there are local networks and consultative forums for regular discussion and review.
- **More creative use of the Carers' Grant:** with the active involvement of the full spectrum of carers' interest groups across the authority. Several local authorities admitted surprise at the level of common interest between what younger and older family carers wanted and their ability to identify local developments which were achievable and met local needs.
- **Partnership with organisations of disabled people** to develop more creative ways of providing family support and 'ordinary lives'. Some respondents told us of tensions between carers' organisations and those representing disabled people. Others noted the common agenda and the importance of alliances rather than competition.
- **Supporting the assessors!** Some local authorities are producing practical information on the Carer's Assessment for assessors, with contact details for local and national organisations and other sources of information and advice (including signposting to other agencies). Many family carers were unsure how their own needs would be assessed and, as one mother of a disabled teenager put it,

We felt very hesitant and vaguely disloyal about saying we were not coping very well.

We had a house, enough money (more or less) but we were exhausted; we talk about community but it doesn't help much unless someone gives it a prod! Actually we needed information as much as anything else – that's why it is such a pity to ration assessments. Often they are as much about self-help as getting a service.

Independence, Well-Being and Choice (2005),³² the Government's Green Paper on future directions in social care, underlines the importance of partnerships between local authorities and their local communities. The Green Paper discusses the need for community capacity building, describing it as:

activities, resources and support that strengthen the skills, abilities and confidence of people and community groups to take effective action and leading roles in the development of their communities.

Richardson and Sefton (2005)³³ reviewed a number of community groups and concluded that certain key factors were necessary if they were to develop capacity and deliver their intended role. Their views were endorsed by the parent and family carer support groups consulted as part of the production of this guide, namely that successful local strategies around support for family carers require:

- Good leadership
- A balance of skills, commitment and interests
- Good relations with the local community
- Strong partnerships between key statutory and voluntary agencies
- Financial and other resources
- An interest in strategic development as well as the individual circumstances of members.

The Carer's Assessment – making it work

Under the 2004 Act, family carers aged 16 or over are entitled to an assessment of their ability to provide and continue to provide care when:

- The carer is not providing such care under a contract (ie, being paid) or as a volunteer for a voluntary organisation.

- The carer intends to provide ‘a substantial amount of care on a regular basis for another individual aged 18 or over’.
- The local authority is satisfied that the person being cared for is someone for whom they can legally provide or arrange the provision of community care services.
- The family carer asks the local authority for a Carer’s Assessment.

The Carer’s Assessment must consider:

- Whether the family carer works or wishes to work.
- Whether the family carer is undertaking, or wishes to undertake, any education, training or leisure activity.

If a local authority has carried out a Carer’s Assessment prior to the implementation of the 2004 Act, the family carer may request the local authority to carry out a reassessment. Reassessment is also appropriate when there have been significant changes in the level or nature of care or of the personal circumstances of the family carer.

Making the Carer’s Assessment work

In carrying out a Carer’s Assessment, local authorities can call upon other statutory (or voluntary) agencies to provide relevant information. They may wish to consult the local health services, the education authority, housing departments or other local authorities if the person concerned has received services outside his home area. Family carers should also think about who knows their family situation and could give useful advice.

Local authorities have a duty to inform family carers (of adults or children) of their right to a Carer’s Assessment and to give them any other relevant information. This information could include contact details for local voluntary organisations, which can give advice or support, or the address of the local Carers’ Centre.

The provision of good quality and sufficient services for the disabled person (whether adult or child) is likely to be the best outcome of any assessment. Many family carers request additional help because they cannot find sufficient affordable

and appropriate care for their relative. Services to family carers are not specified in either the 2000 or the 2004 Acts. Therefore, the local authority has considerable discretion in how it provides any services. It could provide:

- **A Direct Payment in lieu of a direct service.**
Direct Payments are cash payments made by a local authority, following assessment, to enable the disabled person or family carer (acting on his/her behalf) to purchase a service directly. Direct Payments can be used to purchase a range of services (including support with personal care, access to childcare and leisure, respite care, help around the house or garden).
- **Domiciliary care (including childminding, help with personal care)** – As noted above, local authorities can provide or commission such services directly or make a Direct Payment in order for the disabled person or family carer to purchase the service directly.
- **Help with gardening, housework and access to play/leisure services** – In some cases, family carers may want assistance with practical everyday living. For example, one mother wishing to attend a local college was unable to do so because she could not find anybody willing to provide after-school care for her 11-year-old autistic son. He needed outdoor exercise to reduce his problem behaviour, but regularly got out of the house and over the low garden fence. He was therefore judged a bad risk by most of the local services. His mother requested a Carer’s Assessment and asked the local authority to fund a high fence round her garden so that her son could play safely outdoors. They agreed to make a one-off payment to enclose the garden. The family have now been able to employ a local childminder, who was happy to register as an Approved Home Carer and care for the boy in question. She was unwilling to do so before because, though experienced in working with autistic children, she felt that the home environment was unsafe.
- **Providing direct help to the disabled person:**
Sometimes the best support for a family carer is provision for the cared-for person. Under the Carers (Recognition and Services) Act 1995, the assessment of a carer’s ability to care may

influence what services are provided to the cared-for person. Therefore a local authority might agree to fund a day service place for a person with Alzheimer's Disease in order to support the family carer. The 1995 Act did not consider support for education or employment as key outcomes for any assessment of carers' needs. This duty came later with the 2004 Act. However, the 1995 Act is still important because it acknowledges that family carers' quality of life is affected by the nature of any services offered to the cared for person.

A Carer's Assessment and related checklists was developed in partnership with the Valuing People Support Team and interested local authorities and carers' groups. A key objective was to improve the quality of information collected in order to both meet individual needs and permit local authorities to be more strategic in developing local services. This template is shown as an appendix on page 56.

What happens if the disabled person refuses to accept the care on offer?

Disabled people are not obliged to accept the social care services offered to their family carer. In particular, they are not obliged to accept 'services of an intimate nature' if they do not wish to do so. 'Services of an intimate nature' are defined as:

- Lifting, washing, bathing, toileting, administering medication and other physical assistance.
- Assistance with washing, feeding, etc.
- Supervising the cared-for person while they are dressing, bathing or using the toilet.

The provision of such care should be discussed and explained clearly to both the disabled person and family carer. Disabled people (children or adults) may have their own ideas as to what constitutes the most suitable care.

Leon's mother is retraining as an accountant. Her company allows her time out for study, but she cannot get home in time to meet Leon's school transport. Leon is 16 and has cerebral palsy and would have liked to stay on at his school, which offers a range of after-school activities in its capacity as an 'extended school'. He rejects the idea of a childminder or other paid worker coming to the house, saying he 'isn't a child any more' and 'his mates would think he was a baby if he had a nanny looking after him'. The school cannot vary the taxi arrangements. Leon's mother asks for a Carer's Assessment. Because Leon is 16, he is entitled to a Direct Payment in his own right. The local authority agrees to make a payment, which will cover his taxi home three nights a week. One of the staff working in the extended school session is happy to be paid as Leon's escort and to have supper with him while they wait for his mother to come home. Leon feels 'in control' and his mother can continue with her course.

Disabled people can refuse to attend a day centre, use a respite facility or accept personal support from a care worker in their own home. However, effective assessment should ensure that they understand why a service is being offered. In many cases, support for family carers can be provided through leisure activities, visits out in the community and other services which provide positive improvements to the life of the cared for person.

Dani described how she wished to study at her local college and arranged for her husband (recovering from a stroke and needing supervision and support) to attend another course in the same college. The local authority pays for a taxi to and from the college. The college, as part of its response to the Disability Discrimination Act 1995, assesses Dani's husband's support needs and arranges for some additional personal support. This additional staff member was specifically recruited and trained to provide assistance with moving, lifting, medication, etc. and provides such support to three disabled people attending courses at the college. The college has already developed an accessibility action plan, as set out in its Disability Statement and has adapted toilet facilities and access to the main building for wheelchair users.

Charging for services

Local authorities are able to charge carers for the carers' services which they provide. They are given these powers under Section 17 of the Health and Social Services and Social Security Adjudications Act 1983 as amended by the Carers and Disabled Children Act 2000. *Fair Charging Policies for Home Care and Other Non-residential Social Services*³⁴ (2003) provides guidance on how local authorities can interpret the law. Charging policies should be developed locally in consultation with local services and user groups. They should take account of family income and expenditure, and local authorities have the powers to either not charge for certain services or to waive charges in certain cases. Charges on services provided to family carers are separate from those provided directly to a disabled person (who may also be subject to local charging policies). Charges can only be imposed on services provided through the local authority. NHS provision (with the exception of prescription charges) is free at the point of delivery.

With a rapid increase in the numbers of family carers seeking support from the local authority, the majority are introducing charging policies. Our survey identified charging as a major concern to family carers, one, rather, noting that:

I have already had to reduce my working hours by fifty per cent in order to support my wife and also permit my two teenage children to go on to college without feeling worried about their mother's care. The provision of a domiciliary home care service for six hours a week kept us going. If that is to be charged for, I think I will have to reject the service. That means giving up work and living on benefits. I feel that assessment of charges for social care services should pay greater attention to the circumstances of individual families. If I am able to stay in work, then my wife can stay at home longer (because we can afford her additional needs); I am paying tax and my children will not become young carers. If I am to be charged £8 per hour, then I will be asked for £48, which I have not got. What I would have liked would be a proper cross-authority discussion as to why we need charging and what a fair policy would look like. We all live in the real world and carers can be pragmatic too!

One carers' support group suggested that family carers should keep a full record of any expenditure to set against proposed charges. Family carers emphasised:

the importance of recording all relevant expenditure – keeping what the accountants call an 'audit trail'. Many families underestimate the real cost of caring. They should also be aware that if they get a Direct Payment, they will be responsible for providing detailed information as to how they spent the money. We asked family carers to keep a weekly diary of what they spent, when – the odd taxi, the ready-prepared meal, extra heating, etc.

Another parents' group noted the surprising lack of information (and knowledge) on sources of financial support for caring. One mother had received information on tax credits from the 'Disabled Children' section of the Working Families website. She commented that:

We asked our local authority to tell everybody about possible sources of financial support. Most of our members who have children of school age did not know about Child Tax Credits and the enhanced payments of the Working Tax element if you have a disabled child. As one mother put it, 'once I got my tax credits, I could employ a childminder like everyone else. I didn't need a Carer's Assessment. I didn't even need respite care. It's all a matter of sharing information'.

'Fair and reasonable'? Working together around charging policies and practice

The families and local authorities who contributed to this guide emphasised that consultation and transparency were essential if charging was to be introduced. One local authority summed up its own approach as:

- A full public consultation on charging (with accessible information as to why we feel this has to be the way forward).
- Involvement of all relevant local groups – for example, the local Carers' Support Groups, MENCAP, the local Disability Network, organisations for older people and of course collective bodies like the Learning Disability Partnership Board.

- Improving take-up of existing disability allowances and benefits – we started a major publicity campaign (with advice for individuals if required) to improve take-up of DLA, the Carer's Grant, etc. We found that many families were not claiming what they were entitled to.
- We asked family carers (and disabled people) what they wanted care for – ie, to maintain someone in the family, to support employment, to offer childcare. We realised we had not always matched care needs to individuals.
- We asked certain services, in particular children's services and services for older people, to make sure that families got the best possible information. We were shocked at a Disabled Children's Information Day to discover that half the families did not know that they were entitled to enhanced levels of Working Tax Credit if they wished to work.
- We re-visited all our local information services (for example the Children's Information Service and our local authority website) to update people on what they might be entitled to.
- We found that some of our services were actually regarded as 'old fashioned' and not necessarily fit for purpose. Families used them because they were there. We had introduced Direct Payments but we were surprised by how many families said they would prefer to use them.
- In exploring a greater take-up of Direct Payments, we asked families to tell us what they would like to purchase – and what they thought it would cost. Again we were surprised because in most cases the cost was considerably less than our own services.
- However, we also realised that if we were to use more individual (and cheaper) care through Direct Payments, we would need to invest in the infrastructure of support to make it work well. We still needed a charging policy, but we were able to reduce the proposed tariff and to make absolutely sure that everybody understood our system.

The same authority commented that:

In introducing charges, we were responding to our elected members who felt that we could not otherwise maintain an appropriate level

of service and support. In basing any moves towards charging on a full review of what local carers and disabled people wanted from services and engaging them in considering costs and equity in access, we realised that we needed local involvement and support. We shared our budget (and its projected shortfall) with key local user groups – against the wishes of our elected members – and it worked. They had threatened judicial review and there was considerable dissatisfaction with services. When they realised the challenge, they responded positively. We are now reviewing carers' assessments and we will comply with the DDA 2005 and produce a Disability Equality Scheme in December 2006. Partnerships around charging are not easy and we have also engaged our education, housing and health colleagues to see how we can work better together. But we feel that our local carers' strategy is better informed and that we are now working in partnership.³⁵

What happens when carers and cared-for people disagree over services?

The Department of Health³⁶ is clear that cared-for people cannot be forced to accept services they do not wish to receive. In particular cared-for people cannot be forced to accept services of an intimate nature – the Government being concerned that without the right to refuse, services of an intimate nature might be inappropriately delivered to unwilling disabled or frail older people. 'Services of an intimate nature' are described in regulations and include:

- Lifting, washing, feeding, dressing, bathing, using the toilet, administration of medicines.
- Assistance in connection with washing, feeding, dressing, bathing, etc. as above.
- Supervising the cared-for person while they are dressing, bathing or using the toilet.

It is in the nature of personal care that it is intimate and one local authority commented that:

Nobody would choose to be assisted in carrying out their personal care. They may feel frightened, unsafe, undignified and they may refuse immediately. But their health and well-being (and that of their family carer) may be dependent on such care being provided. We see

this as a key area for the carer's assessment – we need to address cultural and religious factors. We need to consider the lifestyle and age of the family concerned. Most importantly we need to train and support our staff to deliver care confidently and in the most appropriate way. We believe that Direct Payments are an encouraging way forward because they put the family in control – but even then we need, as a public body, to be confident of the quality of care provided. Vulnerable people are open to abuse.³⁷

One carers' group told us that they encouraged family carers to take an advocate or at least another friend or relative to any assessment and to make sure that everybody understood what was being requested and what was reasonable. One woman, whose post-graduate degree course was at risk because of the care needs of her frail father and mother, found that their resistance to a home carer assisting them with personal care and accompanying them to the toilet rested on the idea of strangers coming into the house and possibly abusing or robbing them. They were ashamed of their fears but when helped to articulate them, agreed that they would accept help if they could use a Direct Payment to recruit a carer directly. Their daughter identified a neighbour, with a care background, who was happy to take on the role and who was seen as trustworthy and a friend. The daughter is continuing at university and her parents can remain in their own home.

This respondent offered what she described as 'top tips' for persuading a cared-for person (with no previous experience of personal care) to accept support from others in their daily life: She stressed the importance of:

- **Being clear why the help is needed.** In this case, she discovered that her parents thought that asking for personal assistance was the 'thin end of the wedge' for going into a care home. They did not initially see personal support as support for independence.
- **Recognising the sensitivity to receiving personal care.** Many older people in particular are embarrassed and confused at the need for personal care. It needs to be presented positively and not as 'the start of a slippery slope' to dependency.

- **Listen to the views of the cared-for person** – including how they want any care to be provided (including what they are to be called – Christian name or a more formal approach, whether the carer will eat with the person being cared for, how privacy will be maintained, etc.). Very importantly, 'care' should be positively interpreted in terms of access to leisure or other facilities which improve everybody's lives.
- **Regularly checking whether the arrangement is working well** – in particular whether the primary care role is to have a 'safe pair of hands' available if anything goes wrong or whether any paid carer is to carry out specific tasks.
- **Be very clear what care is needed!** In Helen's case, she needed support for her teenage son who was recovering from a head injury. Care had to be flexible to coincide with her university course seminars and other commitments. Her son was reluctant to attend any group care but was happy with a personal assistant employed through a Direct Payment. Together they went out for a drink, to the cinema or just 'hung out' with Joel's friends in the town. But sometimes personal care may be unnecessary if problems in the home are dealt with – for example a downstairs toilet may remove the need for assistance with personal care in the day. One student mother told us that her disabled husband's care needs were resolved through social services' purchase of a small freezer and a microwave with a Direct Payment. He can now prepare his own meals (and those of his children when they come home from school) when he is at home. He prefers to use the residual Direct Payment for taxi rides to a local college for leisure courses. This arrangement has worked so well because:

'Gareth' hated 'meals on wheels' and feeling he was being babied. But having meals in our freezer, home cooked with vegetables from our own garden, made him feel in control. He and the children can manage the microwave and they really feel independent. I also save hours a week because I can freeze fresh food. Gareth didn't want someone coming in to cook for him and he gets a social life by going to the adult education college two afternoons a week. It's also a much cheaper option than having some carer coming in from an agency.

6 The Mental Capacity Act 2005

Managing disagreements around capacity and consent

In most cases, family carers and their relatives agree about the best arrangements to enable them to get on with their lives. But sometimes things go wrong. Disabled people – like any other citizen – have the right to refuse support or treatment. But, particularly if they have a severe learning disability or mental health condition (such as Alzheimer's Disease), problems may arise. The Mental Capacity Act will be implemented in 2007 and aims to protect vulnerable people around decision-making. The Act states that everyone should be treated as able to make their own decisions until it is demonstrated that they can't. It also aims to enable people to make their own decisions for as long as they are able to do so. A person's ability to make a decision will be established at the time that a particular decision needs to be made.

The Act intends to protect people who lose capacity to make their own decisions through:

- Allowing a person, while still able to do so, to appoint someone (eg, a relative or friend) to make decisions on their behalf when they lose the ability to do so. These decisions can relate to health and personal welfare as well as to financial matters.
- Making sure that decisions made on another person's behalf are in their best interests. The Act provides a checklist for decision-makers to work through.
- Publishing a Code of Practice to give guidance on decision-making when the person concerned lacks capacity to do so.
- A new Independent Mental Capacity Advocacy Service is being introduced for particularly vulnerable people.

The Act starts with a presumption of capacity, ie, it is assumed that every adult has the right to make his or her own decisions and must be allowed to do so unless there are strong reasons for doing otherwise.

The principle of best interests always applies – this means that people should be properly supported in making sensible decisions, but they can still make what might appear to be odd or eccentric decisions (providing that these meet a 'best interests' test).

In determining what is in the best interests of the person concerned, family carers have the right to be fully involved. However, they do not have an automatic right to impose a particular action or care plan on their relative, who retains autonomy subject to certain safeguards.

How does the Mental Capacity Act relate to the Carers (Equal Opportunities) Act at local level?

In most cases, families, the person receiving care and the local authority will agree about the best action and package of support. However (particularly if the person receiving care has a condition like Alzheimer's Disease), there may be difficulties arising when he or she refuses to use a service which is crucial to the well-being and coping skills of the family carer.

The Mental Capacity Act makes provision for dispute resolution but it also highlights the importance of open and honest discussion within families when the use of external or domiciliary care is provided. In certain cases, it may be determined that the best interests of the individual concerned necessitate the use of a day or respite care service (for example, if the carer has a serious illness or there is a bereavement in the family). But in general, decision-making will not be imposed and thereby communication (and careful consideration of all options) will be essential to avoid confrontation.

Positive approaches to informed consent

One local authority told us that they were developing a checklist on informed consent, taking into account the requirements of the Mental Capacity Act. This checklist anticipated that:

- **The Carer's Assessment and any related assessment activities should include a careful evaluation of the most appropriate form of care or support.** For example, a young adult might be very happy to attend a college course

or leisure centre with support, but be reluctant to attend a more traditional day service. Conversely, some older people might be reluctant to receive care in the home and prefer 'getting out and about' to local centres or leisure activities for older people.

- **More attention to consent may mean more open (and sensitive) discussion about the need for a service to be used.** One local carer, who needed surgery for breast cancer, was very reluctant to tell her husband that she needed him to either spend three days in a local nursing home or accept a support worker in the family home. He refused initially, misunderstanding the reason for the proposal and feeling extremely anxious that his wife was proposing to leave him. An honest discussion between the couple and a social worker resolved the difficulty. The man agreed to spend three days initially in the nursing home and if further hospital care was needed, he also agreed to consider another placement or possibly domiciliary care.
- **Advocacy matters:** the authority in question is providing some modest additional funding to a local advocacy service, to assist disabled people in making decisions about care which they might not wish to use – but which may be essential to the family.
- **Planning for the future:** a consultation with disabled people in the same authority indicated that 'care' was often an issue when older relatives found it increasingly difficult to provide 24-hour care. The preferred option for a substantial number of the group was not for more or different types of care, but for assistance in identifying and moving to accessible housing and in effect becoming independent of their family carers! The authority is now reviewing its Housing Register and ensuring that younger disabled people who wish it are registered as seeking independent living in the future.

In certain cases, there may be no option but to use the decision-making powers implicit within the new legislation. But its effectiveness will in turn depend upon the quality of communication between local authorities, carers and their relatives with regard to decision-making about care and the maintenance of maximum autonomy in so doing.

What happens when something goes wrong?

All local authorities must have formal procedures for hearing representations or complaints, which are made to them about the way in which they deliver services (or refuse to deliver services). If family carers (or the people they are caring for) are not happy about a service, they may wish to first talk through the problem with a local carers' support group or other voluntary organisation.

It is important wherever possible to discuss any problem early, before it has become a major difficulty. Some areas will have a local Centre for Independent Living, which can give useful advice on employment issues and the use of Direct Payments.

Family carers using Direct Payments (ie, purchasing support services themselves or from an independent contractor) should remember that if they have a complaint in these circumstances, they must make the complaint directly to the provider. They should also remember that family carers themselves have employers' duties when they directly employ a care worker.

If a family carer feels that they or their relative are being discriminated against for a reason relating to their disability, they can seek advice from the Disability Rights Commission (see next section).³⁸

7 The Disability Discrimination Acts 1995 and 2005

The Disability Discrimination Acts 1995 and 2005 (DDA) aim to end discrimination and give equal rights to disabled people. The DDA covers people of all ages (including children).

The DDA does not cover family carers of disabled people directly, unless they are also disabled. However, many family carers report problems in finding practical support because services do not meet the needs of their disabled relatives. Family carers can use the DDA to make sure that they and their relatives get the support they need. This in turn can help them to access education, training or work. The National Network of Family Carers Network told us that:

Positive approaches to delivering the DDA in local leisure services, colleges and on public transport benefit family carers too. Often our 'cared-for person' could and would use a local leisure service, go out to the cinema or round the shopping mall while we work or study. But if they have no access, then they are socially excluded and we have to look for expensive and often non-available care services.

A local authority 'lead' for their local carers' strategy noted that:

We too often regard disabled people and their family carers as people from separate planets. Of course they will sometimes need very different support – but basically they are allies. We realised that making our community services more accessible to disabled people would also help their carers. We are particularly pleased that an energetic access programme in our local FE and adult education services has improved take-up by family carers and disabled people and we are now regarding education as a 'community care' service!

The DDA covers all citizens and sits alongside other equality legislation (for example the Race Relations Amendment Act) and the Human Rights Act.

What do the Disability Discrimination Acts cover?

The DDA says that disabled people have the same rights as other people in:

- Employment
- Education (from pre-school to higher and adult education services)
- Access to goods and services (including provision in the public sector)
- Housing and property
- Leisure activities
- Transport
- Access to the built environment (buildings such as offices or public places like leisure centres).

The key tests for disability discrimination are:

- Whether a disabled person is treated 'less favourably' than a non-disabled person for a reason related to his or her disability, and the provider of the service cannot justify the treatment.
- Whether a disabled person is placed at a substantial disadvantage in comparison with non-disabled people because the provider has failed to make 'reasonable adjustments'.

The DDA duties are 'anticipatory'. This means that providers of services cannot just wait until a disabled person approaches them and asks for a 'reasonable adjustment' to be made. They must think ahead about how they can make their services more accessible over time so that all disabled people can use them.

The DDA has been implemented in different stages, as follows:

- **Stage 1:** From December 1996, it has been unlawful to refuse to serve a disabled person,

offer a lower standard of service or provide a service on worse terms for a reason relating to that person's disability.

- **Stage 2:** Since October 1999, service providers have had to make 'reasonable adjustments' to the way in which they offer services, so that disabled people can use them.
- **Stage 3:** Since September 2002, all providers of education services have been covered by the DDA. The SEN and Disability Act 2001 amended the DDA and introduced a new Part 4 to cover all stages of education and associated services.
- **Stage 4:** Since October 2004, service providers have had to remove or make 'reasonable adjustments' to 'physical features' of their buildings to improve access.
- **Stage 5:** The Disability Discrimination Act 2005 was implemented in December 2006. This Act 'tidies up' the DDA 1995 and clarifies the definition of disabled people. It gives disabled people new rights in access to transport and in protection from harassment or bullying. Most importantly it introduces the 'Disability Equality Duty' (see below). This new duty requires designated public services (including local authorities, job centres, colleges, schools, the health service) to produce 'Disability Equality Schemes' in order to promote equality of opportunity for disabled people.

In 2007/2008, the current three equality bodies³⁹ will be merged into a single Commission for Equality and Human Rights. However, the existing disability discrimination legislation will still apply.

Who is disabled under the Disability Discrimination Acts?

The DDA has a very broad definition of disability. A person is disabled if:

He or she has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

The definition of 'mental and physical impairments' includes sensory and learning disabilities and mental health problems, provided that they have a 'substantial' and 'long-term'

adverse impact on the person's everyday life. The Courts have usually interpreted 'long-term' as 12 months or longer. 'Substantial' is usually interpreted as 'neither petty nor trivial'. Recurrent conditions such as cancer or arthritis are covered.

The Disability Discrimination Act duties are 'anticipatory'. That is to say, providers of services must 'anticipate' that they are likely to include disabled people in the future and should plan 'reasonable adjustments' to improve accessibility over time. Some providers (eg, schools, colleges and universities) have specific accessibility planning arrangements, which form part of regular inspections.⁴⁰

It is important to remember that many family carers will also meet the definition of disability under the DDA and therefore can expect 'reasonable adjustments' to the way in which services are offered to them.

What do we mean by 'reasonable adjustments'?

Service providers have duties under the DDA to make 'reasonable adjustments'. In deciding what is 'reasonable', they can take into account:

- Cost and available resources
- The feasibility of the adjustment
- The impact on other service users
- Health and safety
- The timescale for making an adjustment.

However, service providers cannot refuse to take any action to make life easier for disabled people. For example, a college library may be asked to provide a ramp in order for family carers and disabled people to come in and use the computers, borrow books, etc. The college may say that it is planning to build a ramp within the next two years as part of a major refurbishment plan. This might seem to be a 'reasonable adjustment'. But it would leave disabled people without a service for a further two years. Therefore, it might also be reasonable in the short term to let disabled people and their family carers use an accessible staff entrance or to provide a mobile library service to a local carers' centre, club or day service until the new ramp is built. The key message is that service providers cannot refuse a

service without a proper review of what is possible short, medium and longer term.

The DDA covers public services (like hospitals, social services, colleges and schools), the business sector (like shops and offices), as well as voluntary organisations (like family carers' groups). The DDA says that a service provider must take reasonable steps to provide 'auxiliary aids or services' if this would enable (or make it easier) for disabled people to use a service which it offers to the public.

'Auxiliary aids and services' include aids and equipment. But they can also cover a wide range of other services, including accessible information (eg, on audio tape rather than in print), an induction loop or a sign language interpreter or support from a member of staff.

Improving access and inclusion for family carers and disabled people

Many service providers accidentally discriminate against disabled people because they are worried about risk or cannot see how to improve access to their service. They also frequently believe that making 'reasonable adjustments' will be unreasonably expensive. However, the Centre for Accessible Environments notes that:

The majority of adjustments cost less than £200. Many cost nothing at all (or less than £50), because the service can be offered in a different way. But there is a universal and negative view that disability is expensive. Most disabled people and their families live in ordinary homes. If we ask them what they need, we will usually find it is very modest. Of course, all services should work towards full accessibility, but we should recognise that we can start small, whilst thinking big!⁴¹

The Disability Discrimination Act 2005 and the Disability Equality Duty

As noted above, the DDA 2005 introduces a new 'Disability Equality Duty' for the public sector.⁴² The Disability Equality Duty is a general duty which applies to all public authorities. It also gives additional specific duties to support the majority of public authorities in achieving the outcomes required by the general duty. The definition of a public authority⁴³ includes health, social care, education, the police, environmental services and other functions of local or national government.

The basic requirement for a public authority when carrying out their functions under the Disability Equality Duty is to promote equality of opportunity between disabled people and other people and to eliminate discrimination and harassment of disabled people for reasons related to their disability.⁴⁴

The essential requirement for those public authorities subject to the specific duties⁴⁵ is to publish a Disability Equality Scheme by 4 December 2006.

What must be included in a Disability Equality Scheme?

As noted above, the purpose of the Disability Equality Scheme is to:

- Promote equality of opportunity for disabled people
- Eliminate unlawful discrimination
- Eliminate harassment of disabled people
- Promote positive attitudes towards disabled people
- Take proactive steps towards meeting disabled people's needs (even if this means more favourable treatment).

In order to demonstrate that it is meeting these objectives, the Disability Equality Schemes of the public authorities in question must include:

- A three-year action plan.
- A statement about how disabled people have been involved in developing the scheme.
- Information on how other relevant people have been consulted (eg, family carers, parents and relevant community groups).
- Arrangements for gathering information about the performance of the public body with regard to disability equality.
- Arrangements for assessing the impact of the activities of the public body with regard to disability equality and improving these if necessary.

- Details of how the public body will use the information gathered and, in particular, how it will review the effectiveness of its action plan and prepare for subsequent schemes.

Disability Equality Schemes must be published and should be made available in accessible formats. The statutory guidance⁴⁶ stresses the importance of ensuring that the scheme demonstrates commitment at the very highest level of authority. The Disability Rights Commission recommends that it should be endorsed and signed by the Chief Executive, Chair or their equivalent, with a senior officer taking responsibility for the implementation of the duty and the scheme.

The Disability Equality Scheme is particularly important to family carers and to disabled people themselves because it enables them to:

- Identify local priorities for change (for example, improving accessible childcare at the local FE college or access to local leisure facilities).
- Improve local information services about all available services.
- Get disability firmly into the priorities and strategic objectives of the public body.
- Set clear objectives and specifying how they will be measured.
- Carry out regular impact assessments to ensure that progress is being made.

One lead officer for carers in a local authority described how she had started to plan for the introduction of Disability Equality Schemes. She emphasised the importance of ‘real dialogue’ with the key stakeholders, which included:

- Local organisations of disabled people
- Existing forums, such as networks of disabled staff and carers’ forums and support groups
- The local providers – including colleges, schools, leisure services, children’s centres and childcare provision
- Community groups (with special reference to the black and ethnic minority communities).

She stressed the importance of:

facilitating a real dialogue rather than creating competition between impairment-specific groups and disabled and non-disabled people.

The local authority in question already had a Citizens’ Forum, which met regularly and could discuss specific topics and needs. A meeting on the proposed Disability Equality Scheme brought together a wide range of partners and the senior officer commented that:

The open discussion was very productive. Initially some organisations of disabled people were suspicious of the family carers. Some family carers expected to be marginalised. But in the end both sides realised they wanted the same things. There were some very creative ideas about using scarce resources better, in particular extending the use of Direct Payments. The schools and colleges got some very useful input into their existing accessibility planning duties. From mutual suspicion we have now moved on to seeing the Disability Equality Scheme and our Carers’ Strategy working together. In effect we have moved from crisis intervention to improving life chances – the bigger picture, and one which, being shared, will be much more influential with our elected members in due course. We have created a special action group under the umbrella of our Citizens’ Forum in order to develop, deliver and ultimately to review our Disability Equality Scheme. We believe this will help us better to utilise scarce resources and most importantly we have given ownership of the Scheme to the people who matter – disabled people and their families.

The same authority underlined the importance of disability equality planning not only applying to individual public services but also across the whole authority. She noted in particular that:

Elected members were surprised by the ambitions of both disabled people and their carers. They admitted that they had seen family care as primarily about maintenance rather than personal development. We realised that education is a service for adults as well as for children and a more creative alternative to many of our more traditional services. In effect

we started looking at 'day time opportunities' rather than traditional care.

Putting the Disability Equality Scheme into action

Two family carers' groups were developing checklists to inform the development of local Disability Equality Schemes. One questionnaire, sent to all known family carers (and complementing a questionnaire sent to disabled people) asked:

- What services do you find most useful in supporting you and your relative?
- What barriers, if any, do you experience?
- Are your schools/colleges/libraries and leisure services accessible and user friendly?
- Can family carers get childcare, family support and short breaks?
- What about local play and leisure provision?
- Do you use (or want to use) any educational facilities – after-school clubs, college or other courses or learning for leisure?
- Are there good, accessible facilities for personal care?
- Can you use the local cinemas or theatres if you or your family member has a learning or other disability?
- Is there good and accessible signage and information?
- Are local services affordable for disabled people and family carers? Can you get financial assistance in using them (eg, a leisure pass, direct payment, etc.)?
- Are they open at the right times?
- Do you find it easy to use your local railway station or bus service? Is there a local Dial-a-Ride scheme?
- Do you want to study or work now or in the future? What support do you need to achieve this goal?

- If you are already studying or working, what support do you use?
- What would make things better? Please think short, medium and long term?
- And please share your 'dream' – it may not be achievable, but what would you want if you could design your own service?

Some family carers (and disabled people) undertook 'mystery shopping' in their areas, in order to 'map' and audit local provision. One organisation of disabled people and family carers reported how they assessed the range of local care options and encouraged a more pro-active approach to care for disabled people within mainstream services:

Jenny and members of the Family Carers' Network made a list of all the leisure, childcare and education facilities in our area and then rang up or visited them to ask how they could accommodate a disabled person. We got a lot of initial 'well, we'll try' or 'I don't think our staff could handle that'. But we also had some surprises, some real 'can do' attitudes where we had not expected them. Then we had a meeting, worked out a strategy and went back to the colleges, schools, leisure centre and nurseries and said we thought they had got some things wrong.

The result was good. We didn't threaten, we just said let's work together. The result is some really practical and low-cost improvements in access, some useful training from our local primary care trust on medication, first aid, lifting, etc. Some disabled people and family carers have themselves been giving training – we realised that the 'fear barrier' was the biggest disincentive to change. Everybody was so preoccupied with 'risk' (unquantified but there like a phantom at the feast). All our local services now have accessibility plans – the colleges and schools must have them anyway but best of all, the family carers and disabled people are part of the three-year planning cycle. We've been able to show social services too that things like direct payments can buy very different services – and everybody is happy.⁴⁷

Improving access may require professional advice. A design solution, which works well in one building, may not be suitable for another. Sometimes existing space can be used differently. Some changes to physical features (for example, the creation of a changing space in a toilet) may require planning permission, building control approval and/or other consents. For many people with a learning disability, accessible buildings are no use without accessible information and signage. Similarly, staff may need some additional training.

However, as family carers continually remind us:

'Access' means more than bricks and mortar. Attitudes matter most. Negative expectations cause the greatest barriers.

Information, staff attitudes and assistance, accessible car parking or transport facilities are important to everybody – but they are often forgotten! The Disability Equality Duty offers a new opportunity for local authorities, disabled people and family carers to work together to maximise access and inclusion.

Disability equality – small changes to promote accessibility

Lakhvir has four children. She is studying an Open University course. Her oldest son Saghir has a learning disability. Saghir regularly visits a local leisure centre and gym, which has made major adaptations in order to include disabled people. Saghir likes to visit the gym on his own. He can walk to the centre and he has a leisure pass. But recently he has come home early, anxious and tearful, and now he refuses to attend the centre at any time. Lakhvir uses the time he spends at the centre to study. If Saghir is at home, this is not possible. She finds out that Saghir won't go to the Centre because they have altered the layout to improve physical access. But this means that people using the gym have to follow complicated signs round the building to get to the lift to the third floor. Saghir cannot read and he gets lost. His mother and the local carers' group ask the centre to put up some signs, using pictures and colour, to show how to get to the gym. The Centre Manager refuses 'because they will spoil the newly painted walls'. He says they will buy proper signs with next year's budget. Lakhvir explains about her son and asks if one of the staff could meet him and his friends and take them up to the gym. This is refused too.

Lakhvir goes to the Family Carers sub-group on her Partnership Board and they tell the Centre Manager that he is probably breaking the DDA. He has a duty to make 'reasonable adjustments' and simple signs (or a staff member available to guide users) would be low-cost and reasonable adjustments pending the new signs. They explain that the DDA covers people with learning disabilities who can walk very well, but who need accessible information to use a service. The Centre agrees to put up the signs. And they also agree that a staff member will be on duty for a few weeks to help service users who are not familiar with the new layout of the building. Everything works well and Lakhvir and Saghir are happy. The Centre Manager has reflected on what has happened and has asked some disabled people and family carers to carry out an 'access audit' of the building and suggest how he can make it truly 'open for all'. He will build their ideas into his Local Authority's Disability Equality Scheme.

Many service providers are carrying out access audits, to make sure that they meet the requirements of the DDA. Access audits are a useful way of making an access plan to make a service accessible over time. This access plan can form part of the Disability Equality Scheme. Some changes may involve altering the physical environment, eg, putting in ramps, moving doors and creating more accessible toilets. But others are about changing attitudes, providing accessible information and offering personal support and training where appropriate. Information on access audits is available from the Disability Rights Commission and other organisations listed at the end of this guide.

Do the Disability Discrimination Acts cover public services?

The DDA applies to all services, whether in the public or independent sectors. It protects disabled people from discriminatory (ie, 'less favourable') treatment in the provision of information and access to services. Therefore, it applies to:

- **Provision of information**
- **Access to health services** (including dentists, GP practices, chemists, opticians and hospital health services).
- **Access to education:** DDA duties on education were introduced in the SEN and Disability Act 2001, which applies DDA duties across all education services from pre-school through to higher and adult education provision.
- **The provision of services from the local authority (eg, housing and social services)** but note that the DDA does not require local authorities to deliver any particular packages of care or levels of provision.
- **Access to the business sector** (eg, banks, shops, restaurants, offices).
- **Access to the voluntary sector**
- **Employment**

Service providers can take their financial resources and the practicality of the task into account when deciding whether they can make changes to services or to the physical environment. But they cannot treat a disabled person 'less favourably'

than a non-disabled person for a reason relating to his or her disability. Therefore, family carers should check whether:

- Social services offices are accessible for disabled people, with opening hours which are convenient and transport available if appropriate.
- The written information and/or advice services are accessible and relevant.
- Disabled people and their family carers can access local leisure, sporting and cultural activities.
- People with learning and other disabilities can use their local health services without difficulty.
- Transport is accessible (if provided).
- Disabled people are not discriminated against in the allocation of local authority housing, provision of repairs, etc.

The crucial test for the DDA is 'less favourable treatment' for a reason relating to a disability. However, many instances of alleged discrimination really reflect lack of training and relevant information for staff. It is particularly important that family carers and their support groups should ensure that they are actively involved in any local consultation or planning arrangements about services. They should regularly ask:

- Are service providers making 'reasonable adjustments' to the way in which they offer services for disabled people and their carers?
- Are there short term, medium and longer term plans to improve access and inclusion?
- Are service providers offering 'auxiliary aids and services' (remember this can be personal assistance rather than a piece of equipment!)?
- How can organisations for family carers and disabled people get involved in local inspection arrangements?
- Are family carers consulted and involved in any proposals for community development, to

make sure that services are accessible right from the start?

- Are transport arrangements adequate?
- What training is involved for staff? Training may range from general disability equality training to specific training in giving medication or lifting or moving a disabled person.
- In the case of a public service (for example, social care), how can family carers contribute to the three-year action plan within the Disability Equality Scheme now required under the DDA 2005?

Family carer organisations have an important new opportunity to make sure that local services really are family carer friendly (and to expect change if they are not).

How can the Disability Discrimination Act help family carers?

The DDA covers discrimination against disabled people, not against family carers (unless they are disabled). But many family carers feel discriminated against because their relatives cannot access the same services as other non-disabled people. For example, many colleges now provide childcare and other care facilities to enable everybody to study for qualifications or as a leisure activity.

Family carers may be able to use the DDA if:

- **The childcare or other care facilities do not provide appropriate support for their relative.** Maybe they refuse to include him or her because they are unwilling to provide extra support or because they think there may be health and safety issues.

They should ensure that:

- **The service has an admissions policy, which is positive about the inclusion of disabled people and clear about the support it can offer.**
- **The staff should be willing to make reasonable adjustments in order to accommodate disabled people.** If they cannot include him or her, then they must have a justification. In this case, the discrimination in law is against your relative,

not against yourself. But the impact of the discrimination affects you too, because you may be unable to follow your course!

- **It is important to remember that a growing number of family carers are also disabled.** The DDA definition of disability is very broad and you are protected if you have recurrent conditions like cancer or arthritis.

‘We can’t manage disabled children here – our insurance wouldn’t allow it!’

Mira is 30 and has two children. Ranjit is 4 and has a learning disability and cerebral palsy. He is a lively and happy child but needs assistance with personal care. Mira is a single parent and determined to qualify as a teacher. In the short term, she is studying for her ‘A’ levels at a local FE college. She enjoys the college and feels she is making good progress. But she needs to use the college nursery for three afternoons a week in order to complete her course. Her daughter Sara is easily included. But the nursery is reluctant to admit Ranjit, saying that they ‘can’t accommodate disabled children who need personal care’. Mira is desperate to continue her course. She talks to the local Early Years Development and Childcare Partnership. They explain that Part 3 of the DDA covers the College nursery. The nursery cannot have a policy which excludes disabled children, but must consider what reasonable adjustments they might make. After discussion, the nursery agrees to include Ranjit. They take advice from his physiotherapist on his personal assistance and are able to borrow a portable ramp and install a handrail in the toilet area. The nursery draws up an accessibility plan and proposes to improve physical access over time, using their refurbishment budget. Mira passes her examinations and is now training to be a teacher. She feels she has a new life because the college recognised its duties under the DDA.

Access to education

The SEN and Disability Act 2001 amended the DDA and introduced a new Part 4 into the DDA. Education (for pupils and students of all ages) is now covered by the disability discrimination duties. Detailed information on disability discrimination duties in education is given in the Disability Rights

Commission's Codes of Practice (see Further information at the back of this guide).

The education duties do not specifically address family carers (although family carers would say that finding the right education for their relative is a service for them too!).

The key DDA duties in education state that disabled people must not be discriminated against in access to education. Schools, colleges and universities have duties to progressively improve access to:

- The curriculum
- The physical environment
- Information

Education matters. Many disabled people and family carers will be anxious to learn new skills and where possible get the qualifications necessary in order to work. Others may wish to study as a leisure activity. Some family carers may need access courses in order to begin any formal programme of study. And family carers should remember that there are increasing numbers of courses designed for them – either for enjoyment or to learn new skills.⁴⁸

It is important to remember the DDA education duties cover 'education and associated services' – this means that after-school and breakfast clubs, leisure, sporting and cultural activities are covered in schools, colleges and universities. These are particularly important because family carers and their relatives (of any age) may use different facilities on the same site.

Getting to work – using the DDA to access the after-school club

Grace's son Winston is 16 years old and has a learning disability and a serious egg allergy. Grace needs to work and when Winston's school opens an after-school club as part of the Government's new Extended Schools Programme, she is delighted. Winston will be able to stay on at school with his friends and she knows he will be safe. But the organisers of the after-school club say they cannot consider admitting a pupil with an allergy and a learning disability. They offer all the students an after-school snack and they say that Winston may take the other children's food and have an acute allergic attack. They offer to include him if Grace agrees to come to the school and supervise his 'tea break' but still argue that 'Winston might steal food, mightn't he?' They also say that they won't administer Winston's epipen if an attack occurs 'because we aren't trained for that sort of thing'. Grace is devastated by the refusal. She needs to work and she has been offered a work-based training course. Winston wants to be with his friends. A friend tells her that she may be protected by the DDA. She talks to the SENCO (Special Educational Needs Co-ordinator) in the school and to a local disability group. They talk to the after-school club staff and it is agreed that as all the students eat their snack together, a named member of staff will watch what Winston eats. There will be a notice in the kitchen to list any food allergies or special dietary requirements for children using the club, to remind staff (and volunteers) to be careful. The school nurse is willing to train the staff in using emergency medication. Because the staff are still nervous, the school offers to send them on a first aid course. This will be useful in future jobs! The club organisers check that their insurance indemnifies staff who volunteer to give emergency medication. Winston attends his club and the organisers have made 'reasonable adjustments'. These adjustments prevent discrimination against Winston, but they benefit his mother too! She completes her workplace training and is now working in the finance department of a large company.

The Disability Discrimination Acts 1995 and 2005 both apply to educational establishments across the age range. Early years settings, schools, colleges and universities have duties under Part 4 of the DDA to make reasonable adjustments and to plan progressively over time to improve access to the physical environment, the curriculum and information. They are covered by the Disability Equality Duty set out above and all schools and colleges will be required to produce Disability Equality Schemes, with three-year action plans, to demonstrate how they will improve equality of opportunity for disabled people.

A key message from carers' groups and local authorities participating in our survey was that:

Education matters – although schools and colleges' primary purpose is not to provide childcare or respite, nonetheless they have a crucial role not only in improving family carers' life chances but in offering a range of positive opportunities to disabled children and adults themselves. If schools, colleges and local authorities work together, they can reduce family dependence upon traditional social care and offer more stimulating and appropriate activities to a wider range of people in the local community. However, this cannot be achieved without a strategic approach.

But, as one local authority in a rural area commented:

The Carers (Equal Opportunities) Act made us think laterally. There were good facilities (and linked childcare and leisure activities) at two of our local colleges. Our family carers

and their relatives told us they did not really want to use old-style very institutional day and overnight services. But they couldn't get to the colleges – no buses, and family cars were invariably out with the wage-earner. But we linked together. We used part of our Carers' Grant for Direct Payments for travel. We negotiated with local taxi firms and there was very good take-up. Everybody was happy and two of our mothers have just graduated with degrees in health studies – they will work locally and benefit their isolated community. But it could not have happened without a good working partnership. We are now exploring distance learning as a further option in partnership with the National Extension College.

In the same authority, a family carer (with a disabled husband and a child with a serious health condition) commented that:

Getting involved in developing our local Carers' Strategy and thinking about the local authority's first Disability Equality Scheme helped us all – to move away from thinking in individual boxes and to be creative, putting computers in carers' centres, thinking about distance learning, talking to the colleges about a wider range of courses. It's a human right to have access to education AND you have a right to a family life. The trouble is that the two have often not gone together in the past. Thinking about this Act helped us to join up the circle.

8 The Human Rights Act 1998

The Human Rights Act 1998: key provisions and principles

- The right to life
- Freedom from inhumane, cruel or degrading treatment
- The right to liberty and security
- The right to respect for private and family life
- Prohibition of discrimination
- The right to marry and found a family
- The right to education
- The right to health
- Freedom of thought, conscience and religion
- Freedom of expression
- The right to peaceful enjoyment of possessions
- The right to a fair and public trial (this can include assessments!)

The Human Rights Act (HRA) protects the basic rights of everyone in the UK. All public bodies as well as individuals and private service providers acting in a public function have a duty to comply with it. It applies to both disabled people and to family carers. It is possible to use the Human Rights Act in addition to the DDA and other Acts in a number of situations, for example if the absence of appropriate care or support means that a family carer is deprived of the right to 'privacy and a family life'.

The Human Rights Act is made up of a series of articles and three articles are particularly relevant to family carers:

- **Article 2** – the right to life
- **Article 3** – the right to be free from cruel or degrading treatment

- **Article 8** – the right to respect for private and family life.

The Human Rights Act recognises two types of human rights, namely:

- **Absolute rights** (which apply to everyone, eg, the right to life).
- **Qualified rights** (which require individual rights to be balanced against the rights of others, eg, the reciprocal rights of family carers and the person being cared for).

Human rights and health and safety and risk management

Family Carers might be able to use the Human Rights Act if, for example, the staff at a local day service have a blanket ban on any personal assistance for people who need physical help in getting in or out of a wheelchair or going to the toilet because they regard this as a health and safety issue.

The Disability Rights Commission has successfully argued that this treatment constitutes 'cruel and degrading treatment' under the DDA and HRA and that nobody should be required to wear incontinence aids when, with safe assistance, they could use a toilet. Luke Clements, in a review of the Human Rights Act and its implications for family carers notes that family carers⁴⁹ could also state that they were being deprived of a family life (a key right under the HRA) because, in the absence of appropriate personal care, the disabled relative might have to stay at home – and other family members' quality of life and capacity to work or carry out ordinary family tasks were adversely affected.

Many family carers tell the Disability Rights Commission that they have problems about 'risk'.⁵⁰ They find that support workers are unwilling to lift or move a disabled person. Sometimes they refuse to give medication or to include a disabled person in leisure activities or on trips and outings. Families are told that there will be problems with insurance if they include their relative – and staff are worried that they will be taken to Court if someone has an accident or gets ill.

‘We can’t take the risk’

‘Jenny’, the mother of an eighteen-year-old disabled son, reported that her college refused to allow her son (who had a stair-climbing wheelchair) to access an art and drama course because he ‘might tip backwards and injure other students’. They were willing to make ‘reasonable adjustments’ through the provision of special equipment and some personal support but objected to the wheelchair. Jenny was studying for a law degree and the art and drama class provided support for her disabled son while she studied. The local authority had provided a ‘direct payment’ in order to pay the course fees and transport, but could not control admission to the college. On advice from the Disability Rights Commission, Jenny asked for a risk assessment to be carried out. She brought independent reports from her son’s physiotherapist and from the rehabilitation unit, which had overseen the purchase of the wheelchair and the training necessary to use it. The college agreed that it did not have a robust risk management policy and introduced a new risk assessment procedure. Jenny’s son was able to access his art and drama course and she completed her law degree satisfactorily.

A service provider can take health and safety issues into account when deciding if they can offer a service to a disabled person. But they must take appropriate advice and demonstrate that they have fully assessed any potential risk.

Issues around moving and handling can be more difficult. Practical help is essential for many disabled people and their family carers, if they are to have an ordinary life. Sometimes a refusal to lift or move a disabled person might be considered ‘cruel and degrading treatment’ under the Human Rights Act as well as discrimination under the DDA.

A case in East Sussex ended in a landmark judgment relating to moving and handling. The case focused on the needs of two young women with profound and multiple learning disabilities. East Sussex County Council had introduced a blanket ban on care workers manually lifting any disabled or older person, in order to prevent injury to their backs. But the families found the hoists

were difficult to use and hurt the young women’s backs. They went to Court arguing that the young women were being treated unreasonably and the ruling did not take account of their human rights to dignity, freedom and independence.

The Court ruled that there must be a balanced approach to the rights of disabled people and the rights of workers to be protected by health and safety regulations. The Judge concluded that the young women had a right to participate in community life. He thought that some manual lifting and moving would always be necessary because access to recreation and social activities were essential for quality of life. Although he was clear that there might be instances when lifting a disabled person would not be practicable, he stressed that no ban on lifting should be made without:

- Carrying out a full risk assessment.
- Considering appropriate training, if moving and lifting are required.
- Taking into account the impact of a ‘no lifting’ ban on the disabled person.
- Considering the wishes and feelings of the disabled person and his or her human rights.

Useful practical advice on health and safety and risk management is given in *The Dignity of Risk*.⁵¹ But the challenge of the Human Rights Act, as with the Disability Discrimination legislation, lies within positive assessment, sensible (but sensitive) assessments of risk and – from the point of view of service users and the local authority – clear policies, practices and procedures which are based on local consultation and are transparent and equitably implemented.

9 Welfare Reform Legislation

Implications for family carers

Currently, 3 million working-age people juggle paid employment with caring responsibilities. It is estimated that around 4 million people with caring responsibilities are of working age, but around 1 million are not in work. Around 400,000 family carers receive the Carers' Allowance and around 10% of these undertake very small amounts of work.

Around one-fifth of the 2.7 million Incapacity Benefit claimants are also carers and around 40% care for more 20 hours a week. A study from Sheffield Hallam University⁵² found that poor-quality care services cause high levels of stress to carers who are in employment. Data from the 2001 Census shows that family carers are twice as likely to suffer ill-health if they are providing over 50 hours of care a week,⁵³ with other research indicating very high levels of stress-related disorders where only inappropriate or inadequate support for care was available.⁵⁴ Many of these family carers would themselves meet the definition of disability under the Disability Discrimination Acts 1995 and 2005.

Child Poverty Action Group and the Disability Rights Commission⁵⁵ show that 40% of adults out of work, who are of working age, are disabled. 40% of households with children, where both parents are unemployed, have at least one disabled person in the family. Hence proposals for welfare reform will be directly relevant to these families' life chances, with particular reference to access to learning, training and employment.

The Welfare Reform Bill was introduced into Parliament in July 2006 and brings forward the proposals discussed in the Government's Welfare Reform Green Paper, *A New Deal for Welfare: Empowering People to Work*.⁵⁶

The new legislation changes the current arrangements for claiming Incapacity Benefit and extends the range of services and support offered to people unable to work because of a medical condition or disability and also to people who are unable to work for reasons relating to family care and other individual circumstances.

The Employment and Support Allowance

Part 1 of the Welfare Reform Bill introduces an Employment and Support Allowance in place of the current Incapacity Benefit. A person may be entitled to an Employment and Support Allowance by either satisfying a National Insurance Test (similar to that already required for Incapacity Benefit) or an income test (similar to that required for Income Support). Claimants will also be assessed for limitations on their capacity for work because of their physical or mental condition, and satisfying certain other conditions.

The Welfare Reform Bill will introduce the Personal Capacity Assessment, which primarily focuses on what the person concerned requires in order to move into paid employment.

The assessment phase of applying for an Employment and Support Allowance may include:

- Work-focused health-related assessments to provide additional information about the claimant's functional capacity;
- Work-focused interviews – claimants will be asked to discuss what steps they can take to move towards work. They may be asked to participate in the drawing up of an action plan of work related activity. This action plan will not be obligatory.
- Work-related activity – undertaking activity which would increase the likelihood of getting a job. This could include activities such as work trials, continuing education or training, which may be identified through an action plan. Claimants may also be offered programmes designed to help them manage the health condition which is creating a barrier to employment.
- Support from an individual Personal Adviser, who will not only provide support during assessment and agreement on work-related activity and access to relevant training, etc., but who will also provide on-going support during an induction period.

- Specific advice and support with regard to any special circumstances, such as identifying appropriate childcare or support for another family member, purchases of suitable clothes, etc., and advice on travel and other arrangements.

The Work-Related Activity Premium (WRAP)

The Work-Related Activity Premium (WRAP) will introduce enhanced support for lone parents wishing to enter or return to the labour market. This premium will provide an additional weekly payment for up to six months. Initially WRAP will be made available to lone parents in pilot areas who have been on benefits for at least six months, whose youngest child is aged 11 or over and who engage in some work-related activity (which can include training or relevant education activities). Quarterly work-focused interviews for those lone parents with a youngest child aged at least 11 will also be rolled out alongside WRAP in the pilot areas. As announced in the Budget 2006, the existing lone parent work-focused interview regime is changing to introduce six-monthly interviews for all lone parents not already subject to the quarterly regime (ie, those with a youngest child aged 0–13).

The increase in the schedule of work-related interviews is not intended to be punitive. Lone parents will continue to receive Income Support and any activity to prepare for work remains voluntary. However, the interview schedule should enable parents wishing to work, or to enter vocational training or other education schemes, to get better advice and support at an earlier stage. The emphasis is very much on action planning, although family carers are not required to undertake activities identified within their action plan.

Why will the Welfare Reform Bill ‘make a difference’ to the lives of family carers?

The Welfare Reform Bill should benefit both family carers and those whom they support. Many family carers themselves have health conditions or disabilities which would meet the broad-based definition of disability within the Disability Discrimination Acts 1995 and 2005. Even if the family carer is not disabled, he or she may still benefit from the proposals to provide better information, advice and support to get back into employment (which can include assistance with training or study and with childcare or other cover for the sick or disabled relative).

The Welfare Reform Bill takes a longer-term view of employment prospects than previous legislation. It acknowledges the importance of access to education or training in order to access certain occupations. It acknowledges the successes of the Pathways to Work pilots in enabling disabled people and others who were long-term unemployed to think of ‘careers rather than short term employment’ and to identify and develop essential skills in order to achieve this objective.

In particular, the Welfare Reform Bill will:

- **Simplify the present benefits system for those whose health has affected their capacity for employment**, through the new Employment and Support Allowance. This allowance is designed to encourage people with a range of health problems into, or back into, employment.
- **Introduce a strong presumption of earlier intervention**, with increased support to employers and employees in managing health in the workplace, reducing absence and encouraging stronger partnerships with health professionals in order to provide relevant treatment and support.
- **Provide improved advice and support for individuals with health conditions (including family carers)** to enable them to realise their ambition to return to work. The improvement in individual advice and action planning will build on the existing successful Pathways to Work pilots.
- **Introduce the Personal Capacity Assessment**, which should identify and strengthen the claimant’s own strengths and identify training and care needs to be addressed prior to entering employment.
- **Provide improved information and advice on education and training options**. Consultation on proposals around welfare reform identified real concerns about gaining qualifications and training necessary for future employment. Family carers and disabled people in particular underlined the importance of training opportunities and financial support during the training process.

- **Ensure more ‘customer contact and employment advice and individual support’**, ie, personalised support to ease the transition back into employment or to retain employment where problems have arisen.

Working together: the local authority and Pathways to Work

The pilot Pathways to Work schemes have helped 25,000 people back into employment. By December 2006, it is estimated that Pathways to Work was available across 19 districts. By April 2008, the scheme should be available to all new Incapacity Benefits claimants.

The proposed changes have implications for local authorities as well as family carers. For family carers, the Welfare Reform Bill should mean:

- A more transparent and equitable assessment system for people who are disabled or have a health condition which affects their ability to work.
- Better information, advice and support in accessing training or skills development necessary for future employment.
- Specific assistance in ‘action planning’ and engaging in ‘work related activities’ (which include education and training) for single parents and others wishing to enter or re-enter employment.
- Longer-term support through the expansion of the Pathways to Work schemes.
- In certain circumstances, assistance with specific concerns such as childcare, family support and other services necessary to enable family carers to engage in activities outside the home.

For local authorities, the new arrangements also have important implications with special reference to meeting the requirements of the Carers (Equal Opportunities) Act. These include:

- Stronger partnerships between Job Centre Plus and other local employment services and local authorities in terms of providing information, advice and support for work or work-related training.

- Reviewing local services for parents of disabled children and support for family carers with regard to supporting training and employment.
- In carrying out Carers’ Assessments, ensuring that family carers are aware of financial and other support available through DWP, Pathways to Work and similar schemes.
- In assessing the support needs of disabled people, ensuring that they are aware of support that might be available through Pathways to Work, Access to Work and similar schemes.
- Working with the local Job Centre Plus and the Learning and Skills Council to explore positive ways of engaging family carers in work-related activities (Carers’ Assessments and collectively within the Carers’ Strategy, including access to continuing education and training) and providing information both individually.

As one local authority commented:

The ‘next generation’ of family carers (and of course disabled people) will expect ‘ordinary lives’. Historically we have provided care and support but not necessarily seen our role as facilitating education, training or employment. Now, if we get the partnership right, we can help more carers and disabled people to achieve independent lives. Our key role in supporting welfare reform may be to be more flexible in our support. Modest direct payments may be more useful than traditional centre-based care – which we have to ration anyway. Independent living is a key Government objective. To achieve it, we will need much closer working relationships and mutual understanding between education, health, employment and social care services.

The Work and Families Act 2006

The proposed welfare reforms are of particular relevance to family carers who wish to work or to train or continue education in order to pursue a particular career path. There are likely to be stronger strategic partnerships between Job Centre Plus and other employment services and local authorities. They are also likely to support a more flexible and dynamic approach to employment and training for women (and men) with family

responsibilities. In response to a report from the Women and Work Commission⁵⁷, a Women's Enterprise Task Force has been established to provide high profile leadership to accelerate women's enterprise development throughout the UK. Similarly, HM Treasury is supporting a project to improve employment opportunities for women of South Asian origin in Yorkshire and Humberside, targeting inactive Asian women and using female role models to demonstrate the range of quality jobs that local women can do – and to promote opportunities for study and training in order to access similar opportunities. These initiatives and the Women and Work Commission acknowledge the importance of flexible (often part-time) working for many women (and a growing number of men) who have childcare or other caring responsibilities. Hence the Work and Families Act is of particular relevance to family carers because it:

- Extends statutory maternity pay
- Provides additional paternity leave and pay
- Extends the right to request flexible working to carers of adults and
- Introduces deregulatory measures to help business manage absences relating to childcare or other caring responsibilities.

The right to request flexible working was introduced in the Employment Act 2002. This Act gave the right to request to parents of children under six or parents of disabled children under the age of 18. The Work and Families Act extends this right to carers of disabled adults. Although family carers do not have an absolute right to flexible working or parental or carers' leave, the employer must consider such requests sympathetically and be prepared to justify refusal. For many family carers, positive responses to requests to work more flexibly or on a part-time basis would enable them to remain in employment and to have 'ordinary lives'. One local authority had already anticipated the new legislation and was permitting two staff who were also family carers to work flexibly and part-time. Despite some initial concerns from senior managers, they noted that:

We had invested a considerable sum of money in training these two key staff. They were unable to continue in full-time employment and were anticipating moving to lower level, less satisfactory and poorer paid employment in order to get the flexibility they now needed. In fact the flexibility worked to everyone's advantage. We are now looking more widely at job shares, acknowledging that in many human services flexibility for staff means flexibility by staff – for example one of our two staff in question was very happy to do evening visits and assessments or even to work at weekends when other relatives were at home. Therefore she and her colleague are progressing their careers. They need less support from social care and we have retained two experienced staff members. We are now including information and advice on employment and training within our Carers' Information Pack. We realise that traditional roles and attitudes to caring are changing and we can use resources differently.

The Disability Rights Commission has noted that many family carers are themselves disabled. The right to flexible or part-time working, commensurate with qualifications and aspirations, would be warmly welcomed. It is therefore vital that local authorities ensure that their Carers' Strategy provides information on employment options and support, which is available through the expanded New Deal and Pathways to Work programmes.

10 Looking to the future

The Carers (Equal Opportunities) Act 2004

Key messages from the local authorities and carers and parent support groups, which contributed to this guide include:

- Seeing the Act as an opportunity to inform, support and strategically engage family carers in the development of local social care services.
- Recognising the importance of information (often with regard to other legislation) to ensure that family carers are not dependent upon social care services because they have been unable to access their preferred training, continuing education or employment.
- Acknowledging the contribution made by family carers and the physical and emotional strain which caring (however much valued) may place on a family. The Act requires local authorities and partners to think more strategically about carers' needs. These must include practical help.
- Using the voluntary sector more effectively. The Carers (Equal Opportunities) Act applies across the life-cycle but, as one carer commented:

You feel as if you cross the frontier to a new country when your child leaves school or when your partner reaches retirement age. Age-appropriate care matters. But it matters just as much that we have continuity of care and 'whole authority planning'. Some of us are disabled as well as carers, or caring for several people in one family. Don't leave us out.

As the final evaluation of the ACE Project⁵⁸ noted:

ACE identified the development of carer awareness training materials for dissemination by Job Centre Plus, trade unions and local authorities as one of its desired policy outcomes. New resources of this type are being produced and carers' lives are being transformed. But it has not been possible to judge the take-up and wider impact of these resources at this stage.

... An important question which arose frequently in our discussions was the need for more general carer support throughout the country. Support for carers is complex. While ACE Projects and/or general carer support delivered by specialist agencies help carers to overcome individual barriers, systems and labour market barriers may still remain.

ACE highlighted a continuing and challenging agenda for action, namely widespread concerns about:

- Inflexible or poor quality local social care
- Variable opportunities for continuing education or training (changing career directions often being a major concern for women carers)
- Unclear eligibility criteria for support
- Some confusion about the role of social care in supporting training or employment
- Transport – frequently the biggest barrier to good services
- Cultural attitudes and expectations around caring
- An increasing number of people with complex disabilities and high individual support needs living at home (including policy trends such as early discharge from hospital with the assumption that the family will provide a high level of care)
- The benefits trap.

However, SCIE⁵⁹ notes emerging positive practice, with local authorities realising the importance of proactive partnerships in meeting the needs and aspirations of a changing group of family carers. SCIE notes that:

The extent to which carers are disadvantaged can be viewed in terms of the social model of disability, in that it is the barriers in society rather than a person's caring role that restricts

them. Inflexible services and lack of awareness, both within and without social care, can contribute to the social exclusion of carers.

The 2004 Act requires that other public bodies give due consideration to requests from the local authority for assistance in planning services for carers. Cooperation between authorities is essential for the support of carers. It will not only raise awareness among other public bodies of their responsibilities towards carers, it will also encourage society as a whole to support and value carers rather than leaving them just to social services.

As large-scale employers, public services (including social services) are themselves in a position, at a time of major change, to set an example for good practice in employment. In addition to this, links should be made with local employers to promote a carer-friendly approach to employment.

As SCIE acknowledges, local authorities have a critical leadership role. The Carers (Equal Opportunities) Act 2004 provides a holistic and broad-based approach to assessing and making provision for family carers. It inter-relates with other legislation and Government policy and it acknowledges a changing role for family carers, who increasingly expect to have an active life in family and community in addition to their caring roles.

This guide provides a framework for local development, emphasising the importance of building on family carers' own aspirations, abilities and personal resources whilst acknowledging the many challenges faced by families within their caring roles.

Further information is set out in the Appendices to this guide.

11 Appendix 1: Carers' assessments – what's in it for you?

Ideally, you should not be sent a form to complete on your own, unless you request this or you're just sent it to look at in advance, and/or go through to prepare yourself.

Even if you do choose to fill in the forms yourself, the assessor should go back through the forms with you to check they understand your situation properly and to agree the things that might need to happen in future to support you better.

It's also a good idea to have a friend or someone who knows your situation well at your assessment with you, to help you speak up and complete the forms.

Fatima with her daughter, Zanib
Fatima is 75 and cares at home for her daughter, Zanib. With the support of a social worker and bi-lingual carers support worker, both Fatima and Zanib's needs were explored thoroughly and Zanib now enjoys a great deal more support. Fatima says: 'As an older carer it is fantastic to finally get respite care. I enjoy my time alone, especially knowing that my daughter is having a great time'.

Where will the assessment take place?

You should be able to choose where and when your assessment happens. Ideally, the person you care for should not be present during your assessment, so that you can talk freely without worrying about upsetting them. Most people like to meet at home but sometimes it's good to go somewhere where you feel able to talk freely in privacy.

How long will the assessment take?

Some people go through the form quite quickly, especially if they've looked at a copy of the form in advance. Others take a long time and may need several visits from the person going through the form with them. It should all depend on you and you should not be made to feel you have to rush – it's too important to get this right!

How should I prepare in advance?

It isn't always easy to remember all the extra things you do as a carer. If you work through the checklist in this booklet (or a similar 'pre-assessment checklist' that your local area might send you) it will help you focus on all the things you do and what support you would find helpful.

Everyone in the family who is a carer should fill in the checklist.

Checklist for the Carer's Assessment

Many family carers (and local authorities) tell us that they would find a good checklist helpful in preparing for a Carer's Assessment. The following checklist was developed by the Foundation for People with Learning Difficulties on behalf of the Valuing People Support Team (VPST) and the Care Services Improvement Partnership (CSIP). We are very grateful for their permission to reproduce the checklist in this guide. The checklist forms part of a wider booklet on Carers' Assessments, which can be accessed (together with further information on the work of the Valuing People Support Team and the Care Services Improvement Partnership) on their website at: www.valuingpeople.gov.uk.

Do you help the person you care for... Remember, 'helping' includes prompting, having to remind someone and more – it's more than what you physically do to help a person	Yes	No	I/we would like more help with this
Everyday help			
Getting in and out of bed?			
Washing, dressing, bathing and undressing?			
Toileting and/or using continence aids?			
Cleaning, housework, gardening and jobs around the home?			
Shopping and cooking and/or help with a specialist diet?			
Eating and drinking?			
Laundry and/or changing and washing bed sheets and clothing?			
Dealing with money, personal correspondence and form filling?			
Arranging transport or using public transport?			
Getting out and about to different social and leisure activities?			
Making sure they are safe in the daytime and at night?			
Being awake or waking regularly to give support?			
Coping with their feelings and difficult behaviour (emotional support)?			
Communicating and being understood?			
Helping the person you care for to speak up?			
Understanding information and dealing with people or organisations?			
Being an appointee for finances?			
Health needs			
Arranging and going to routine and specialist health appointments (including GPs, dentists, opticians and so on)?			

Do you help the person you care for... Remember, 'helping' includes prompting, having to remind someone and more – it's more than what you physically do to help a person	Yes	No	I/we would like more help with this
Filling prescriptions and collecting medication?			
Making sure medication is taken in the right dose at the right time?			
Other health needs (for example helping with feeding tubes or catheters or checking insulin levels)?			
Getting information about different health conditions?			
Watching for side effects of medications?			
Monitoring on-going medical condition?			
Dealing with health professionals?			
Going to and staying in hospital?			
Cutting toe nails and finger nails?			
Thinking about yourself			
Do you have a disability or illness that affects your ability to care?			
Would it help you to have your own needs assessed separately and not just as a carer (for instance, if you are older or disabled)?			
Do you manage to get any spare time to yourself for leisure, hobbies, or meeting up with friends?			
Do you feel quite isolated?			
Would you like to be able to meet new friends?			
Does your caring role sometimes cause problems with your relationships with family and friends?			
Does your GP know that you are a carer and give you the support you need?			
Are you working?			
Would you like to work but find that your caring responsibilities make this difficult?			
Are you studying or training?			
Would you like to study or train, but find that your caring responsibilities make this difficult?			
Getting breaks from caring			
Do you regularly get some time to yourself?			
Do you usually get a full night's sleep?			
Do you ever get a complete break from caring?			
Are you able to get away on holiday to somewhere you want to go to?			

Do you help the person you care for... Remember, 'helping' includes prompting, having to remind someone and more – it's more than what you physically do to help a person	Yes	No	I/we would like more help with this
Can the person you care for be left alone safely for short periods of time, such as when you go to the local shop?			
Do you know what short break or respite services are available locally?			
Practical things that might help you			
Can you manage well in the property you are in?			
Do you feel that some equipment or adaptations might help you and/or the person you care for? (Examples include handrails, raised toilet seats, washing machines, stair lifts, and so on).			
Do you feel confident you are getting all the financial benefits you may be entitled to, such as carers' allowance and council tax benefit?			
Do you have the right phone numbers and information that you may need to get help in an emergency?			
Do you feel safe in your home, or would you like a home safety check to discuss things like smoke alarms and door chains?			
Do you get information, services and support provided in a language and format that you understand, and that suits your culture and religion?			
Do you know where to go for practical advice and support?			
Do you know how to get information and advice about leaving money or property to the person you care for without affecting their benefits?			
Have you had some training and advice in things like moving and handling or first aid that might be useful to you in your caring role?			
Your feelings			
Do you feel that you are willing and able to carry on caring the way you are doing now?			
Do you feel you have a choice about going on caring in the same way that you are doing now?			

Do you help the person you care for... Remember, 'helping' includes prompting, having to remind someone and more – it's more than what you physically do to help a person	Yes	No	I/we would like more help with this
Do you feel that caring is affecting your relationship with the person you look after, family and friends?			
Do you have people you can talk to in confidence about how you are feeling?			
The future			
Do you feel confident that the person you care for will be supported well if something unexpected happens to you?			
Do you know who would look after the person you care for, if there was a family emergency?			
Do you feel confident about what will happen to the person you care for in the long-term future?			
Do you feel confident that there will be people who can support the person you care for to speak up in the future, or to advocate on their behalf?			

Show the checklist above to the person who comes to do your carers' assessment so they understand more about your caring role and what would help you. Ask them to help you think about ways you can get any help you need. Even if they say something cannot be done ask them to write it down anyway so that services know the sorts of help that should be on offer.

Appendix 2: A checklist for positive practice

- 1. The Carers' Strategy.** An opportunity to work creatively with local carers, recognising changing expectations and new opportunities (eg, access to, or retention in, education, training and employment).
- 2. Carers' Assessments.** Have family carers been involved in developing local arrangements for Carers' Assessments? How responsive is the local authority when a family carer requests a Carers' Assessment? Are Carers' Assessments regularly monitored, reviewed and information on gaps in services fed into local planning and commissioning systems? Carers' assessments should be dynamic and proactive. Do they focus on outcomes for both family carers and disabled people (ie, on life chances as well as on any immediate care needs)? Do they actively promote access to education, training, employment and leisure, signpost to other agencies and inform the improvement and further development of local resources?
- 3. Positive partnerships between family carers and disabled people's interest groups.** Family carers are directly affected by the quality of support and services offered to their disabled relatives (and their relatives' willingness to use services which may not be 'fit for purpose'). Improvements in access to education, training or employment for disabled people will also benefit their family carers.
- 4. Information and data collection.** Who are the family carers? Does the local authority have comprehensive information on the full range of local services? What do family carers actually want? How does the local authority communicate with family carers?
- 5. Managing diversity.** Family carers may include parents of disabled children, disabled parents, young carers, family carers wishing to study or work, older family carers and families where there are multiple caring needs. Family carers come from all communities and cultural and social backgrounds. The Carers' Strategy must reflect this diversity and therefore complement and contribute to other strategic functions of the local authority, eg, the Children and Young People's Plan.
- 6. Auditing local provision.** An audit of local provision should include information on support offered through statutory and voluntary sector providers. It should gather information on the local service users, including where possible information on their employment status, ethnicity, age, etc. and identify gaps in provision, particularly where there is inequality between different groups of family carers. Data collected through the audit should inform the development of a commissioning strategy with local partners to address gaps in service and to anticipate future demand.
- 7. Multi-agency strategic planning.** Are the full range of local partners involved, eg, health, housing, education? Does the Carers' Strategy address the evolving needs of children and young people, disabled people as family carers, family carers wishing to study or work, or older family carers?
- 8. Leadership and capacity building.** Has a 'carers' lead' been appointed within the local authority (with similar leads identified in other statutory services)? Responsibility for carer support does not rest solely with the local authority.
- 9. Positive partnerships.** Local strategic partnerships should ensure that links are made with local employers, Job Centre Plus and the Learning and Skills Council with the aim of providing accurate information on local opportunities for learning or employment and support for family carers in any academic or career choices.
- 10. Fair access to care.** Are the eligibility criteria transparent, reflecting local need and developed and regularly reviewed in consultation with the full spectrum of family carers in the area? Are policies on charging for services reasonable and understood by local carers?
- 11. A Welfare MOT!** Are family carers receiving the disability allowances and other benefits to

which they are entitled (including support for study, training or for a return to, or retention in, employment)?

- 12. Health and well-being.** Local authorities should work in partnership with Primary Care Trusts to ensure that moves towards practice-based commissioning take account of the needs of family carers and support both their own health and well-being and any health-related support for their relatives.
- 13. Education matters.** The Carers' Strategy should acknowledge the importance of access to education and training in improving family carers' health, well-being and life-chances. Support for learning could include personal support for the disabled person, assistance with transport or access to leisure activities which also provide cover for the relative, payment of fees for local or distance learning courses and 'short breaks' to cover residential courses (eg, summer schools) or examination periods. Partnerships with Job Centre Plus should improve access to funded training linked to future employment or to assistance with transport, equipment, etc. when a disabled person wishes to study or work.
- 14. Carers' emergency cover.** Recognising that some family carers need minimal help except in an emergency – the Carers' Strategy should explore options for emergency care (including cover for employment or family illness).
- 15. Cultural sensitivity.** No presumptions should be made that families from the black and minority ethnic communities do not need access to support services. It is important to check policies, procedures and take-up of services (including recruitment of staff from the relevant BME communities) and to support the engagement of local community groups within strategic planning at local level.
- 16. Flexible funding.** Explore the option of Direct Payments or individual budgets (with clarity about support for 'new users' and the purpose of such budgets). Not all family carers wish to organise and purchase their own support. However, many family carers wish to do so and, with appropriate practical guidance, can identify cost-effective options to meet their individual needs.

- 17. Making it work – The Disability Equality Scheme.** Local authorities, as public bodies, have a duty under the DDA 2005 to produce a Disability Equality Scheme, with a three-year action plan. The duty focuses upon equality of opportunity for disabled people, but should take into account others (including family carers) who are affected by it. The Disability Equality Scheme offers an opportunity to plan and review progressive improvement in the full range of services offered to disabled people and their families in an area. Family carers' participation in the development of the three-year action plan and its related impact assessment should ensure partnership in planning and a more strategic approach to implementing the Carers (Equal Opportunities) Act 2004 as intended – ie, to promote the life chances of family carers, as well as providing practical help with day-to-day living.

Appendix 3: Paying for care

Disability allowances and benefits which may help

All adult learners need to make certain that they are claiming all the allowances and benefits they may be entitled to. Many families do not claim allowances to which they are entitled – or claim them at the wrong level. Many allowances and benefits are not specific to supporting adult learners with caring responsibilities – but they can make a great deal of difference to meeting the extra costs of disability. It's important to remember that if a disabled child or other family member is eligible for disability benefits or allowances, they may be able to get additional help with childcare or family support costs as a student.

One Carers' Centre decided to work with the local authority in offering 'Welfare Benefits MOTs' to all carers who wanted them, including those carers who were trying to fund access to learning or training alongside their caring roles. Lucy had a disabled son and was trying to complete her law studies whilst caring – and paying the bills. The Welfare MOT revealed that her son was entitled to a higher level of the social care element of the Disability Living Allowance and for the first time to the lower level of the mobility component. This in turn enabled her to claim the higher level of the working tax element of Child Tax Credits. Lucy had not been aware that she could now use her Child Tax Credits to pay for approved childcare in her own home. She had been paying £40 a week in taxi fares to get her child to an after-school club on the other side of town. The approved home carer could now greet him after school, prepare his tea and look after him until she returned from her regular evening classes.

What might a 'Welfare MOT' cover?

The Disability Living Allowance (DLA) is the main allowance for disabled children and adults. DLA is not means tested and is in two parts. The care component is paid at three rates and helps with personal care. The mobility component helps with mobility and is paid at two rates. If the disabled person is eligible for the higher rate of the mobility component, he or she may be eligible for a Blue Badge for disabled parking and road tax exemption. The higher mobility rate can be converted into a payment to Motability, which can provide a car or scooter. Although in many cases the family carer will drive the vehicle, it must be used for the purposes of the disabled person and not as a general family car.

DLA is an important 'passport benefit' because it can help family carers to claim enhanced payments, for example in Income Support, Jobseekers' Allowance or Council Tax Benefit. Families claiming Child Tax Credits can receive a higher rate of Working Tax Credit if their child or a parent receives DLA. The Attendance Allowance is paid for people of 65 or over and is similar to DLA. Both DLA and the Attendance Allowance can be paid at enhanced rates if the disabled person's care needs change. Success in applying for both allowances is likely to be greater if families have help and advice. Contact a Family and Carers UK (contact details on page 64) can provide information packs and a Help Line to support applicants.

The Carer's Allowance helps carers who provide a minimum of 35 hours a week and whose relative receives the middle or highest rate of the care component of DLA. The allowance is means tested. The allowance can be claimed by students providing that they are not studying for more than 21 hours a week.

The Carer's Allowance can't usually be claimed if the carer is receiving certain other allowances such as Maternity or Jobseekers' Allowances. But it can help carers qualify for other means tested benefits such as Income Support.

Some carers may be eligible for the Carer Premium, which is an extra amount added to the means tested benefits described above.

Child Tax Credit and Working Tax Credit can be important sources of extra income for parents with a disabled child. Working Tax Credit is a means tested tax credit for working people on low incomes. Child Tax Credit is a means tested tax credit for people with children. There are enhanced rates if there is a disabled child or student under 19 in the family, if the parent carer is disabled and for certain 'approved' childcare costs. Contact a Family (see page 64) has produced a useful Tax Credits Guide as a 'ready reckoner' for working out entitlement.

The Benefits Enquiry Line (0800 88 22 00) offers free information on all allowances and benefits. Organisations also offering advice services are listed in Appendix 2 of this guide.

Appendix 4: Further information

These contact details and websites can give you useful information about help with the costs of learning and also with the costs of caring.

4Children: Information on school and pre-school-based care, including children's centres, out-of-school and holiday schemes in your area. Ring them on 020 7512 2112 for advice or go to their website at: www.4children.org.uk

Career Development Loans can sometimes help students who want to study a vocational course. The loan can last for up to two years and can include childcare or other care costs. Contact 0800 585 505 for further information.

Carers UK provides information and advice to carers (and professionals and local authorities working with carers) through a range of publications, newsletters and a Carers Line (0808 808 7777). Carers UK can put you in touch with local carers' groups and activities. More information is available on www.carersuk.org

Childcare Link (phone: 0800 096 0296) is a Government-funded information line on childcare options (including childminders, nurseries, and advice on childcare to enable you to study or work). It can give special advice on childcare arrangements for disabled children or young people. It can also give employers advice on paying for childcare. Remember that the Childcare Act 2006 now requires local authorities to provide childcare for young disabled people up to the age of 18.

Children's Information Service: Every local authority must provide a Children's Information Service to provide information on childcare options in your area and also to give advice on local arrangements to help with the costs of childcare. Call 0800 096 0296 for further information on your local service.

City and Guilds Learning for Living Courses: Details of the City and Guilds Centres which are running the programme are available on their website at: www.learning-for-living.co.uk City and Guilds courses are particularly useful for students wishing to return to learning, to refresh their skills or simply to increase their confidence for the future.

Contact a Family is a national organisation, with local groups providing information and advice to parents of disabled children. Their helpline can be accessed on 0808 808 3555. Their website gives further details at www.cafamily.org.uk Contact a Family is particularly interested in helping parents and family carers to find suitable childcare for work or study and can advise on the costs of childcare, including tax credits.

The Daycare Trust is another national organisation giving information on childcare for parents, for providers and for local authorities. It can give advice on funding childcare (including employers' schemes to contribute to childcare costs) and childcare for disabled children. More details are available on www.daycaretrust.org.uk

The Department of Trade and Industry (DTI) has a range of information on its website on your right to flexible working, parental and carers' leave and childcare vouchers, etc. Go to www.dti.gov.uk/workingparents Remember that the Government has now ratified the European Directive on Age Discrimination, and older workers should also have the right to flexible working and carers' leave!

Department of Work and Pensions is the key Government Department for disability benefits and allowances. You can find information on how to apply for Disability Living Allowance, Carers' Allowance and other benefits on their website at www.dwp.gov.uk Many family carers do not claim allowances to which they are entitled, so check this website, which has regular updates on benefits.

Directory of Social Change has a number of useful guides on grants from over 2,500 trusts and charities. Phone 08450 77 77 07 for further information.

The Disability Alliance publishes an annual *Disability Rights Handbook* (an authoritative guide to disability benefits and allowances) and regular bulletins. These can be ordered through www.disabilityalliance.org

The Disability Rights Commission can provide information and advice for disabled people, their carers, providers of care and for local authorities and others who are planning or commissioning care services. It also works with schools, colleges and universities to make sure that they fully include disabled people. All providers of childcare, other family support and care services and all education and social care services are covered by the Disability Discrimination Acts 1995 and 2005. Call their Helpline on 08457 622 633 or go to their website at www.drc-gb.org If you want information on the new Disability Equality Duty, which came in on 4 December 2006, you can find some special information leaflets on www.dotheduty.org

Early Support Programme: The Early Support Programme is a national programme providing a range of tools and services to support parents of young disabled children and the professionals and services working with them. There are Pathfinder Programmes running in a number of local authorities. Further information is available on www.earlysupport.org.uk

Equal Opportunities Commission: The Equal Opportunities Commission can provide advice to family carers (men and women!) on family friendly working, access to study and combining caring with study or employment. Information is available on their website at www.eoc.gov.uk

Family Fund: The Family Fund can give individual grants for specific items needed by families caring for severely disabled children under 16. It can also offer a comprehensive information and advice service (for example on finding and paying for childcare for study or work). Further information is available from their Helpline at 0845 130 4542 or through their website at www.familyfund.org.uk

Family Welfare Association: This can provide grants for specific purposes (applications must be made by a social worker on behalf of the applicants). Further information is available through their website at www.fwa.org.uk

Inland Revenue Tax Credits Helpline can give you information on anything to do with tax credits on 0845 300 3900. Parents of disabled children should remember that they may be eligible for an enhanced level of tax credits and that the tax credits scheme has been extended to cover 'approved home' care for families wishing to use childcare in their own home for a disabled child. Contact them on 0845 300 3900.

Job Centre Plus: Information on a wide range of employment and training issues (including help with child or family care when you are training or starting a new post). Remember that the Government's Welfare Reform Bill currently going through Parliament will enable Job Centres to offer additional help to parents and family carers wishing to study, train or get back into work despite their caring responsibilities. Regularly updated information is available on www.jobcentreplus.gov.uk or on the Department of Work and Pensions website referred to above at www.dpw.gov.uk

Learndirect is the national learning website, offering a wide range of regularly updated information on courses and funding issues. Further information is available on www.learndirect.co.uk

Learner Support Funds can help FE students with the costs of books, equipment, etc. and can help pay for child or other family care while you study. Arrangements vary locally and you should contact your LEA or ring the central Help Line on 0800 100 900.

MENCAP offers help and advice to family carers of children and adults with a learning disability. Go to www.mencap.org.uk for further information.

National Centre for Independent Living can give you information on your local Independent Living Centre, their role and location. A growing number of local authorities are now giving Individual Budgets or Direct Payments to disabled people and family carers to purchase their own support. Centres for Independent Living are good sources of information on local funding and services, on managing personal care and using tax credits and direct payments. Further information is on www.ncil.org.uk

National Childminders Association can advise you on finding a childminder (or on training childminders, if you are providing childcare services). NCMA can also advise on finding and using other home-based care (such as a nanny) and on using tax credits to pay for the cost of home care. More information is available on www.ncma.org.uk

National Extension College: The National Extension College runs an Equal Access to Open Learning Scheme, which can offer concessions on courses for carers who are on low incomes. It also provides a number of distance learning courses, some with 'learning networks' on-line for students who find it difficult to attend college courses. Information is available on www.nec.ac.uk

National Grants Directory: This is published and updated annually by the Directory of Social Change. Information is available on www.dsc.org.uk

National Network of Family Carers (NFCN) is a network of organisations supporting or working with family carers of a person with a learning disability. The NFCN can put carers in touch with local support groups and services. Further information is available on www.nfcn.org.uk

National Union of Students: The NUS can provide a wide range of services to students of all ages, including students with caring responsibilities. It provides a national information and advice service, including child and family care. Go to: www.nusonline.co.uk

New Deal for Lone Parents: Call 0800 868 868 for information on finding work, job training or childcare if you are a single parent.

NHS: There is information on support for childcare and information on the Childcare Allowance for NHS-funded students on 0845 009 2559.

New Start is a new scheme to help people get back into work, perhaps through retraining or starting their own business – the scheme is particularly helpful for applicants who may have had to change careers because of a disability or health problem. The scheme provides grants, assistance with business plans and access to training and mentoring. More information is available on www.newstart.org.uk

NIACE (National Institute of Adult Continuing Education) promotes lifelong learning and has a particular interest in helping carers to access education. It offers up-to-date information on funding for adult continuing education and on the range of provision round the country. Further information is on www.niace.org.uk

The Open University provides a wide range of flexible learning opportunities and gives concessions on courses to students on benefits or with very low incomes. Further information is on www.open.ac.uk

The Princess Royal Trust for Carers runs a wide range of carers' centres and services and can offer bursaries for study. It has a comprehensive information and advice service. Details of national and local services are available on www.carers.org

SCIE (Commission for Excellence in Social Care) publishes a range of practical guidance on good quality in social care services. For further information, go to www.scie.org.uk/carers

SKILL (the former National Bureau for Handicapped Students) can give useful advice and financial support for disabled students in further and higher education. Details are on www.skill.org.uk

Sure Start: The Government's Childcare Strategy and the creation of children's centres and extended schools nationwide should benefit families with a disabled child who are looking for childcare cover to work or study. You can download free leaflets on childcare for disabled children and young people and a booklet on looking for childcare on www.surestart.gov.uk

Tax Credit Helpline: Parents with disabled children may be able to get help in paying for childcare through Child Tax Credit and Working Tax Credit. You can get information through the Tax Credit Help Line on 0845 300 3900 or go to: www.taxcredits.inlandrevenue.gov.uk

Trades Union Congress runs the 'Know your Rights' Help Line on 0870 600 4882 for information on parents' and family carers' rights in employment (including the right to training).

Working Families provides information and support to parents. They can offer information on childcare and disabled children, and support a network of working parents with a disabled child or young person. Contact their Help Line on 0800 013 0313 or their website at www.workingfamilies.org.uk

Worktrain is the Government's national employment and learning website at www.worktrain.gov.uk

12 Notes

- 1 The Childcare Bill 2004 for the first time requires local authorities to provide sufficient and appropriate childcare for families of disabled children who wish to work. Support for appropriate education and training are included within this new duty.
- 2 Dr Stephen Ladyman (Parliamentary Under-Secretary of State), House of Commons Standing Committee, 10 March 2004.
- 3 T Jarrett and A Mellows-Facer (2004), Carers (Equal Opportunities) Bill Research Paper 04/13.
- 4 Luke Clements (2005), *Carers and their Rights – the Law Relating to Carers*, Carers UK.
- 5 P Russell (2005), *A Guide to Support for Adult Learners Caring for Disabled Children or Other Family Members*, The Nuffield Foundation.
- 6 The Childcare Bill 2004 for the first time requires local authorities to provide sufficient and appropriate childcare for families of disabled children who wish to work. Support for appropriate education and training are included within this new duty.
- 7 National Network of Family Carers, personal communication.
- 8 L Buckner and S Yeandle (2006), *Who Cares Wins: Working Carers – Evidence from the 2001 Census*, Sheffield Hallam University, ACE Project and Carers UK.
- 9 P Sloper et al (2006), *British Medical Journal*, 1 November 2006. P Russell (2006), *Ending Child Poverty: Families with Disabled Children*, paper for the Disability Rights Commission and Treasury 'Round Table' on ending child poverty, July 2006. Eric Emerson and Chris Hatton (2005), *The Socio-economic Circumstances of Families with a Disabled Child*, University of Lancaster.
- 10 A copy of the Act is available at www.hmso.gov.uk Explanatory notes on the Act are available at www.legislation.hmso.gov.uk Or via the Carers UK website at www.hmso.gov.uk
- 11 Department of Work and Pensions, (2006) *Carers Aspirations and Decisions Around Work and Retirement*, www.dwp.gov.uk
- 12 Carers UK, Parliamentary Briefing on the Carers (Equal Opportunities) Act 2004, available on www.carersuk.org.uk, Carers UK, *Without Us: Calculating the Value of Carers' Support*.
- 13 Carers UK (2003), *Missed Opportunities: the Impact of New Rights for Carers*.
- 14 TUC, *Full Employment – the Next Steps*: a TUC report on working age inactivity in Britain and in the rest of Europe.
- 15 All educational establishments are covered by the Disability Discrimination Acts 1995 and 2005. They must make 'reasonable adjustments' to accommodate disabled students. Information on these duties is available on the Disability Rights Commission website at www.drc-gb.org
- 16 Department of Health (2002), *Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care*, Circular LAC (2002) 13.
- 17 L Clements (2006), *Carers and their Rights – the Law Relating to Carers*, Carers UK.
- 18 C Heron (1998), *Working with Carers*, Jessica Kingsley.
- 19 Department of Health and Department for Education and Skills (2002), *Framework for the Assessment of Children in Need and their Families*, HMSO.
- 20 Department of Health (2005), *Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004: Combined Policy Guidance*, DH Publications Unit or www.dh.gov.uk
- 21 DH/DfES (2002), *The Framework for the Assessment of Children in Need*.
- 22 Princess Royal Trust for Carers (2006), *Practical Guidance for Carers*.
- 23 SCIE (Commission for Excellence in Social Care) (2006), Practitioners' Guide 5: *Implementing the Carers (Equal Opportunities) Act 2004*.
- 24 DfES/DH (2006), Information on the Common Assessment Framework and Every Child Matters is available at www.everychildmatters.gov.uk
- 25 Disability Rights Commission (2002), *DDA 1995, Part 4, Code of Practice or Schools and DDA 1995, Part 4, Post-16 Duties* (revised version of Post-16 Code to be published summer 2006).
- 26 Carers UK (2006), *Missed Opportunities: the Impact of New Rights for Carers*.
- 27 DH (2006), *Your Health, Your Say, Your Care, White Paper on Future Directions in Health and Social Care*, Department of Health Publications.
- 28 Prime Minister's Strategy Unit (2005), *Improving the Life Chances of Disabled People*, Cabinet Office.
- 29 Department of Work and Pensions (2006), *A New Deal for Welfare: Empowering People to Work*, The Stationery Office, London.
- 30 Disability Rights Commission (2006) *Closing the Gap: a Formal Investigation into Health Inequalities in Accessing Primary Care Services*, in press.
- 31 Disability Rights Commission, response to survey for Formal Investigation into Health Inequalities op cit.

- 32 Department of Health (2005), *Independence, Well-being and Choice: Future Directions for Social Care*, Department of Health.
- 33 L Richardson and L Sefton (2005), *Community, Work and Family*, Volume 8, Number 1.
- 34 DH (2002 and 2003,) *Fairer Charging Policies for Home Care and Other Non-residential Social Services*, Department of Health.
- 35 Personal communication – the local authority in question has subsequently appointed a new Family Carers’ Sub-Group which brings together representatives from local young carers, disability, children’s and other carers’ interest groups and contributes proactively to local planning and review arrangements. The group has regular meetings with the Directors of Children’s and Adult Services respectively.
- 36 Department of Health (2005), *Carers and Disabled Children Act 2000 and Carers Equal Opportunities Act 2004 Combined Policy Guidance*, Department of Health.
- 37 Personal communication from a local authority.
- 38 Contact details for the Disability Rights Commission are given on page 65.
- 39 The current three equality bodies are the Disability Rights and Equal Opportunities Commissions and the Commission for Racial Equality. The new single equality body, the Commission for Equality and Human Rights, will bring the current three equality bodies together, also including three new equality strands of work around religion, older people and sexual orientation. The rationale behind the creation of a single equality body is the UK becoming a signatory to the European Convention on Human Rights. This convention expects protection from discrimination across all six strands.
- 40 Information and Codes of Practice available on the Disability Rights Commission website at www.drc-gb.org or SKILL at www.skill.org.uk
- 41 Centre for Accessible Environments (2005), *Developing Access Audits – Practical Approaches*.
- 42 Disability Rights Commission (2006), *Code of Practice on the Disability Equality Duty and Doing the Duty: an Overview of the Disability Equality Duty for the Public sector*. Available from www.drc-gb.org (can be ordered as hard copies).
- 43 The definition of a ‘public authority’ is set out in the DRC Code of Practice (see note 4 above). Government has the right to extend or further clarify this definition by regulations over time. However, all statutory services (ie, health, education, social care, housing, the police, environmental services) come under the new duty.
- 44 ‘Harassment’ includes bullying and hate crime. It applies to children and adults.
- 45 See note 4 above for clarification.
- 46 Disability Rights Commission (2006), *Code of Practice on the Disability Equality Duty and Related Practical Guidance* (in press) – available on www.drc-gb.org
- 47 Communication through Disability Rights Commission focus group.
- 48 A range of modular courses designed specifically for family carers are being developed within LDAF (the Learning Disability Accreditation Framework) and in partnership with CSCI (Commission for Social Care Inspection).
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