The equality and diversity of carers

- Equality and carers
- Carers rights and entitlements
- Diversity of carers
  - hidden carers
  - young carers
  - carers from black and minority ethnic (BAME) communities
  - caring and gender
  - carers from lesbian, gay, bisexual and transgender (LGBT) communities
  - mutual caring
  - carers of those with mental health issues
  - carers of people who misuse substances
  - carers in rural communities
  - caring in older age
  - caring and people with learning disabilities
- Signposting to further resources.
The equality and diversity of carers

Equality and carers

The Home Office identified these six strands of diversity to categorise or group together common human differences. The law currently makes discrimination in relation to these six ‘protected characteristics’ (age, gender, race, religious belief, disability and sexual orientation) unlawful.³

Carers should be recognised explicitly as existing within each of these strands and deserving particular attention in the planning and delivery of services.

Ensuring that carers are not directly or indirectly discriminated against while promoting and enabling their participation in society and local communities requires careful planning and well thought out action.

³ HM Govt 2010 Government ‘The Equality Act’ 2010
Carers’ rights and entitlements

Carers were first mentioned in legislation in 1986. In the first 15 years the legislation focused on how carers should be supported to carry out their caring role; more recently, and particularly with the introduction of the Carer’s Equal Opportunities Act 2004 and the Work and Families Act 2006, there is an increasing requirement to view carers as individuals with a right to a life beyond caring and a right to their own support.

Most significantly The Equality Act 2010 creates a seventh strand to the equality framework described above, by requiring public authorities to undertake impact assessments to ensure their policies do not have a detrimental effect on carers. These Equality Impact Assessments are likely to provide an important mechanism for increasing awareness of carers’ needs and rights through large parts of the public sector. They may prove to be valuable tools for carers’ organisations challenging circumstances where they feel that carers’ needs have been overlooked (Carers UK 2009).

The Equality Act 2010 also means that carers cannot be directly discriminated against or harassed by their employer because they are caring for someone who is disabled. The new rights protect carers in situations where they are provided with a poorer service than someone who is not caring for a disabled person, as well as protecting carers where they are discouraged or prevented from using a service because they are caring for a disabled person.

Earlier carers’ legislation and guidance places more specific obligations and good practice expectations upon health and social care organisations.5

For example:

- Social services departments must inform carers of their rights to an assessment of their own needs and the services that are available to support them.
- Social services departments must consider carefully how they address a carer’s needs where a ‘critical’ level of risk has been identified through a carer’s assessment.
- It is good practice for primary health care providers (GPs) to identify carers, keep a register of all carers in their practice, and provide support to maintain their health.
- Hospitals must ensure patients are ‘safe for discharge’ in order to return home and cannot ignore the risks to the carer.
- The regulations for providers of adult health and social care services encourage them to understand, value and respect the important work that carers do, and urge them to work cooperatively with carers when meeting the needs of the people who use their services (CQC 2009).

---

4 An equality impact assessment is a tool for identifying the potential impact of a public body’s policies, services and functions on its residents and staff. It can help staff provide and deliver excellent services to residents by making sure that these reflect the needs of the community, including carers.
5 The main legislation that sets out local authorities’ responsibilities for supporting carers is the Carers and Disabled Children Act 2000 and the accompanying ‘Carers and people with parental responsibility for disabled children practice guidance’ (Department of Health 1st March 2001).
Diversity of carers

Hidden carers

Many carers do not recognise themselves as carers. They simply see themselves as husband, wife, parent, son, daughter or friend. The majority of carers do not access formal services and therefore could be missing out on valuable support. Many carers report concerns about the difficulties they experience in accessing services but they do not experience caring or the effects of caring equally. Some groups of carers experience additional barriers to accessing support or services for themselves or the people they care for. These are described in the sections that follow.

Young carers

Whilst many staff might spend the majority of their time working with adults they may still come into contact with families. Children and young people within these families may be carers, providing direct care or taking on additional responsibility for household chores in order to support others in a caring role. There are additional relevant resources available to those who work, or occasionally come into contact with families and children or young people, which may be particularly relevant when working with young carers. The Common Core of skills and knowledge for those working with children and young people, which may be particularly relevant when working with young carers. The Common Core of skills and knowledge for those working with children and young people will help to identify the skills and knowledge all staff need when working with children and young people. The six areas of expertise in the Common Core offer a single framework to underpin multi agency and integrated working, professional standards, training and qualifications across the children and young people’s workforce.

See http://www.education.gov.uk

When considering the Common Core Principles for Working with Carers in relation to young carers it is important to consider the following:

■ Workers should recognise that young people can care for a member of their own family and that they have a right to a family life with well-supported parents.
■ Workers should be able to identify young carers and offer support and information to prevent social isolation and vulnerability.
■ Workers who support the parents, siblings and relatives of young carers should also listen to and support the young carers themselves.

Four other points to consider:

■ Workers should prevent young carers from falling into appropriate caring roles by putting in place adequate support for the parent or relative with care needs (including out of hours/emergency support).
■ Workers should make links with other services in order for the whole families’ needs to be addressed (including health and education).
■ Workers should recognise that young carers can also be experts in the illness/condition of the person with care needs and consider their views when putting support into place for the person needing care.
■ Workers should also recognise the many young adult carers aged 16-25 and their particular needs. These may include combining education and caring or entering the job market for the first time. For further support and information see; www.niace.org.uk
Carers from black, asian and minority ethnic communities (BAME)

Carers from BAME communities have broadly the same needs as other carers but can experience additional barriers when trying to access support for the person they care for or for themselves.

In a Carers UK 2007 survey of around 2,000 carers in England, Scotland and Wales, nearly 10% were from minority ethnic backgrounds. This research found that compared with other carers, carers from BAME communities are:

- More likely to report that they struggle to make ends meet
- More likely to be caring for their children, particularly children aged 20-25
- Less likely to be caring for someone over the age of 85
- More likely to be caring for someone with a mental health problem
- More likely to say they are using direct payment arrangements to pay for services
- More likely to combine working life with caring responsibilities.

BAME carers are also more likely than other carers to say that they were unaware of local services, that services were not sensitive to their needs and that their use of services was limited due to cost or a lack of flexibility. A number of people made comments about a lack of cultural appropriate support and services, although when present, it was much appreciated, even if things did not always run smoothly.

Lack of information about available support services is reported as an issue affecting BAME carers. There are a number of reasons why this may be the case: people may not seek information about support because care-giving is perceived as a ‘duty’ and the family’s responsibility; information is not given in a culturally appropriate way; there are language barriers between service providers and caregivers; issues of social isolation, and concealment of illness due to stigma. In addition, the term ‘carer’ itself is a relatively new term in social policy which may not have resonance in some minority languages. There is in fact no translation of the word for carer in some languages and it is therefore a difficult concept to convey.

There are further sources of information and support on how to improve services for BAME carers at;

http://www.carersuk.org/professionals/resources/practice-guides/item/2233-bame-toolkit

and;


---


7 The Afiya Trust 2008 ‘Beyond We Care. Putting Black Carers in the Picture’.

8 National Black Carers and Carers Workers Network.

8 For further details on BAME carers, please see ‘Half a Million Voices – Improving Support for BAME Carers, 2011’.
Caring and gender

The gap in care provision between men and women is closing but women remain more likely to provide personal and ‘heavy duty’ care.

Of the 4.27m carers in Great Britain, 1.8m are men and 2.4m are women, with women providing around 70% of caring hours. The changing employment patterns of women is one of the key factors affecting the future supply of carers and demonstrates the need to support people to combine paid work and care. Women working in the public sector are more likely than other full-time workers to be carers, as are women with a history of working in a caring profession.

Carers from lesbian, gay, bisexual and transgender (LGBT) communities

In the past and often still today, LGBT people have not been acknowledged as valuable members of their local communities, and have often felt discouraged from taking part in local community decision-making for fear that their voices are not wanted and will not be heard.

LGBT people may also be carers. In addition to the usual barriers experienced by carers, there are LGBT-specific barriers to them accessing local services and support.

The Equality Network has developed a how to guide on Involving LGBT people in community planning. This guide aims to provide a brief introduction to some of the challenges planners face in involving LGBT people, and some suggestions for overcoming these barriers. This guide has been developed in consultation with local planning departments and LGBT organisations. Whilst the guide’s focus is on involving LGBT people in community planning, the barriers people experience to getting involved may also apply to LGBT carers who need access to local information and services to support them in their caring roles. The guide aims to provide an LGBT slant on the National Standards for Community Engagement, focusing in particular on practical, concrete suggestions for better engagement that will equally apply to engaging LGBT people in a caring situation.

You can download the guide from www.lgbtcommunity.org.uk
Mutual caring

More people are living longer than ever before, including people with learning disabilities. As a result, an increasing number of people with learning disabilities are still living at home with family carers who are now 70 or older. Those carers may be parents, siblings, grandparents, or other close relatives or friends. They have often spent a lifetime caring.

Over the years, as family carers start needing more support themselves, the families have often developed routines and ways of coping that mean that both the older person and the person with learning disabilities are looking after each other. This is known as mutual caring.

An increasing number of people with learning disabilities are providing regular and substantial care for their ageing relatives. This care ranges from help with personal care, medication, cooking and cleaning to help with shopping and keeping them company as they go out and about less. In many cases, without each other's support, neither person would be able to remain living independently within their local community.

Mutual caring amongst older families is increasing but often remains hidden. Some of the main issues for people with learning disabilities who are carers include:
- feeling proud of helping out and returning the care and support that has been provided to them by their parents for so many years
- generally not being recognised for their role as carers
- not always offered many choices about continuing to care or the way that other support is being provided
- fear from both the person with learning disabilities and the older family carer of being judged and separated if workers discover the extent of the mutual caring that is happening
- lack of information that is accessible and easy to understand about peoples’ rights as a carer, support that might be available and the different health conditions that their elderly relative may be suffering with
- lack of practical support that could make a big difference, such as with shopping, changing light bulbs, getting to appointments, getting the right benefits
- feeling isolated and having reduced opportunities for friendship and breaks.

All of the points above are issues that all carers often struggle with anyway. The struggle is even more difficult if a person has learning disabilities.
Audio – visual resources

The Foundation for People with Learning Disabilities is part of the Mental Health Foundation, a registered charity that provides information, carries out research, campaigns and works to improve services for anyone affected by mental health problems.

They have developed a range of resources called ‘Mutual Caring’ which focus on the growing number of people with learning disabilities living with an elderly relative. Often, as their relative needs more support, the person with learning disabilities takes on a growing caring role, known as mutual caring. The resources include a DVD which highlights families’ stories, information and planning booklets and a policy briefing.

Molly Mattingly, Assistant Director, states ‘Mutual caring is often unrecognised by services, which means that families do not receive the support and services they need. We developed the resources as a way of raising awareness of this issue’.

Further information is available on the website:
www.learningdisabilities.org.uk
or via Molly Mattingly, Assistant Director (mmattingly@fpld.org.uk).
Carers of those with mental health issues

For carers caring for someone with a mental health condition there can be additional difficulties arising as a result of the caring role.

Often carers in this role are providing intense amounts of care whilst the person is unwell but far less care when the person is well again. The nature of this care at these different times can vary greatly from intensive amounts of physical and emotional care to occasional guidance with daily life. This cycle can persist for many years and can impact on the carer’s ability to cope with being a carer. It can also impact upon professionals’ perceptions of whether the carer should be involved in the discussions about the person.

Due to common prejudices and misunderstandings about mental health, carers are less likely to discuss caring with friends and family or go to professionals for help meaning that they can end up isolated and trying to cope alone. A survey by the Princess Royal Trust for Carers in 2007\(^\text{10}\) found that 86% of these carers had not been offered any services in their own right before contacting their local Carers’ Centre. In addition, conventional respite services may not be appropriate to the needs of people with mental health conditions so families can find it difficult to get a break.

Mental illness is often hidden and unpredictable and carers may be dealing with changes in the personality of the person they care for. Carers suffer higher than normal levels of stress and poor health and this is particularly the case for this group of carers. Professionals respecting the confidentiality of the patient can be reluctant to share important information with a family member. This can leave carers feeling unsupported and, in some cases, vulnerable. It may be difficult for them to provide the care needed without enough information about the condition, treatment, medication and care plan. Professionals working with people in these situations need to involve the cared for person and carer in conversations to agree information sharing at an early stage.

You can find out more about carers of those with mental health problems at: www.nsun.org.uk (National Survivor User Network).

10 Princess Royal Trust for Carers 2007.
Carers of people who misuse substances

Carers of people who misuse substances experience many of the prejudices and difficulties described for carers of those with mental health problems and, in some cases, also face involvement with the criminal justice system.

Figures from the UK Drug Policy Commission (UKDPC)\textsuperscript{11} show that nearly 1.5 million adults in the UK are significantly affected by a relative’s drug use. About 575,000 of those affected are spouses, 610,000 are parents and 250,000 are other family members, such as grandparents or siblings. There are over 140,000 family members living with someone who is receiving treatment for illicit drug use.

With substance misuse often comes stigma and this may prevent many carers coming forward to gain support and help. Many cite feeling ‘alone’ and isolated and are often taking on other caring responsibilities (such as looking after grandchildren) whilst also caring for the substance misuser.

It is also important to note that there are also estimated to be ‘between 250,000 and 350,000 dependent children living with parental drug misuse and 920,000 living with parental alcohol misuse’.\textsuperscript{12} Many of these parents will not be known to any services, which conceals young carers in this situation.

There is more information about young carers of those with mental health and/or substance misuse issues at:

\url{www.carers.org/help-directory/mental-health}

\textsuperscript{11} UK Drug Policy Commission 2010 ‘Supporting the Supporters; Families of drug misusers’.
Carers in rural communities

Carers in rural settings experience similar barriers to accessing services, although rural carers are more likely to be unaware of local provision and to be held back in their use of services because of their expense. However, rural carers are slightly less likely to say that services are not sensitive to their needs, perhaps reflecting less diversity in their characteristics and those of the people they care for. One particular issue often raised by rural carers is the difficulty in travelling to and from services, with travel often time consuming and costly.

Caring in older age

The proportion of carers providing more intensive levels of care rises sharply from age 65, and the number of hours spent caring rises with age. Among the oldest carers, around 44,000 people aged 85 and over provide care, with around half of these (51 per cent) caring for 50 or more hours a week. Over a third of adults with learning disabilities living at home are supported by someone over 70. The situation of older carers is compounded by the increased risk of financial hardship as well as isolation and social exclusion among older people generally. Issues that arise for older carers in particular are:

- Co-caring and reciprocal caring
- Carers neglecting their own health because of their caring commitments
- Lack of information about benefits and services
- Isolation and difficulty in accessing services.

---

13 Carers UK 2010.
More people with learning disabilities and their family carers are growing old together. The situation can become quite complex, with parents still seeing themselves in a perpetual parenting role whilst at the same time becoming increasingly dependant on their son or daughter for certain aspects of their own care. In these situations it is important that the caring role played by the person with a learning disability is recognised and supported without undermining the role of the parent. This is further discussed in the ‘mutual caring’ section.

People with learning disabilities are becoming carers for their partners and friends as well as their parents, as more have the opportunity to be supported to live independently. Until recently this group of carers has gone unrecognised and more is now being done to provide information and support in an accessible way.

For more information, please see Mencap www.mencap.org

The Foundation for People with Learning Disabilities
Signposting to further resources relating to diversity of carers

The Equality Bill and Carers
Carers UK at: www.carersuk.org

BAME carers; Afiya Trust
27-29 Vauxhall Grove, London SW8 1SY, United Kingdom
Tel +44 (0) 20 7582 0400
www.afiyatrust.org.uk

LGBT carers
Equality Network, 30 Bernard Street, Edinburgh EH6 6PR, Scotland, UK
Tel +44 (0) 7020 933 952
Fax +44 (0) 7020 933 954
Email en@equality-network.org
www.equality-network.org

Mutual Caring from the Foundation for People with Learning Disabilities at:
www.learningdisabilities.org.uk

Mental health
http://www.rcpsych.ac.uk/campaigns/partnersincare/carersandconfidentiality.aspx
http://www.carers.org/professionals/health/mental-health,809,PP.html

Carers of those who misuse substances

Caring for people with Learning disabilities
www.lifetimeofcaring.org.uk
www.mencap.org.uk
www.thecbf.org.uk
www.hft.org.uk/family_care_support

Skills for Care, in partnership with Dementia UK, have produced a guide for the social care workforce who are supporting the family carers of people with dementia.

You can access this at:
www.skillsforcare.org.uk/carers