

When things go wrong

This paper is about the rights of adults with learning disabilities and their family carers in England. It outlines what action can be taken by them or their family when a person has a complaint or grievance or things go wrong. Its focus is on health and social care.

Many family carers are concerned about cuts to services for their relatives and want to know if anything can be done about these. Sometimes there are worries about provision that someone is receiving; for example healthcare, short-term breaks, day time opportunities or the place where they live. Sometimes there are cases where people are abused. In 2011, the Panorama programme about Winterbourne View, near Bristol, showed appalling treatment of residents.

Family carers need information about what they and/or their relatives can do if they have a grievance – and what they themselves can do if they are dissatisfied with the support that has been agreed that they should receive as a carer.

In the endnotes/contacts and resources list you can find references to publications/websites where you can obtain more information.

It is important to emphasise: it is better to see if disputes can be settled informally by people taking time to listen to one another's point of

view, before going down the path of formal complaints or going to court. Sometimes advocacy or mediation can help.

This paper was written early in 2012, at a time when many changes were being planned. For example, legal aid was under review and the Health and Social Care Act had just passed through Parliament. This includes the provision that, from 2013, Primary Care Trusts' duties will transfer to Clinical Commissioning Groups.

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Rights legislation

Rights for adults with learning disabilities are enshrined in law, enabling them to challenge decisions or to go to court if these rights are infringed and they cannot get their concerns addressed by discussing them with the people involved.

The Equality Act (2010)¹

The Equality Act offers protection against discrimination on grounds of disability, race, gender, age, sexual orientation and religion. It also offers protection to family carers against 'associative discrimination' (that is to say discrimination because of their association with someone protected by the Equality Act, such as a disabled person).² The Act enshrined in legislation the decision in 2008 in Sharon Coleman's successful case against her employer. She had been denied flexible working hours to enable her to care for her disabled son, Oliver.

The Act provides protection for people with learning disabilities and their families in a number of areas including employment, where an employer must not discriminate against or harass a disabled person and must make 'reasonable adjustments.' It also applies to education; access to goods, services and facilities including larger private clubs (over 25 people) and land based transport services; the buying of land or property; and functions of public bodies such as issuing licenses. The public sector equality duty means that bodies like hospitals, colleges and libraries must pay 'due regard' to the promotion of equality for disabled people. They have to consider what disabled people need when planning their services. There is also a requirement for public bodies to consider the impact on equality of their policies and to keep a record of how they considered the impact.³

The Equality Act replaces most of the Disability Discrimination Acts (DDA) and

streamlines previous anti discrimination legislation. It strengthens the requirement to make 'reasonable adjustments'. It has additional measures to prevent discrimination and harassment, including discrimination and harassment against a person because of their association with a disabled person.

The **Human Rights Act** (1998) can be a powerful tool in enabling disabled people and their families to receive better treatment, to challenge discrimination or degrading treatment and to increase participation in society. As a result of this Act, individuals have been able to challenge the way their care has been provided and to enforce their rights under the European Convention of Human Rights in UK courts. The Human Rights Act has strengthened the ability of people to challenge bad practice and negotiate better services.⁴ It does not necessarily mean going to court!

The following articles of the Act are particularly relevant:

- the right to life (article 1)
- the right not to be treated in an inhuman or degrading way (article 2)
- the right to respect for private and family life (article 8)
- the right not to be discriminated against in relation to any of the rights contained in the European Convention (article 14).

For example a challenge might be made if a family carer was harassed because colleagues thought that they took too much time off on account of their caring role. In a residential setting, a person's dignity would not be respected if they were forced to wear incontinence pads because the staff did not have time to take them to the toilet. The right to a private and family life would not be respected if someone's preference for support to live independently was overlooked and they were obliged to

go into residential care against their wishes. The right to life could be invoked if someone could not look after their own serious health condition because they had inadequate support in their caring role.

You can use aspects of the Human Rights Act in a complaint, for example to a local authority, if you think rights have been infringed.

The Equality and Human Rights Commission,⁵ set up in 2007, can provide advice through its helpline. It can also take legal action, but it is only likely to do so in a very limited number of cases, usually as a test case.

The Mental Capacity Act (2005)

The Mental Capacity Act came into force in 2007.⁶ It clarifies the responsibility for decision making and the role that families can play, especially when a person with a learning disability is assessed as lacking the capacity for a particular decision. A decision must be made in their best interests. It is important to note that neglect and ill treatment are offences under the Act.

Family members and those close to the person should usually be consulted in the decision making process where a person is assessed as lacking capacity for a particular decision. They also have a role to play in supporting individuals to get the information they need to make informed decisions that they are able to make.

For some major decisions, if family members cannot be involved for any reason and there are no friends available, an independent mental capacity advocate (IMCA) may be appointed. An IMCA may also be appointed if there is serious disagreement amongst family and/or friends.

If you believe that the process of reaching a decision has been flawed or you question whether the decision reached is in the person's best interests, the Code of Practice advises that you always work to resolve the problem informally. An advocate for the person deemed to lack capacity for a particular decision can often make a useful contribution. If the dispute is with a health or social care organisation and informal approaches do not work, each organisation will have a published complaints procedure (see below page 5).

The Court of Protection and the Office of the Public Guardian

Sometimes the Court of Protection appoints a Deputy to make major decisions on a person's behalf. A family carer can fulfil that role. There are two types of Deputies: a health and welfare Deputy and a property and affairs Deputy. However, if the person's assets derive from benefits then they are likely to have a Welfare Benefits Appointee. People over 18 with the capacity to make the decision to do so, can apply for someone to act on their behalf through a Lasting Power of Attorney. Again there are two types: personal welfare and property and affairs. A personal welfare Attorney can only use the LPA once the person is unable to make a particular health or welfare decision themselves. Some people prefer their property and affairs attorney to manage their financial affairs even though they could manage them themselves. Others may specify they only want their finance LPA to come into use when they lack capacity for such decisions.

The Court of Protection⁷ can make a ruling if other avenues are not suitable, but you would probably want to consult the Citizens' Advice Bureau or a lawyer before going down that path. The Court can be concerned with disagreements (for example, about capacity for a particular decision), disputes about best interests or the infringement of the Deprivation of Liberty Safeguards (see below).

The Public Guardian is supported by the Office of the Public Guardian (OPG).⁸ It can give advice and information about disputes under the Mental Capacity Act. Its duties include registering Deputies and Attorneys acting under a Lasting Power of Attorney, supervising Deputies, reviewing reports from Deputies and those acting under a Lasting Power of Attorney and investigating complaints about them, including making reports to the Court of Protection.

The Mental Capacity Act Deprivation of Liberty Safeguards (DOLS)

Formerly known as the 'Bournewood' safeguards, these came into force in 2009.⁹ They cover patients in hospitals, and people in care homes registered under the Care Standards Act 2000, whether under public or private arrangements.

The MCA DOL Safeguards apply to anyone aged 18 and over, who

- a. is not being detained under the Mental Health Act
- b. lacks the capacity to give informed consent to the arrangements made for their care and/or treatment
- c. for whom deprivation of liberty is considered, after an independent assessment, to be necessary in their best interests to protect them from harm.

There are three elements to the safeguards:

- to provide the person with a representative (who can be a family member)
- to allow a right of challenge to the Court of Protection against the unlawful deprivation of liberty

- to provide a right for deprivation of liberty to be reviewed and monitored regularly.

A care home must apply to the local authority and a hospital to the appropriate commissioning body for authorisation to restrict a person's liberty if they feel it is necessary, having explored other options first.

If you believe someone is being deprived of their liberty and there is no authorisation, you should talk initially to the manager of the home or a health professional in a hospital. If this does not lead to a satisfactory outcome, your next step would be to ask the local authority or PCT/Clinical Commissioning Group to investigate.

The Mental Health Act 1983 amended in 2007

The Mental Health Act enables people with a mental disorder who are a danger to themselves or to others to be legally detained for compulsory assessment or for treatment. People with learning disabilities are usually considered not to fall under the definition of mental disorder under the Act unless their learning disability is associated with abnormally aggressive or seriously irresponsible conduct. A small number are detained.

People being treated under the Mental Health Act are not covered by the Mental Capacity Act in regard to compulsory mental health treatment, which can be given without their consent, following strict rules. For example they can be legally detained for assessment for up to 28 days; for treatment for up to six months (this can be renewed) and in an emergency for 72 hours. As a result of the 2007 Act, treatment may sometimes take place in the community. This is called a Compulsory Treatment Order.

The person's 'nearest relative' (who under certain circumstances may be a parent) has a number of rights under the Act, including the right to:

- be told if the Approved Mental Health Professional (AMHP) applies for a patient to be detained for compulsory assessment
- be consulted about, and object to, an AMHP applying for the person to be detained for compulsory treatment
- receive written information about the patient's detention, rights and discharge, unless the patient objects.

When a person is detained, staff on the ward must inform them about their rights. They have a right to appeal. They need to know how to contact hospital managers and the Mental Health Tribunal. They have the right to seek legal representation. All detained patients have access to the independent mental health advocacy (IMHA) service. Patients must receive free 'aftercare' on discharge. The Care Quality Commission (CQC) regulates and carries out inspections of mental health services and investigates complaints.

For further information Mind has produced a useful outline guide that explores more fully than possible here the implications of the Acts.¹⁰

Dissatisfaction about social care and health services

The single complaints procedure

There is now a single complaints procedure for health and social care services set out in the Local Authority Social Services and National Health Service Complaints Regulations (England) 2009. It is important to note that complaints cannot be made if a legal process has started.

A complaint can be made about their care by the person themselves, usually within 12 months unless there are good reasons for a delay. In certain circumstances complaints can be lodged by another person if they are affected by what has happened. Family carers may want to complain on behalf of their relative: if the person lacks capacity to make the complaint or has asked them to make the complaint for them. Complaints can be made verbally, by email or in writing, but the organisation to which you are complaining must put in writing what you have said.

Accessing records

Under the **Data Protection Act (1998)** if you are legally able to act on behalf of a person you are caring for, you can ask for a copy of their file. You should receive information within 40 days, but the local authority or health agency can charge for doing this. Nothing in law prevents a healthcare professional from showing you your records and so you may be able to access health records informally by just asking your GP, for example.

Complaints about social care

There are several agencies to which you might want to complain:

- The local authority: It must have a published complaints procedure. Ask for a leaflet.
- The service provider: Each service regulated by the Care Quality Commission must have a complaints procedure.

Often it will be practical to start with the service provider if there is an aspect of the service with which you are unhappy. You may want to complain to the local authority if, for example, you are dissatisfied with where someone has been placed and you don't think it is meeting their assessed needs.

The local authority must follow certain laid down principles. There must be a senior staff member to lead on complaints and to learn from them. There must be a complaints manager.

An organisation must:

- acknowledge the receipt of the complaint in three working days
- deal with the complaint efficiently and investigate properly and appropriately
- give assistance during the procedure
- write to the person complaining on completion of the investigation, explaining how it has been resolved, what action has been taken and telling them about their right to go to the Local Government Ombudsman¹¹ if they are not happy with the outcome.

You should get a written response within 6 months either saying what is going to happen or telling you about the progress so far.

If you are complaining to two bodies, they must work together to respond. It is a good idea to keep written records at all stages and to send copies of a complaint to the complaints manager of that organisation. You can also approach your local councillor or MP for advice and support.

If you subsequently decide to go the Local Government Ombudsman, it must be because you believe there has been some 'maladministration', i.e. unreasonable delay; bias or unfairness; failure to follow proper procedures; poor standards of decision-making or incompetence on the part of the local authority. which has caused an injustice that has not been put right. It should not just be because you disagree with their decision.

Self directed support and complaints

The thrust of Government policy is towards personalisation. This includes the option of receiving personal budgets and direct payments. There are a number of fact sheets on aspects of self directed support on the Mencap and In Control websites.¹² If someone has a personal budget, they can think creatively about how to spend it, but the money must be spent to meet their care needs as assessed by the local authority. When the Resource Allocation System (RAS) is used to calculate how much money they should receive, it is only an indication of the amount to be allocated. The person needs to draw up a support plan. Others for example a family member, friends, a circle of support, a care manager or social worker can help them. If after doing this they are unhappy with the amount offered, they can ask why a certain figure has been reached. The local authority should show how they believe the allocation can meet the assessed needs of the person. Talk to the care manager or social worker to try to find a way forward before you make a formal complaint.

If there is a dispute with a provider, those who fund their own social care or arrange it directly (for example, using a personal budget), must first explore whether they can resolve the matter with the provider. Since 2010, they can then apply directly to the Local Government Ombudsman if they do not feel the matter has been resolved. Previously they had no such right. The complaint can be made by the person themselves, a family member or representative or others affected by the actions of the care provider.

It is important to remember that anyone employing staff will have the usual legal obligations of an employer. Some people prefer to use an agency to employ staff.

Challenging the way services are provided - or not provided

Challenging the way services are provided – or not provided – under community care law can be complicated. It is most straightforward when a public body has failed to do something clearly required by law. For example, this could be:

- the failure to carry out an assessment of a service user – or carer if a carer has requested it
- not fulfilling the duty to provide the care assessed as necessary to meet the disabled person's needs in their own home
- if the local authority has not followed guidance from the Government that is binding
- if it has a blanket policy where guidance is not binding. For example, an authority is not obliged to provide a service following a carer's needs assessment, but if no one has a service as a result of a carer's assessment it could then be challenged. It would also be illegal for an authority to say they never pay for anyone to access a service out of their local authority area.

Local authorities ration care according to the money available by having eligibility criteria under Fair Access to Care Services (FACS) guidelines.¹³ Some authorities are now only providing services to those with 'substantial and critical' – or even just 'critical' – risks to independence. If there is a failure to take individual circumstances into account and there is a blanket policy, the local authority is acting illegally. Sometimes local authorities can be challenged if they do not follow procedure. For example, there is a right to a fair hearing if someone is threatened with the removal of a direct payment. There have been several successful

challenges to local authorities that have changed the level of assessed need they will meet without doing an Equality Impact Assessment.

If you are dissatisfied with an aspect of your support as a carer or that of your relative, it is a good idea to keep a diary or written record and to keep records throughout any dispute. You must complain within 12 months, unless there are strong reasons for a delay.

Charging for services

Local councils can make reasonable charges for community care, such as day services and care in the home. Since 2003 there has been guidance to councils on charging.¹⁴ In 2010 further guidance¹⁵ was issued in the light of more people using personal budgets.

It is important to make sure at the time of assessment that you and your relative work out the costs that your relative incurs as a result of their disability – or your costs as a carer. You should be asked about these costs.¹⁶ The Disability Alliance has produced a useful Factsheet on charging.¹⁷ If you think the procedures have not been followed or the charges are unfair, you should complain. It is important to note that, when the local authority hands over the money to the service user to make decisions and organise their own support and things go wrong, you cannot complain to the local authority unless it manages the payment or budget on the person's behalf.

When can services be reduced or withdrawn?

If services generally are to be cut, the local authority must consult. With respect to individuals, if someone has been assessed as needing a service, they must have a reassessment before the service can be removed. If someone has moved to a personal budget using a Resource

Allocation System (RAS), it does not in itself justify a reduction of service. You would only expect a reduction where an assessment has identified a need for less support.

A service can be removed:

- if the person's assessed needs have reduced
- if their needs can be met in a different way
- if the local authority's eligibility criteria have changed and they no longer fall within them
- if the service user behaves unreasonably.

So far the legal challenges to reduction of services have allowed local authorities to take into account the money available.¹⁸ However, there is a duty of care and if someone is at significant risk of harm then the local authority must give support.

A judicial review

You can seek a judicial review¹⁹ if you believe that a public body has not acted in a lawful way in reaching a decision. This will not look at the rights and wrongs of the decision but at the process. A judicial review can be expensive, and legal aid is under review. It is advisable to use the other ways to resolve difficulties if at all possible. You cannot both contact the Ombudsman and go for a judicial review.

The role of the Care Quality Commission (CQC)

The CQC began operating in 2009, replacing the Commission for Social Care Inspection, the Healthcare Commission and the Mental Health Act Commission.

It is the independent regulator of health and social care in England. It includes adult social care in registered care homes and personal care through domiciliary care services. It monitors care to ensure this meets Government standards. You can

contact them by letter, phone or their website. You may want to complain to CQC if you think the service is not meeting minimum care standards or regulations: for example, where a service provider has not adhered to their regulations, such as their complaints procedure. You can contact the CQC while in conversation with the provider or making a formal complaint to the local authority. The CQC does not have the same duty to respond to individual complaints as the local authority, but it must respond if, for example, it believes people to be at risk. (See page 9 for concerns about abuse.)

What about health issues?

When you and your relative have a current grievance or concern about a service received from the NHS, you are entitled to make a complaint, have it considered and receive a response from the NHS organisation. This may for example be a hospital, a doctor's surgery or a PCT/ Clinical Commissioning Group.²⁰ You can complain on behalf of someone else as long as it is agreed you are an appropriate person: if the person has asked you to do so or if they lack capacity to do this. If you are expecting financial compensation, you must go through a solicitor.

Each health organisation should have its own complaints policies and procedures. You should ask for information about these. If you can have a discussion and change things before a formal complaint is made, it is better. You may automatically get sent a complaints form, but before filling it in it is a good idea to seek a meeting to discuss your concerns.

As with social care, complaints should usually be made within 12 months from the time that the event you are complaining about occurred or when you became aware of it.

There are increasing choices about where you can receive treatment.²¹ It is important

to note that you do not have an entitlement to a specific treatment. There is good practice guidance for a growing number of conditions through the National Institute for Health and Clinical Excellence (NICE) and the professional bodies and you can use the complaints process to protest if this guidance has not been followed. Then you might force the clinicians concerned to explain why they did not follow the guidance. Ultimately the Ombudsman and/or the relevant professional regulator might conclude that they were wrong not to have followed the guidance. However, a very large proportion of health care does not yet have such robust evidence-based guidance and it comes down to professional judgement.

The Parliamentary and Health Service Ombudsman

You should first exhaust the local complaints procedures. If you are still not satisfied at the end of the process, you can apply to the Parliamentary and Health Service Ombudsman.²² Complaints can be made in person, by email, by phone or in writing. A complaint will be acknowledged within two days and then assessed to see whether it falls within the legal remit of the Ombudsman. If it does not, you will receive a full explanation. The Ombudsman will be looking to see if there is an administrative fault or a service failure and if so whether there has been injustice or hardship as a result. If 'maladministration' (i.e. unreasonable delay; bias or unfairness; failure to follow proper procedures; poor standards of decision-making or incompetence and/or injustice) is obvious, the Ombudsman will work towards a resolution. Otherwise she will carry out an investigation first.

NHS continuing healthcare

Because of the complexity of their needs, a person may be receiving NHS continuing healthcare²³ i.e. a package of healthcare

funded solely by the NHS to meet their personal needs as well as their physical and/or mental health needs. You can ask for an Independent Review Process (IRP) if you disagree with the procedure in reaching a decision about possible eligibility or the application of the criteria about eligibility. If you have other reasons for making a complaint, you would follow the usual process for making a complaint about a health service as described above.

Getting help with your complaint on health issues

You can get information and advice from the **Patient Advice and Liaison Service (PALS)**²⁴ to help resolve the matter more quickly. PALS operate in each NHS body in England. They are not part of the complaints procedure, but they may be able to help to resolve your complaint informally and they are able to point people in the right direction to get their problem sorted more formally.

When you begin a complaints procedure you should be told about the **Independent Complaints and Advocacy Service (ICAS)**²⁵ that provides advocacy and support to patients and carers who want to take forward a formal complaint about health matters.

Concerns about abuse

Abuse can be carried out in a range of ways including financial, emotional, racial, physical and sexual. It can be online as well as face to face. Neglect is also a form of abuse. All sorts of people harm others, including those using services. Awareness raising about abuse is important.

Local authorities, health services and other agencies providing and commissioning services should be doing all they can to ensure that no one is employed who is likely to abuse a vulnerable person. They should be doing this by following up references rigorously

and carrying out CRB (Criminal Records Bureau) checks. There are plans for the Criminal Records Bureau and the Independent Safeguarding Authority to be merged into a Disclosure and Barring Service (DBS).

If you suspect that someone is in immediate danger and that a crime may have been committed, you should contact the police. If the law appears to have been broken (for example, a theft, sexual assault, physical assault or rape), the police must be involved immediately. The police should also be called if there are instances of hate crime. This is defined by the Home Office as an incident that constitutes a criminal offence that is perceived by the victim or any other person as motivated by prejudice or hate.

If you think someone is at risk, but is in less immediate danger, you should contact the local adult safeguarding board (ASB) or partnership. Contact details should be available on your local authority website. These multi agency boards²⁶ were set up as a result of the 'No Secrets' guidance (2000). The guidance was reviewed in 2008/9. In 2011 the Government published a Statement on Government Policy about Safeguarding.²⁷ It is likely that the 'No Secrets' guidance will remain in force until at least 2013, but in due course it is likely that there will be specific legislation for statutory ASBs.

To have sexual relations a person must be able to consent. **The Sexual Offences Act (2003)** established that a relationship between a care worker and a person with a learning disability is an offence, whether the person can consent or not.

You can get advice from Voice UK²⁸ if someone has been the victim of crime or abuse. The Ann Craft Trust (ACT) works to make sure organisations are aware of abuse issues and carries out research.²⁹ If someone needs therapy because of experiencing abuse, Respond³⁰ may be able to offer help.

How can we help to prevent things going wrong?

Sadly things sometimes go wrong, but there are steps that will help prevent this.

Asking questions

Families can ask questions about the policies and procedures of the organisations with which their relative is involved. For example:

- Do they follow person centred approaches?
- Are people with learning disabilities able to live with friends of their choice?
- Are people with learning disabilities involved in the selection of staff?
- Do they enable people with learning disabilities to choose those who provide their personal care if they are in residential care?
- Are visitors welcome?
- Are there robust systems to protect their money?
- Does their relative have access to advocacy?
- Is low level abuse or disrespect clamped down on?
- Are there good training programmes for staff, including programmes on adult protection?
- Do people with learning disabilities have training and information about abuse and keeping themselves safe?

Your relative will benefit from having as many people as possible to look out for them. Do they have a circle of support or an advocate? Your relative may appreciate belonging to a self advocacy group such as People First. If you have contact with other family carers, it will help you to find out where things go well and where things do not go so well.

Influencing policy and practice

You may want to influence national and/or local policies.

In some places Learning Disability Partnership Boards meet and they provide useful ways to have influence. Local HealthWatch bodies will be set up in 2013. These will supersede Local Involvement Networks (LINKs).

Through the Health and Social Care Act (2012), Health and Wellbeing Boards are intended to enable commissioners across

health and social care to make plans with elected representatives and representatives from HealthWatch to obtain better outcomes in health and well being in their area. Health and Wellbeing Boards will be charged with drawing up Health and Wellbeing Strategies, based on their Joint Strategic Needs Assessments.

You may want to join local and/or national campaigning organisations or write to newspapers, councillors or your MP where you feel things are wrong. Pressure can bring about change.

Contacts and resources

For information

Carers UK has useful information about complaining and cuts to services.
e.g. www.carersuk.org/help-and-advice/practical-help/managing-someones-affairs/disagreement-with-social-services
Carers Advice Line 0808 808 7777
www.carersuk.org

Mencap

Helpline 0808 808 1111
www.mencap.org.uk

The Family Carer Support Service

at Hft provides useful information
www.hft.org.uk/supporting-people/family-carers/family-carer-support-service
Telephone 0117 906 1751

Mind, although its focus is better mental health, has useful and relevant information on making a complaint

Making a complaint to the local authority: what steps can I take?

www.mind.org.uk/help/rights_and_legislation/how_to_complain_about_health_and_social_care

In Control offers information on self directed support

Telephone 01564 821650
www.in-control.org.uk

Patients Association campaigns for better information for patients, equality in healthcare and the right of patients to be involved in decision making

Helpline 0845 608 4455
www.patients-association.com

The British Institute of Learning Disabilities (BILD) has information on advocacy
www.bild.org.uk

People First groups

See www.peoplefirst.org.uk/pflinks.html

Legal advice

The Disability Law Service provides advice and information
www.dls.org.uk

Telephone: 020 7791 9800

It has a series of useful fact sheets including one on English Social Services Complaints Procedure

www.dls.org.uk/advice/factsheet/community_care/english_SS/English%20Social%20Services%20Complaint%20Procedure.pdf

Community Legal Services Direct

can help you find a solicitor who specialises in community care law
Telephone: 0845 345 4345

Civil mediation service

www.civilmediation.justice.gov.uk

There is likely to be a cost.

You can also get advice about mediation from the charity LawWorks

Telephone: 01483 216815
(Information on the above website)

Footnotes

1. See www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068
2. *Equality Act 2010: What do I need to know as a carer?* www.homeoffice.gov.uk/publications/equalities/equality-act-publications/equality-act-guidance
3. See www.equalityhumanrights.com/uploaded_files/EqualityAct/PSED/essential_guide_update.pdf
4. See the work of the British Institute of Human Rights www.bihhr.org.uk Some of the examples are based on those in the report *The Human Rights Act: Changing lives*
5. For information about the Equality and Human Rights Commission (EHRC) see www.equalityhumanrights.com/uploaded_files/who_we_are.pdf
The helpline for EHRC is Telephone 08456 046 610
Textphone 08456 046 620
6. www.justice.gov.uk/about/opg
www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/Makingarrangementsincaseyoulosementalcapacity/DG_185924
Making Decisions: A guide for families, friends and other unpaid carers (2009)
Office of the Public Guardian OPG 602
www.justice.gov.uk/downloads/guidance/protecting-the-vulnerable/mca/opg-602-0409.pdf
Using the Mental Capacity Act: A resource for families and friends of people with learning disabilities (2011)
www.hft.org.uk/Family_Carer_Support/MCA_Resource_Guide
7. The Court of Protection Telephone 0300 456 4600
8. The Office of the Public Guardian www.justice.gov.uk/about/opg.htm
Telephone 0300 456 0300
9. The Alzheimer's Society has a useful fact sheet about DOLS including templates for letters of complaint http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1327
10. See Mind outline guide which includes the changes made in 2007
www.mind.org.uk/help/rights_and_legislation/mental_health_act_1983_an_outline_guide
11. For complaints to the Local Government Ombudsman
www.lgo.org.uk/adult-social-care
Advice line: 0300 061 0614
12. See In Control website or Mencap website for a series of factsheets about self directed support
www.in-control.org.uk/resources/fact-sheets.aspx?page=0
www.mencap.org.uk/search/apachesolr_search/In%20control%20fact%20sheets
13. *Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care – guidance on eligibility criteria for adult social care, England 2010* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154

14. *Fairer Charging Policies for Home Care and other non-residential Social Services – Guidance for Councils with Social Services Responsibilities* (September 2003)
www.hft.org.uk/Supporting-people/family-carers/Resources/News-digests
15. *Fairer contributions guidance 2010: calculating an individual's contribution to their personal budget* – This document provides guidance for councils in England to use when determining what contribution, if any, a person receiving a personal budget should make towards it. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_121224
16. See Family Carer News Digest 17 for October 2010 for suggestions on pages 9–10 on possible costs to take into account
www.hft.org.uk/Supporting-people/family-carers/Resources/News-digests
17. Disability Alliance Factsheet 3 *Charging for Community Care*
www.disabilityalliance.org/f3.htm#England
18. See for example cases (*R v Gloucestershire CC ex p Barry [1997]* and *The appeal judgement of R (KM) v Cambridgeshire County Council February 2012*)
19. For information about a judicial review see www.publiclawproject.org.uk/downloads/WhatIsJR.pdf
20. For information about making a complaint on health issues see www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx
21. See NHS Choices www.nhs.uk/Tools/Pages/Patientchoice.aspx
22. About information about complaints to the Parliamentary and Health Service Ombudsman www.ombudsman.org.uk/make-a-complaint
Telephone 0345 015 4033
23. Age UK has a useful fact sheet on continuing healthcare and NHS funded nursing care www.ageuk.org.uk/BrandPartnerGlobal/oxfordshireVPP/Documents/CHC%20Fact%20Sheet%2020%20Sept%2010.pdf
24. See The Patient Advice and Liaison Services (PALS) website for a list of local PALS services www.pals.nhs.uk
25. For information about Independent Complaints and Advocacy Service see www.carersfederation.co.uk/nhs-complaints-process
26. The National Family Carer Network (NFCN) has produced resources in response to family carers' concerns around safeguarding. The 'Top Tips' is a 4 page briefing, that provides suggestions about preventing harm from happening in the first place and what you can do if things go wrong. The 'Essential Guide' is a 16 page booklet covering some of the key terms family carers may come across in relation to safeguarding and suggests what you can do to keep your relative safe and how to act if they have been harmed. A Resource Pack (including useful examples of good practice around safeguarding, supported by film clips featuring people's stories), produced by Hft, will follow in Autumn 2012. For further details visit www.familycarers.org.uk or www.hft.org.uk/safeguarding
27. See Statement of Government Policy on Safeguarding www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_126770.pdf

28. www.voiceuk.org.uk email voice@voiceuk.org.uk or tel: 0808 802 8686
29. www.anncrafttrust.org/aboutus.php
30. www.respond.org.uk or tel: 0808 808 0700

This paper was written by Hazel Morgan, independent consultant, for the National Family Carer Network. This information is offered in good faith as an overview. You should follow up the relevant resources before acting on anything referred to. Neither the Network nor Hazel can accept any liability regarding this information.

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