

# When things go wrong

**This paper is about the rights of people with learning disabilities and what action can be taken by them or their family when a person has a complaint or grievance or things go wrong.**

**For example, many family carers are concerned about cuts to services for their relative and want to know if anything can be done about these. Sometimes there are worries about provision that someone is receiving; for example health provision, short-term breaks, day time opportunities or the place where they live. Sadly there are cases where people are abused, recently exemplified by the investigations in Cornwall and Sutton and Merton.**

**Family carers need information about what their relative 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.**

**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 mediation can help.**



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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## **Rights legislation**

Over recent years the **Disability Discrimination Acts (DDA) 1995 and 2005**, the **Race Relations (Amendment) Act (RRAA) 2000** and the **Human Rights Act 1998** have enshrined in law, rights which people with learning disabilities can enjoy, 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 **DDA (1995)** introduced measures to prevent discrimination on the grounds of disability in the areas of employment: access to goods, facilities and services; and buying, renting land or property. Businesses, libraries, places of worship and work places for example have to make 'reasonable adjustments' to meet their needs. For example in the work place it might be obtaining some equipment that would help the person to do the job or providing easy read materials. The DDA was extended to cover schools, colleges and universities in 2001.<sup>1</sup>

The **DDA (2005)** led to the introduction of the Disability Equality Duty in 2006. Public 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. Hopefully this will mean that disabled people will be more likely to get their needs met.

The Disability Rights Commission (DRC)<sup>2</sup> can provide information and support. It is being replaced by the Commission for Equality and Human Rights from October 2007.<sup>3</sup>

The **RRAA (2001)** introduced a similar scheme to promote equality and end discrimination<sup>4</sup>, which is important for people with learning disabilities and their families from minority ethnic communities.

The **Human Rights Act** 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 enforce their rights under the European Convention of Human Rights in UK courts.

## **The Mental Capacity Act**

The Mental Capacity Act, which is coming into force in 2007, clarifies the responsibility for decision making and the role that families can play particularly when a person with a learning disability lacks the capacity for a particular decision. The Code of Practice sets out the best ways to settle disagreements and disputes about issues in the Act. (See briefing Making Decisions: An introduction to the Mental Capacity Act) For disputes about finance for someone

who is assessed as lacking capacity for complex money issues it is usually best to go to the Office of the Public Guardian.

## **Dissatisfaction about social care services**

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

- The service provider
- The local authority
- The Commission for Social Care Inspectorate

This will depend on the nature of the complaint.

When services are commissioned by local authorities or inspected by the Commission for Social Care Inspectorate (CSCI) the service provider must have a complaints procedure. For some complaints about the way your relative is being supported, it is best to start here if you are dissatisfied with the care or support that you or your family member has received.

You may want to complain to the local authority, for example if you are dissatisfied with where someone has been placed and you don't think it is meeting their needs which have been assessed. You may want to complain to CSCI if you think the service is not meeting minimum care standards or regulations. CSCI will not investigate individual cases of alleged abuse or mistreatment, they only have a duty to investigate where a service provider has not adhered to their own regulations, such as their complaints procedure, or they have not met minimum care standards.

Challenging the way services are provided - or not provided - under Community Care Law can be complicated. It is clearest when a public body like a social services department 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; or the duty to provide care home provision for someone who has been assessed as needing it; or the duty to provide the care assessed as necessary to meet the disabled person's needs in their own home. In addition some government guidance to local authorities is binding and if this is not followed the local authority can be challenged. Even where guidance is not binding, a local authority can still act illegally if it has a blanket policy. 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.

Local authorities ration care according to the money available by having eligibility criteria. Some authorities are now only providing services to those with substantial and critical - or even just critical need. They have a local **Fair Access to Care Services** policy for which there is guidance. 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.

## **Can services be reduced or withdrawn?**

If someone has been assessed as needing a service, they must have a reassessment before the service can be removed. A service can be removed if the person's assessed needs have changed or if their needs can be met in a different way or if the local authority's eligibility criteria have changed and they no longer fall within them. If the service user behaves unreasonably their service can be removed. If you believe a service has been wrongly reduced or withdrawn you can make a complaint.

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

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.

Under the **Data Protection Act** you can ask for a copy of your file or if you are legally able to act on behalf of a person you are caring for. You should receive information within 40 days, but the local authority or health agency can charge for doing this.

Each **local authority** will have a **complaints procedure**. The process has recently been revised to get swifter outcomes. There are three stages.

### **1. The informal stage or local resolution stage**

You can tell the local authority about your concerns. When the local authority receives your complaint, it will try to resolve it informally and this should happen within a maximum of 20 days.

### **2. Formal stage**

You can go straight to this stage if you prefer or go on to it if you are dissatisfied with the response at the informal stage. You need to put your complaint in writing to the Director of Social Services or the Complaints Manager, asking that it be dealt with under the formal investigation stage. Social services have 25 working days (and a maximum of 65 working days) to complete the investigation and provide a response. The investigator is usually appointed by the local authority, but they may appoint someone to shadow the investigator in complex cases.

### 3. Review stage

If you are still dissatisfied or the investigation has gone beyond the time limit, you can request a review. You must do so within 20 days of receiving the report from stage two or if the time limit for that stage has expired. A panel comprising three people, two of whom will be independent, will review the council's decision. The complainant can attend with a supporter. The panel must be convened within 30 days of receiving the complainant's request for a review. They have the power to recommend a course of action to the Director of Social Services, who should implement it unless there is a good reason not to.

If you are still unhappy, you can contact the **Local Government Ombudsman** if you believe there has been maladministration. This can be done for up to 12 months from the time that you first knew about matter you are complaining about.

You can seek a **judicial review** 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 the process. A judicial review can be expensive, but people on low incomes can get help with the costs. It is advisable to use the other ways to resolve difficulties if at all possible. You cannot both contact the Ombudsman and go for judicial review. (See list of useful contacts at the end of the briefing)

### What about health issues?

When you and your relative have a current grievance or concern about a service you have received from the NHS you are entitled to make a complaint, have it considered and receive a response from the NHS organisation or the primary care practitioner (GP, dentist, physiotherapist etc). You can complain on behalf of someone else as long as the hospital or practice agrees you are an appropriate person.

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

In the NHS a complaint should be made within 6 months of the incident. The first stage or the local resolution enables you to complain to the organisation or primary care practitioner and it may be possible to resolve the problem quickly through discussion and conciliation.

If you need to go down the formal route you should complain to the organisation or practitioner. This does not have to be in writing but it is better if it is recorded. The complaints manager of the organisation must make a written record of the

complaint. The practitioner should reply within 10 working days or the Chief Executive of the NHS organisation concerned within 25 working days. You should be told about the **Independent Complaints and Advocacy Service (ICAS)** that provides advice and support to patients and carers who want to take forward a formal complaint about health matters.

If you are not satisfied with the result of the investigation, you can refer the complaint to the **Healthcare Commission** and ask for an independent review. They will appoint a Case Manager. They will need consent to see the relevant documents. They may still try to work to get a local resolution. If this proves not to be possible, they will conduct a review seeking all the relevant information and sometimes seeking an independent view on clinical matters. This should take no longer than 12 months.

If you are unhappy with the outcome you can contact or make a complaint to the **Health Service Ombudsman**.

Regulations about trying to settle disputes locally do not apply in NHS Foundation Trusts. It is necessary to check out their complaints process. The independent review stage of the Healthcare Commission does apply to Foundation Trusts and they come under the Health Services Ombudsman.

## **The Human Rights Act**

The Human Rights Act has strengthened the ability of people to challenge bad practice and negotiate better services.<sup>5</sup> It does not necessarily mean going to court!

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) and the right not to be discriminated against in relation to any of the rights contained in the European Convention (article 14) are particularly relevant.

For example a challenge might be made if someone in caring role was harassed because colleagues thought she took too much time off because of her caring role. 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.

## Concerns about abuse

Abuse can be financial, emotional, racial, physical and sexual. Neglect is also a form of abuse. All sorts of people sadly harm others, including those using services. Awareness - raising about abuse is important.

**Social services** in 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 through following up references rigorously, **Criminal Records Bureau (CRB)** checks and consulting the **Protection of Vulnerable Adults (POVA)** list which records those who have abused, neglected or harmed a vulnerable adult in their care, or placed them in a situation where they can be harmed. The current POVA list does not apply to those who fall outside the Commission for Social Care inspections - it does not cover those who are in health or educational settings – but they should be subject to CRB checks.

It also means that those employing their own staff under for example direct payments do not have this protection unless they are employing staff via an agency. In October 2008, the POVA scheme will be superseded by an independent vetting and barring scheme.

**Organisations** should have policies and procedures to protect vulnerable adults and in each local area there will be a **Safeguarding Adults Policies and Procedures committee/ Adult Protection committee** with membership from a range of different agencies and a local adult protection coordinator. If you suspect abuse you should use the organisation's complaints procedure and also complain to social services through your relative's care manager. In evenings and at the weekend there are emergency duty teams.

If the law has been broken and for example there has been theft, a sexual assault, physical assault or rape the police must be involved immediately. They should also be called if there are instances of hate crime. This is defined by the Home Office as an incident which constitutes a criminal offence which is perceived by the victim or any other person as motivated by prejudice or hate.<sup>6</sup>

To have sexual relations a person must be able to consent. **The Sexual Offences Act** establishes a relationship between a care worker and a person with a learning disability is an offence whether they can consent or not.

If a person with learning disabilities is going to give evidence, as a vulnerable witness they are entitled to special measures and for example may have communication needs which should be met. If the case gets to court they can give evidence over a video link and can have the services of an intermediary to support them.

You can get advice from Voice UK if someone has been the victim of crime or abuse. If someone needs therapy because of experiencing abuse Respond can 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.

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? Are there good training programmes for staff, including programmes on adult protection? Is low level abuse or disrespect clamped down on?

Do people with learning disabilities have training and information about abuse and keeping themselves safe?<sup>7</sup>

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 go not so well.

The Department of Health has put out a consultation document, 'Making Experiences Count: A new approach to responding to complaints.' It proposes to unify and reform ways of making complaints across health and social care. Responses have to be in by October 17<sup>th</sup> 2007. This is a chance to have your say.

## **Contacts and resources**

The Department of Health provides detailed information. See 'Learning from Complaints: Social service complaints procedure for adults' [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4137785](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4137785)

How to make a complaint about the NHS  
[www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Complaintspolicy/NHScomplaintsprocedure/DH\\_4080897](http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Complaintspolicy/NHScomplaintsprocedure/DH_4080897)

Carers UK has useful information about complaining and cuts to services.

[www.carersuk.org](http://www.carersuk.org)

Ring the Carers Line 0808 808 7777 on Wednesdays or Thursdays 10-12 noon or 2-4 pm

Mencap has a helpline 0808 808 1111 Monday, Tuesday, Thursday, Friday 9.30- 4.30 and Wednesday 9.30 – 1.00

The Disability Law Service provides advice and information

[www.dls.org.uk](http://www.dls.org.uk) tel: 020 7791 9800

The Local Government Ombudsman

[www.lgo.org.uk](http://www.lgo.org.uk) tel: 0845 602 1983

The Commission for Social Care Inspection

[www.csci.org.uk](http://www.csci.org.uk) tel: 0845 015 0120 or 0191 233 3323

For advice about complaints see

[www.csci.org.uk/how to complain/care home or care services.aspx](http://www.csci.org.uk/how%20to%20complain/care%20home%20or%20care%20services.aspx)

Community Legal Services Direct

provides information and can help you find a solicitor who specialises in community care law [www.clsdirect.org.uk](http://www.clsdirect.org.uk) tel:0845 345 4345

See their pamphlets 18 Rights for Disabled People: Dealing with discrimination

19 Community Care: Your legal rights

For healthcare complaints

See The Patient Advisory Liaison Service (PALS) website for a list of local PALS services [www.pals.nhs.uk](http://www.pals.nhs.uk)

For the Independent Complaints Advocacy Service

See

[http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Complaintspolicy/NHScomplaintsprocedure/DH\\_4087428](http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Complaintspolicy/NHScomplaintsprocedure/DH_4087428)

This gives regional contact details.

The Healthcare Commission

[www.healthcarecommission.org.uk](http://www.healthcarecommission.org.uk) tel: 0845 601 3012 or 0207 448 9200

The Health Service Ombudsman

[www.ombudsman.org.uk](http://www.ombudsman.org.uk) tel: 0845 015 4033

To find out more about a judicial review see

[www.publiclawproject.org.uk/simpleguide.html](http://www.publiclawproject.org.uk/simpleguide.html).

The Housing Ombudsman deals with complaints about registered social landlords in England. This applies mostly to housing associations, but also many landlords who manage homes that were previously run by the local authority and some private landlords. [www.ihos.org.uk](http://www.ihos.org.uk) tel: 020 7836 3630

For information about the Mental Capacity Act  
The Public Guardianship Office (From October - The Office of the Public Guardian)  
[www.guardianship.gov.uk](http://www.guardianship.gov.uk) or tel: 0845 330 2900

### **Organisations supporting people who have been abused**

Voice UK  
[www.voiceuk.org.uk](http://www.voiceuk.org.uk) email [voice@voiceuk.org.uk](mailto:voice@voiceuk.org.uk) or tel: 0845 122 8695

Respond  
[www.respond.org.uk](http://www.respond.org.uk) or tel: 0808 808 0700

The Ann Craft Trust  
[www.anncrafttrust.org](http://www.anncrafttrust.org) or tel: 0115 9515400

*For additional information that will be useful when things go wrong please see separate briefings on*

- *Making Decisions: An introduction to the Mental Capacity Act*
- *Circles of Support*
- *Getting help and support in your caring role*

<sup>1</sup> Special Educational Needs and Disability Act 2001

<sup>2</sup> See [drc-gb.org](http://drc-gb.org)

<sup>3</sup> See [www.cehr.org.uk](http://www.cehr.org.uk)

<sup>4</sup> See [www.cre.gov.uk/legal/rra\\_scope.html](http://www.cre.gov.uk/legal/rra_scope.html)

<sup>5</sup> See the work of the British Institute of Human Rights [www.bih.org.uk](http://www.bih.org.uk) Some of the examples are based on those in The Human Rights Act: Changing lives

<sup>6</sup> See <http://www.homeoffice.gov.uk/crime-victims/reducing-crime/hate-crime/>

<sup>7</sup> See Voice UK pamphlet: 'Stop No More Abuse' and DVD from Speak Up Rotherham 'Abuse is Bad' [www.speakup.org.uk](http://www.speakup.org.uk)

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