



Section five: the history of complaints

“If you’re young, or you’ve got a disability or something, you don’t stand a chance really [in making a complaint]. That’s how I see it, anyway.” **p11**

“I ended up wanting to make a complaint about the complaints process because I was so fed up with it.” **p15**

“I want someone to properly listen, to take me seriously, and then DO something.” **p18** **Department of Health 2007¹**

It is widely acknowledged that complaining is something that is difficult for many people irrespective of their abilities or disabilities. There have been changes in both Health and Social care procedures in recent years (**Health and Social Care Act (Community Health and Standards) Act 2003, NHS (Complaints) Amendment Regulations September 2006** and **The Local Authority Social Services Complaints (England) regulations September 2006**)^a. Guidance as to good practice in complaints handling in social care and the NHS has been provided.^{2,3} Services such as **PALS (Patient Advice and Liaison Service)** and **The Independent Complaints Advocacy Service (ICAS)** set up within the NHS in 2002 and 2003 respectively have striven to improve the experiences of people with complaint against the NHS.

What is a complaint? A complaint can be defined as ‘an expression of dissatisfaction, disquiet or discontent about the actions, decisions or apparent failings of service provision which requires a response.’

National Audit Office 2008⁴

In the report ‘**Making things better? A report on reform of the NHS complaints procedure in England**’ (2005)⁵, the Health Service Ombudsman highlighted five key weaknesses

- Complaints systems are fragmented within the NHS, between NHS and private health care systems, and between health and social care
- The complaints system is not centred on the patient’s needs
- There is a lack of staff capacity and competence to deliver a quality service
- The right leadership, culture and governance are not in place
- Just remedies are not being secured for justified complaints

A Healthcare Commission report [**Spotlight on Complaints; Healthcare Commission, 2006**]⁶] highlighted some good practice but pointed out that

^a A summary of key changes in complaints procedures can be found at the end of this section



complainants usually wanted a better explanation of their care or decisions taken by the health care provider. Frequent problems included

- A failure to acknowledge that a complaint is valid
- A failure to apologise, even where local shortcomings are identified
- Responses which do not explain what steps have been taken to prevent the recurrence of an event, which has given rise to a complaint
- Responses containing medical terms, which complainants may not understand
- A failure to involve staff directly concerned in the complaint the in local investigation

In addition, this report pointed out that different procedures for health and social care were unhelpful as many people receive services across a variety of providers and the fragmentation of procedures was unhelpful. Uncertainty about who to complain to was even greater in social care than in health.

A number of serious inquiries including that of **Harold Shipman (2005)**⁷ have all highlighted the failure of those in positions of authority in the NHS or in the regulators to detect signs of unacceptable or incompetent professional behaviour and to take effective and timely action.

The third annual report on second stage complaints about NHS services⁸ published by the Healthcare Commission in February 2009 points out that the NHS **still** has much room for improvement in how it deals with complaints locally. In the relatively low number of complaints (24) relating to people with learning disabilities, familiar key themes emerge

- People with a learning disability had **negative experiences in acute hospitals**.
- Trusts **failed to adhere to the principles of *Valuing People*** – and to indicate in responses that they will improve training for staff.
- Doctors in an accident and emergency department showed a **negative attitude** towards a mother's concerns about her daughter who had a learning disability.
- **Poor communication between agencies** resulted in missing opportunities offered by specialist services and voluntary agencies.
- Medical and nursing staff in some hospitals had **not read care files** accompanying individuals with a learning disability.

In the White Paper '**Our Health, Our Care, Our Say (January 2006)**⁹ the Department of Health committed to develop a single system across health and



social care by 2009 which would ‘focus on resolving complaints locally with a more personal and comprehensive approach to handling complaints’. (p160)

The focus of this approach would be to:

- Resolve complaints quickly and locally – a more personal and flexible approach.
- Make sure people who have complaints have access to effective support – particularly important for those who find it difficult to make their views heard.
- Support organisations to improve the services they provide by routinely learning from people’s experiences.

Making Experiences Count (Department of Health 2007)¹⁰ seeks to make this a reality in social and health care complaints procedures.

Our consultation document, *Making Experiences Count - A new approach to responding to complaints*, set out our proposals to reform the way health and care services respond to people’s complaints within the broader context of the Health Reform programme and person-centred care. It described a radical review that goes beyond simply unifying the current complaints processes across health and social care. I want to move away from the current rigid set of processes to a more open, flexible and personal approach to responding to complaints and concerns which is focused on people and their experience. Equally importantly, I want it to be easier and more beneficial for organisations receiving complaints to respond properly and ensure that people’s experiences help to improve services. I fully appreciate that the shift to this new approach may be challenging for some organisations, but a number have already adopted these principles whilst working within the current systems, and are already seeing positive effects for all concerned. The next steps include a programme of Early Adopter sites that will help to develop the details of the new approach. This programme will mark a crucial phase in our drive to ensure the provision of fair, responsive, high-quality services to all users of publicly funded health and social care.

Ann Keen MP
Parliamentary Under Secretary of State for Health Service



Making Experiences Count aims to:

- Increase people's confidence that their complaints will be taken seriously and that services will improve as a result of their experiences
- Create a flexible approach to resolving complaints, including effective support
- Take a simple, consistent, unified approach across health and social care
- Promote a culture of openness and fairness when dealing with complaints
- Make the approach fair to people using and delivering services
- Place emphasis on early and effective resolution
- Have a greater emphasis on excellent local leadership/accountability that supports the resolution of complaints.

In practice this means:

- Focusing everyone's efforts on sorting things out quickly, at a **local level**
- **Advocacy being a right** for anyone who needs support to make their views heard
- The responsibility of the most **senior managers** to ensure that complaints are dealt with properly and learning from complaints is used to improve services
- Making sure that complaints professionals have the **skills, experience and support** that they need in order to work in this new way
- Giving the **regulator** the task of making sure that all providers of NHS or social care services, in the public or independent sector, have effective complaints arrangements in place that meet people's needs and make services better
- Upholding the current role of the **Ombudsmen**.

In February 2009 the Government published regulations and a series of advice sheets and resources to support the new combined complaints procedures due to commence in April 2009. There are three components to the new arrangements:

- New Regulations for flexible and responsive complaints systems that focus on the specific needs of the complainant, seek to reach speedy local resolution and enable coordinated cross-boundary complaints handling.
- The introduction of a single local resolution process replacing the previous tiered approach taken in local authorities.
- A new single system for independent review by the Parliamentary and Health Service Ombudsman for healthcare.

The new Regulations were laid before Parliament on 27 February, came into effect on 1 April 2009 and are available on <http://www.opsi.gov.uk/stat.htm>.



The Department of Health has produced a 'Guide to Customer Care'¹¹ to accompany the new regulations based around the three principles of

- **Listening** - taking a more active approach to asking for people's views.
- **Responding** – dealing with compliant more effectively.
- **Improving** – using the information received to learn and improve.

For more information visit www.dh.gov.uk/mec

The need for extra support for more vulnerable people is recognised in both Our Health, Our Care, Our Say (2006) and Making Experiences Count (2007).

"We must also ensure that people with concerns or who wish to complain have access to effective support. This is particularly important for people who find it difficult to make their views heard. To ensure people are supported, the Patient Advice and Liaison Service (PALS) will need to continue to develop its capacity..."

(Department of Health 2006)¹²

"You need someone to help you understand it, and to help you say what you want to say."

(Department of Health 2007 p20)¹³

The provision of advice and access to advocacy to people making complaints is essential. Whilst PALS and ICAS are essential components of complaints handling in the health service, there is a commitment in Making Experiences Count to either develop parallel services in social care, or extending the role of PALS and ICAS. Local authorities are obliged to provide advice on advocacy services to children or young people who complain – that obligation should be extended to vulnerable adults also.

We recognise that the people who rely most on services are often the people least able to make their views known and are committed to ensuring that in future their voice is supported through a right to advocacy.

Department of Health 2007¹⁴ p26



Complaining and people with learning disabilities

In 1995^{15, 16} Ken Simons published accounts of his research into newly introduced statutory complaints procedures in Social Service Departments. The work focussed on the experiences of people with learning disabilities and their families. Many of the issues this research highlighted remain pertinent today.

Complaining is rarely easy. Most people prefer to avoid conflict and although complaints procedures are – at least in part – intended to depersonalise conflict, they will never completely do away with the stress in challenging others. **(1995a p4)**

Simons points out (1995a p5) that complaining is harder when

- People are vulnerable through stress, illness, inexperience or lack of knowledge
- People have difficulty expressing their views
- There is a big disparity in status between complainant and those complained about
- Those being complained about have continuing power over the complainant
- People are isolated
- In the early 1990s, with the move to include people with learning disabilities more meaningfully in services, many attempts at assisting people to understand and access the complaints procedures of both health and social care were developed

Simons attempted to find out why people with learning disabilities and their families tended not to complain about services through nine discussion groups on the subject. Some of the themes that emerged were

- Most people with learning disabilities thought the idea of complaining was probably good but tended to stick to 'safe' subjects such as cold food
- A minority of people with learning disabilities thought complaining was bad – some thought it was not possible to question staff

Given that it is not unusual to hear staff 'jolly' users along and telling them not to be 'miserable', there is inevitably confusion between complaining and moaning. **(1995a p32)**



- People with learning disabilities were not always clear about **who** to complain to
- There was a lack of knowledge about complaints procedures
- There was fear of the consequences of complaining
- Conflicting messages were reported (eg generally 'discouraging noises' from services about making complaints, the failure of existing consultation mechanisms to effect any change, conflicting demands and even implicit threats from staff)

They say "if we give it to you, we've got to take it away from someone else" **(1995a p36)**

- People were reluctant to criticise otherwise valued services

"I don't want no one to get into trouble" **(1995a p36)**

- Making complaints about the independent sector was perceived to be even harder

Despite the barriers to effective complaints identified by Simons, he remained upbeat about people with learning disabilities and their families being supported and even encouraged to make complaints where necessary.

Complaints procedures can be made to work for people with learning difficulties. With the right support and encouragement, some users and carers have been able to take on the system. However, the procedures are not a magic wand. In themselves they are not enough to carry the burden of expectation placed upon them; there have to be other complementary mechanisms to ensure that vulnerable people are both encouraged to speak up, and are heard by decision makers. **(1995b p199)**

Since Simon's report there have been major service developments that have attempted to address some of the concerns he raised and recommendations made, including:



- A change of attitude amongst service providers as to the value of complaints
- The lack of access to advocacy
- The lack of 'accessible' information
- The under representation of vulnerable groups

Many services have attempted to make their complaints processes more accessible to their service users through the use of videos to provide information both on local procedures and for use in awareness raising and education about the whole topic of complaints.

Some examples of video and other resources on complaining for people with learning disabilities

This is my life – effective feedback procedures for people with learning difficulties (video) Marlyn Hillier 1994

Don't take no for an answer – how to complain (video) Essex County Council 1995

Mary complains (video) Pavilion Publishing 1996

How to complain if you are unhappy Oxfordshire Learning Disabilities NHS Trust 1996

Where can I go for help (video) Speakup self advocacy 1996

I am not complaining but ... a training resource for people with learning difficulties and users of services, their families and professionals Pavilion Publishing 1997

Listen Up: Helping children with a learning disability to complain about the services they use Mencap/Community Fund

Listen to us (DVD) Learning Disabilities Services Somerset (2004)

I want to complain Tameside Learning Disabilities Services (2005)

Would you complain? (DVD) Inspired services (2008)



Alongside this, many local services have developed a range of easy read complaint leaflets and information attempting to demystify the complaint procedures for people with learning disabilities who use their services. Some services provide on line complaint forms in addition to paper versions (although frustrating an attempt to access one such facility produced the following message “The complaint facility has been closed temporarily due to the volume of inappropriate messages received”!)

Some examples of easy read or ‘accessible’ information on complaining

Listening to you: How the NHS will listen to your views, questions and complaints (information on the PALS service and NHS complaints procedure) North Staffordshire Combined Health NHS Trust

Have your say about your services: Compliments, Comments and Complaints, Telkin and Wrekin Council

Making a complaint Lancashire County Council Social care services

How to complain: a guide for residents, tenants and service users Advance Support and Housing service

Hearing your views Cambridgeshire Learning Disability Partnership

Are you unhappy? a complaints poster Camden Learning Disabilities Service

How to make a complaint to the National Forum National Forum of People with Learning Disabilities

How to complain Surrey and Borders Partnership NHS Trust

Adult social care; Making a complaint: guide for people with learning disabilities Wolverhampton City Council

An easier to read guide to making a complaint Nottingham City Council



And yet messages such as the one below still appear on national forums

I'm a woman with a severe Learning Disability - I attend a day service - six weeks ago I went out with 2 support workers and myself, there was an incident and I got upset. My main carer was also not happy with the attitude of the staff and we made an official complaint. The day service complaints procedure is in 4 stages - the manager by passed all stages of the complaints procedure and took the complaint to the Chief Executive. The Chief Executive asked for statements from the staff - I received a letter saying she supports the staff and basically if I don't like it I can lump it - the letter is not nice. At no time was I interviewed or my main carer as part of the complaint, the Chief Executive has taken the staff's word as law, I'm very sad as I don't seem to matter. I cannot vocalise my feelings. And because the complaints procedure was bypassed I cannot take it to the next stage. Social Services are supportive and are concerned at my treatment, they will be contacting the Chief Executive - the day service is a specialist day service for people with my disability and charge for my placement. I'm saddened that I or my main carer wasn't interviewed or asked my thoughts - so much for valuing people. Can you please give me some advice?

rights-and-values@ldforums.org 9th February 2009

So, despite all these efforts, there is still considerable evidence to suggest that many people with learning disabilities continue to find it difficult to make complaints. This was certainly the feedback we received from our consultation with people with learning disabilities at the Build for the Future group, the management committee of Somerset Advocacy group and Speak Up groups in Somerset (see appendices 1, 2 and 3)

The remarkable reply rate to a message posted on the Foundation for People with Learning Disabilities Forums produced a deluge of replies from professionals and carers – all of whom indicated this was a topic of ongoing concern. Many shared their local 'easier to read' complaints information but a significant number shared our concern that all this accessible information activity did little to address the needs of those most seldom heard by services – those with profound and multiple learning disabilities or other complex communication needs.



Some typical forum responses

Your project looking at ways to complain and voice your views if you find communication tough sounds fab... **training consultant**

Keep us all updated with how the project goes...sounds very worthwhile (and exciting!) ... **family carer**

I am interested in any work that is being completed/sought to look at the barriers faced by people with learning disabilities (particularly those with complex communication and other needs) when wanting to complain ... **health trainer**

I am really interested in your work. I don't think this is an area where we as a Trust put enough effort. I have attached our accessible leaflet ... **communications officer**

We have developed a service user accessible complaints leaflet in our Learning Disability Service ... **clinical psychologist**

What about people with multiple impairments who do not use language and do not understand concepts such as making a complaint? I think they have as much right to be 'heard' or perhaps 'observed' as others who are vocal ... **mother**

I saw your call for ideas around supporting people who are 'seldom heard'. What a lovely way of putting it. I have a special interest in this area, particularly around people who don't use formal or intentional communication ... **speech and language therapist**

We have developed an accessible PALS leaflet within our organization ... **modern matron**

It is really helpful for people to be specific about time, place and person. This is going to be difficult for some people but if there is something happening that is ongoing a parent/advocate/buddy to help keep records would be very helpful ... **independent complaints investigator**



The scandals of **Cornwall (2006)**¹⁷, **Sutton and Merton (2007)**¹⁸ and **Death by Indifference (2007)**¹⁹ and the issues highlighted in **Six Lives (2009)**²⁰ continue to remind us of the potential for abuse and neglect and infringement of human rights that can result when people's voices go unheard. Those who rely most on services are often also those most likely to be seldom heard. It is vital that accessible and responsive complaints procedures are embedded in a culture that listens to and values all members of society – however disabled or marginalized.

Key changes in NHS and Social Care complaints procedures

1991 The statutory complaints procedure for adult social care services introduced, consisting of **three local stages** (managed by the local authority), with the **Local Government Ombudsman** as ultimate reviewer.

1994 Being Heard, a report led by Professor Alan Wilson, identified shortcomings in the NHS complaints procedures and recommended a common local system for handling complaints across the NHS.

1996 A common **three stage** system for dealing with NHS complaints is introduced with local resolution, independent review (carried out by lay panels) and referral to the **Health Service Ombudsman**.

2000 Listening to People: A consultation on improving social services complaints procedures seeks views on proposed amendments to arrangements for handling social care complaints.

2001 The Department of Health's independent evaluation of the 1996 NHS complaints procedure found processes thought to take too long and not be sufficiently independent with no systematic way of ensuring that lessons were learned or making improvements to service provision as a result.

2002 PALS (Patient Advice and Liaison Service) was established for the NHS.

2003 The Department of Health proposed reforming the procedures for second stage review of NHS complaints, including making the Healthcare Commission responsible for independent review. **The Independent Complaints Advocacy Service (ICAS)** was set up within the NHS.

2004 The **Healthcare Commission** became responsible for the independent review of complaints about the NHS.



2004 The Department consulted on changes to procedures for adult social care services including a proposal to make the **Commission for Social Care Inspection** responsible for the second stage independent review of complaints.

2005 The March 2005 budget announced that the **Commission for Social Care Inspection**, the **Healthcare Commission**, and the **Mental Health Act Commission** would merge. The independent review role envisaged for Commission for Social Care Inspection was shelved.

2006 The White Paper **Our Health, Our Care, our Say** committed to a comprehensive single complaints system across NHS and social care by 2009.

2006 Amendments to legislation imposed a duty on NHS bodies and local authorities to cooperate when complaints relate to both NHS and social care services.

2006 The **Local Authority Social Services Complaints (England) Regulations 2006** come into force. Three local stages were retained but there was a new time limit for making complaints, a requirement for local authorities to appoint a complaints manager, revised guidelines on review panels and powers to fast track some complaints to the Local Government Ombudsmen after Stage 2.

2006 Launch of the **Voices for Improvement Action Network** to provide a forum for health and social care complaints managers to exchange experiences about national developments and develop joint approaches.

2007 **Making Experiences Count: A new approach to responding to complaints** was published as proposals for a single, comprehensive system across NHS and social care, including removing the Healthcare Commission's independent review role.

2007 The **Regulatory Reform Order (2007)** was introduced enabling the Parliamentary and Health Service Ombudsman and the Local Government Ombudsmen to work jointly on cases which crossed their boundaries.

2008 The Department publishes its response to **Making Experiences Count**.

2009 The Local Authority Social Services and National Health Service Complaints (England) Regulations 2009 introduced with implementation of joint complaints procedures from April 2009.



¹ **Making Experiences Count: A new approach to responding to complaints A document for information and comment** Department of Health June 2007

² **Learning from Complaints; social services complaints procedure for adults** Department of Health, Care Services Directorate (July 2006).

³ **Supporting Staff, Improving Services - Guidance to support implementation of the: National Health Service (Complaints) Amendment Regulations 2006** Department of Health (1 September 2006)

⁴ **Feeding back? Learning from complaints handling in health and social care**, National Audit Office (October 2008)

⁵ **Making things better? A report on reform of the NHS complaints procedure in England** Health Service Ombudsman (March 2005)

⁶ **Spotlight on Complaints;** Healthcare Commission, (2006)

⁷ **Shipman - the final report** HMSO (January 2005)

⁸ **Spotlight on Complaints;** Healthcare Commission, (2009)

⁹ **Our Health, Our say, Our Care** Department of Health (2006)

¹⁰ **Making Experiences Count** (as above)

¹¹ **Listening, responding, improving: a guide to better customer care** Department of Health 26 February 2009

¹² **Our Health, Our say, Our Care** (as above)

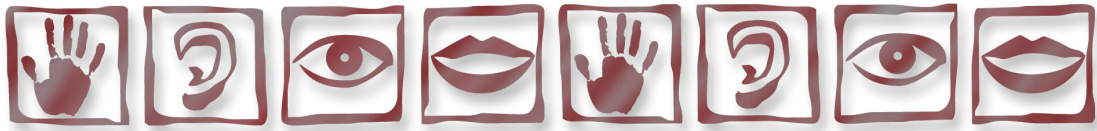
¹³ **Making Experiences Count** (as above)

¹⁴ **Making Experiences Count** (as above)

¹⁵ **I'm not complaining but ... Complaints procedures in Social Services departments**, Simons, K (1995a) Joseph Rowntree Foundation

¹⁶ **I'm not complaining; the right to complain: making complaints procedures work for people with learning difficulties** Simons K (1995b) In Philpott T and Ward L (eds) (1995) Values and Visions. Changing ideas in services for people with learning difficulties Butterworth Heinemann Ltd

¹⁷ **Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust** Commission for Social Care Inspection (July 2006)



¹⁸ **Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust** Healthcare Commission (January 2007)

¹⁹ **Death by Indifference; following up the Treat Me Right! Report** Mencap (March 2007)

²⁰ **Six lives: the provision of public services to people with learning disabilities, Part one: overview and summary investigation reports. 23 March 2009** (downloadable from www.ombudsman.org.uk)