

# Six lives: the provision of public services to people with learning disabilities

Part one: overview and summary investigation reports

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## Second report

Session 2008-2009

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## Foreword

I am laying this report before Parliament under section 14(4) of the *Health Service Commissioners Act 1993* (as amended).

The report relates to six investigations which I have conducted as Health Service Ombudsman for England, three of them jointly with the Local Government Ombudsman, Jerry White, in accordance with the powers conferred on us by amendments to our legislation due to *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007*.

The complaints were made by Mencap on behalf of the families of six people with learning disabilities, all of whom died between 2003 and 2005 while in NHS or local authority care.

The complaints were made following Mencap's report, *Death by indifference*, published in March 2007, which led to the setting up of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities by Sir Jonathan Michael MB BS FRCP (Lond) FKC, commissioned by the then Secretary of State for Health. The Inquiry's report, *Healthcare for All*, was published in July 2008.

The complaints were made against a total of 20 public bodies. They all concerned the quality of care which was provided and the majority of them also included concerns about the way in which subsequent complaints about the quality of that care had been handled at local level, and by the Healthcare Commission.

The report is in eight Parts (or volumes).

**Part 1** provides an overview of the work we have undertaken, identifies the themes and issues arising from our work, and makes some general recommendations to address those issues. Part 1 also contains a summary of each of the individual investigation reports.

**Parts 2 to 7** are the full reports of the six investigations.

**Part 8** is an easy read version of Part 1.

*Note: Unusually, the summary reports and the full investigation reports are not fully anonymised. This is because some of the names of the complainants are already in the public domain as a result of Mencap's earlier report; and because Mencap have confirmed that the families are content to be named in the published reports. We have taken into account the public interest and the interest of the complainants and the other people affected by our reports and consider that it is necessary in that context to include the names of the complainants.*

### Our findings

Our investigation reports illustrate some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care.

Our investigations found maladministration, service failure and unremedied injustice in relation to a number, but not all, of the NHS bodies and local councils involved. In some cases we concluded that there had been maladministration and service failure for disability related reasons. We also found in some cases that the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality.

Our findings contrast markedly with the first Principle of the recently published *NHS Constitution for England and Wales*, which says that '*The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion or belief. It has a duty to each and every individual it serves and must respect their human rights*'.

A similar contrast is evident for social care. *Independence, Well-being and Choice*, published by the Department of Health in March 2005, set out a vision for adult social care and established a standard for social care which was endorsed by the white paper *Our Health, Our Care, Our Say* in January 2006. It says that '[Social care services] should treat people with respect and dignity and support them in overcoming barriers to inclusion... They should focus on positive outcomes and well-being and work proactively to include the most disadvantaged groups'.

### The wider context

This report is timely in a number of respects.

On 19 January 2009 the Department of Health published *Valuing People Now: a new three-year strategy for people with learning disabilities*, which reaffirms the commitment to the principles of equality, dignity, rights and inclusion set out in *Valuing People: A New Strategy for Learning Disability for the 21st Century*, published by the Department of Health in 2001. The strategy places strong emphasis on leadership at all levels through the public sector from central government, through regions, to health and local authorities.

On 1 April 2009 a new regulator, the Care Quality Commission, comes into being and from April 2010 a new registration system will come into effect for all health and social care providers.

Finally, this report is laid before Parliament at a time of imminent change in the complaint handling landscape for both health and social care which will take effect from 1 April 2009. I welcome those changes and the opportunity to remind public bodies of the value of dealing with complaints promptly and effectively and, where complaints are justified, offering appropriate remedies.

Together with my Local Government Ombudsman colleague, I am also committed to ensuring that the learning from complaints is fed back to those responsible for the design and delivery of public services so that they can use that feedback to improve those services for the future. There is much to learn from the findings of these investigations, and much to improve. I hope that all NHS bodies and local authorities, together with the relevant regulators and the Department of Health, will respond positively to the recommendations in this report and demonstrate a willingness to learn from it, and that this might provide some small consolation to the families and carers of those who died.



Ann Abraham  
**Parliamentary and Health Service Ombudsman**

March 2009

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# Overview summary

## Introduction

In March 2007 Mencap published a report, *Death by indifference*, which set out case studies relating to six people with learning disabilities. Mencap believe that they died unnecessarily as a result of receiving worse healthcare than people without learning disabilities.

On behalf of the families involved, Mencap asked the Health Service and Local Government Ombudsmen to investigate complaints about all six cases, three of which span both health and social care. Summaries of each of the investigation reports follow this Overview and the full reports of each individual investigation are published as Parts 2 to 7 of this report.

The investigation reports illustrate some significant and distressing failures in service across both health and social care. They show the devastating impact of organisational behaviour which does not adapt to individual needs, or even consistently follow procedures designed to maintain a basic quality of service for everyone. They identify a lack of leadership and a failure to understand the law in relation to disability discrimination and human rights. This led to situations in which people with learning disabilities were treated less favourably than others, resulting in prolonged suffering and inappropriate care.

The issues range from a complaint about the care provided in a single hospital to complaints about service failures which involve the whole system of health and social care, including the ability of organisations to respond appropriately to complaints. A total of 20 organisations were involved, including 3 councils and 16 NHS bodies. Complaints about the Healthcare Commission's handling of complaints were made in 5 of the 6 cases.

Our reports look at the experiences of:

- **Mark Cannon**
- **Warren Cox**
- **Emma Kemp**
- **Edward Hughes**
- **Martin Ryan**
- **Tom Wakefield**

All of these people died between 2003 and 2005, in circumstances which Mencap alleged amounted to institutional discrimination.

We did not uphold all of the complaints and it should be noted that complaints were not upheld against many of the public bodies involved. In particular, none of the complaints against GPs were upheld. We did see some examples of good practice.

This does not mean we have always been uncritical of the public bodies concerned. There were a number of examples where health professionals in particular could have been more proactive, acted on the advice and information that was given to them by the families or care staff who knew the person best, or adjusted their practice to better meet the needs of the individuals concerned.

In one case we concluded that the death of the person concerned occurred as a consequence of the service failure and maladministration identified. In another case the Health Service Ombudsman concluded that it was likely the death of the person could have been avoided, had the care and treatment provided not fallen so far below the relevant standard. In two cases, although we upheld complaints of service failure and maladministration, we could not conclude that the person's death was avoidable. Mencap have asked us to say that, whether the death could have been avoided or not, this should not detract from the



unacceptable standard of care and treatment that was experienced in those cases. We agree and have no difficulty in doing so.

In four of the six cases we upheld the complaint that the person concerned was treated less favourably, in some aspects of their care and treatment, and in the services of some of the bodies about which complaints were made, for reasons related to their learning disabilities. We also found in four of the six cases that the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality.

## Role of the Ombudsmen

The Health Service Ombudsman is empowered to carry out independent investigations into complaints made by, or on behalf of, people who have suffered injustice or hardship because of poor treatment or service provided by the NHS. The Local Government Ombudsman has a similar remit in respect of services provided by councils, which include social care.

Both Ombudsmen look thoroughly at all the circumstances surrounding a complaint and try to resolve it in a way which is fair to all concerned. Where the complaint is justified we look to the public bodies involved to provide an appropriate and proportionate remedy for the injustice or hardship suffered by complainants.

In 2007 a Regulatory Reform Order amended our legislation to give new powers to the Ombudsmen to work together more effectively in investigating and reporting on complaints which cross our respective jurisdictions. These new powers have been relevant in three of the six cases we have investigated. It has enabled us to produce joint investigation reports in those three cases and this joint Overview.

## Relevant policy and good practice guidance

Each of the individual investigation reports sets out in detail the relevant legal, policy and administrative framework for the NHS, for social care services commissioned or provided by councils in the three reports where this is relevant, and for arrangements for co-operation between the two. The individual reports also describe the relevant standards and guidance, including professional standards which were in existence between 2003 and 2005, at the time when these deaths occurred.

Of particular relevance is *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Valuing People) issued in 2001, which requires public services to treat people with learning disabilities as individuals with respect for their dignity. Other general guidance, in particular the professional standards set out by the General Medical Council and the Nursing and Midwifery Council, stresses the importance of looking at the individual, of personal accountability, the interests of patients and the need for co-operative working.

One of the most distressing features of our investigations has been the evidence in some cases that these fundamental principles were not being consistently upheld, to the extreme detriment of the individuals concerned.

## Treating people as individuals

The *Disability Discrimination Act 1995* makes it unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified. It is also unlawful for service providers to fail to make reasonable adjustments for people with disabilities, where the existence

of a physical barrier, practice, policy or procedure makes it impossible or unreasonably difficult for a person with a disability to use the service provided, unless such a failure is justified.

Equality for people with disabilities does not mean treating them in the same way as everyone else. Sometimes alternative methods of making services available to them have to be found in order to achieve equality in the outcomes for them. The focus is on those outcomes.

In many of the organisations whose actions we investigated it did not appear that this level of understanding of the need to make reasonable adjustments had become embedded, even at the most senior levels, despite the legislation and the extensive guidance available. Our investigations uncovered a lack of understanding of how to make reasonable adjustments in practice, which suggests there may be a need for further training on the practical implementation of the *Disability Discrimination Act 1995*.

When the UK Government introduced the *Human Rights Act 1998* it said that its intention was to create a new 'human rights culture'. A key aspect of that culture is the observance of the core human rights principles of fairness, respect, equality, dignity and autonomy for all. Our investigation reports demonstrate that an underlying culture which values human rights was not in place in the experience of most of the people involved.

### **Doing the basics well – an issue of leadership**

Guidance on standards of practice across a range of health and social care functions is regularly issued and sets out a broad and consistent approach which should be familiar to all professionals in

these fields. These standards will, if observed consistently, offer many of the safeguards essential to ensuring that the needs of people who are vulnerable for any reason are addressed, and appropriate adjustments made to their care.

On many occasions in the lives of the people concerned, basic policy, standards and guidance were not observed, adjustments were not made, and services were not co-ordinated. There was a lack of leadership and in some situations it appeared that no one had a real grasp of what was happening.

The full investigation reports give details of the various complex factors which led to failure to offer good care to individuals in very vulnerable situations. It is this complexity which in itself requires strong leadership to maintain a focus on the experience of and outcomes for people with learning disabilities and, in all probability, many other people with complex needs.

The areas of concern included:

- Communication
- Partnership working and co-ordination
- Relationships with families and carers
- Failure to follow routine procedures
- Quality of management
- Advocacy.

## Complaint handling

Most of the complaints which we investigated had been reviewed first by the NHS or council complaints systems. The families told us that their experiences of these systems had left them drained and demoralised and with a feeling of hopelessness.

They gave repeated examples of failures to understand their complaints, with little effort made to clarify matters with them; confused and fragmented systems; poor investigations with little rigorous testing of evidence; defensive explanations; a failure to address the heart of the complaint; and a reluctance to offer apologies. Our investigations generally confirmed this picture.

Complaints against NHS bodies at the time of these events followed a second stage review process by the Healthcare Commission. The families who asked the Healthcare Commission to review their complaints said they had hoped that the Healthcare Commission's review would give them the explanations they sought. In practice, they experienced many of the same problems of delay, lack of contact, poor specification of complaints and a lack of clarity about the process that they had experienced at the first stage of the process. Clinical advice was not always appropriately sourced, explanations were inadequate and the families remained unclear as to what had changed as a result of their complaints. Again, our investigations generally confirmed this picture.

For the most part the NHS bodies and the councils concerned, and the Healthcare Commission, have subsequently acknowledged and apologised for the failings in their complaint handling and have provided information on improvements they have made to their services and to their complaint handling arrangements.

Nonetheless, it remains the case that poor complaint handling compounded the distress which resulted from the failures in service experienced by the families of those who died. These families should not have had to wait so long and fight so hard for the explanations and apologies to which they were entitled.

From 1 April 2009 changes introduced by the *Health and Social Care Act 2008* will implement a single comprehensive complaints process across health and social care, focused on resolving complaints locally with a more personal and comprehensive approach. The Healthcare Commission will be removed as the second tier complaint handler and the Ombudsmen will provide the second and final tier of the new system across health and adult social care. The changes in the system provide an excellent opportunity for health and social care organisations to review their systems and to put in place good arrangements for the future handling of complaints.

## Remedy

The unremedied injustice which the Ombudsmen concluded had resulted from the maladministration and service failure identified include:

- An avoidable death and a death which was likely to have been avoidable.
- Unnecessary distress and suffering for the aggrieved.
- Unnecessary distress and suffering for the families of the aggrieved, in particular about those failings which occurred for disability related reasons.

- Distress at unanswered questions of what difference would have been made if there had been no service failure or maladministration. Would the person concerned have lived longer? Could there have been some improved enjoyment in the last period of their life?
- Distress compounded by poor complaint handling leaving questions unanswered.
- Distress arising from a failure to live up to human rights principles.

The remedies which were provided by the councils and NHS bodies concerned, prior to the Ombudsmen's investigations, included:

- Senior level personal apology and offer of meetings.
- Offer to involve family in planning services.
- Actions to address failings and to minimise risk of reoccurrence; action plan notified at Board level and to the regulator.
- Commitment to learn lessons from the investigations, and to work openly and collaboratively with local and central bodies.
- Identification of lessons learnt.

The further remedies recommended and secured by the Ombudsmen include:

- Further personal apologies and offers of meetings.
- Public apologies through the published investigation reports.
- Financial compensation for distress ranging from £5,000 to £40,000.

## Conclusion and recommendations

We do not extrapolate from these cases to suggest that all health and social care in respect of people with learning disabilities is poor. Nevertheless, the recurrent nature of the complaints across different agencies leads us to the view that understanding of the issues is at best patchy and at worst an indictment of our society.

In writing this report we have been motivated by the desire to bring positive change from the experiences of these people and their families, which could in itself provide some redress for all those concerned. We are not looking to '*make this a priority for 2009*', but to change underlying attitudes and behaviour on a lasting basis. We do not underestimate the challenges involved.

We have made individual recommendations to address the specific unremedied injustice we have found in the cases where we have upheld the complaints (and for the most part these individual recommendations have been accepted by the public bodies concerned).

However, the findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities.

We have thought long and hard about what general recommendations we could properly and usefully make in the light of our investigation findings, and the themes and issues we have identified in this Overview. We are Ombudsmen, not regulators and we do not seek to usurp their role. Nonetheless, we are committed to ensuring that the learning from complaints investigated by us is fed back to those responsible for the design and delivery of public services so that they can use that feedback to improve those services.

We see no point in repeating the detailed recommendations of Sir Jonathan Michael's Independent Inquiry into Access to Healthcare for People with Learning Disabilities, *Healthcare for All*, although we do not disagree with those recommendations.

We welcome the simplified complaint handling arrangements for health and social care which are being introduced from 1 April 2009 and therefore make no specific recommendations for improvements in the complaint handling system.

We have not found any shortage of policy and good practice guidance on the planning and provision of health and social care services for people with learning disabilities; on making reasonable adjustments in order to comply with the requirements of the *Disability Discrimination Act 1995*; or on observing the core human rights principles of fairness, respect, equality, dignity and autonomy for all. We have noted the very recent publication by the Department of Health of *Valuing People Now: a new three-year strategy for people with learning disabilities*. So we make no recommendations for further guidance.

Nonetheless, we are still left with an underlying concern that similar failures to those identified in the investigations will occur again – and indeed may be occurring today in services provided or commissioned by NHS bodies and councils across the country. We believe it is legitimate, in the light of the very serious findings of our investigations, to ask all NHS bodies and councils with social services responsibilities to satisfy themselves that is not the case.

As we have said above, we have concluded that the findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities. This is not a question that we, as Ombudsmen with a very specific remit, can or should answer but it is, we suggest, a question which those responsible for commissioning and providing health and social care services should ask themselves; which those responsible for the regulation of health and social care services should ensure is addressed in their regulatory frameworks and performance monitoring regimes; and about which the Department of Health should properly be concerned. Our recommendations are therefore addressed to the leaders of those bodies.

**We recommend:**

**First, that all NHS and social care organisations in England** should review urgently:

- the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas;

and

- the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities;

and should report accordingly to those responsible for the governance of those organisations within 12 months of the publication of this report.

**Secondly**, that **those responsible for the regulation of health and social care services (specifically the Care Quality Commission, Monitor and the Equality and Human Rights Commission)** should satisfy themselves, individually and jointly, that the approach taken in their regulatory frameworks and performance monitoring regimes provides effective assurance that health and social care organisations are meeting their statutory and regulatory requirements in relation to the provision of services to people with learning disabilities; and that they should report accordingly to their respective Boards within 12 months of the publication of this report.

**Thirdly**, that the **Department of Health** should promote and support the implementation of these recommendations, monitor progress against them and publish a progress report within 18 months of the publication of this report.



Ann Abraham  
**Parliamentary and Health Service Ombudsman**



Jerry White  
**Local Government Ombudsman**

March 2009



# Overview report

## Introduction

In March 2007 Mencap published a report, *Death by indifference*, which set out case studies relating to six people with learning disabilities. Mencap believe that they died unnecessarily as a result of receiving worse healthcare than people without learning disabilities. Following that publication, Sir Jonathan Michael MB BS FRCP (Lond) FKC, was invited by the then Secretary of State for Health to chair an Independent Inquiry into Access to Healthcare for People with Learning Disabilities. Sir Jonathan's report, *Healthcare for All*, published in July 2008, found significant gaps between the law, policy and the delivery of effective services for people with learning disabilities. He made ten recommendations designed to strengthen the systems for assuring the quality of health services at all levels.

Following the publication of *Death by indifference*, Mencap, on behalf of the six families involved, asked the Health Service and Local Government Ombudsmen to investigate complaints about all six cases, three of which span both health and social care. Summaries of each of the investigation reports are included at the end of this Overview and the full reports of each individual investigation are published as Parts 2 to 7 of the report.

The investigation reports illustrate some significant and distressing failures in service across both health and social care. This is despite extensive policy and guidance published over a number of years concerning the quality and nature of services which should be available to everyone, including people with learning disabilities. It is also despite the expressed commitment of professionals to meeting the needs of individuals. They show the devastating impact of organisational behaviour which does not and apparently cannot adapt to individual needs, or even consistently follow procedures designed

to maintain a basic quality of service for everyone. They identify a lack of leadership and a failure to understand the law in relation to disability discrimination and human rights. This led to situations in which people with learning disabilities were treated less favourably than others, resulting in prolonged suffering and inappropriate care.

Taken together, the investigation reports demonstrate an urgent imperative for organisational and cultural change coupled with individual leadership and commitment. Central government and professional organisations have set out clear expectations in policy and guidance for many years. However, our investigations have found clear evidence of instances in which implementation of these basic requirements was at best patchy and at worst entirely lacking. It seems to us unlikely that these are isolated cases and that they are likely to be indicative of a wider problem. In this situation, the overarching questions arising from our work are to ask what action is required, and by whom should it be done, to ensure that, no matter what their situation, everyone receives the care and support they need in a timely and effective way.

We have investigated six cases in which people with learning disabilities have died. In describing them as 'cases' we are using a shorthand expression to represent information about them, their families and all their personal circumstances. The use of the term is not intended in any way to diminish their individuality and relationships or the grief and distress of their families at their loss.

The issues range from a complaint about the care provided in a single hospital to complaints about service failures which involve the whole system of health and social care, including the ability of organisations to respond appropriately to complaints. A total of 20 organisations were involved, including 3 councils and 16 NHS bodies.



Complaints about the Healthcare Commission's handling of complaints were made in 5 of the 6 cases.

We did not uphold all of the complaints and it should be noted that complaints were not upheld against many of the public bodies involved. In particular, none of the complaints against GPs were upheld. We did see some examples of good practice.

This does not mean we have always been uncritical of the public bodies concerned. There were a number of examples where health professionals in particular could have been more proactive, acted on the advice and information that was given to them by the families or care staff who knew the person best, or adjusted their practice to better meet the needs of the individuals concerned.

The brief illustrative examples given in this Overview highlight the issues but are no substitute for a thorough reading of each of the investigation reports. Our reports look at the experiences of:

- **Mark Cannon** aged 30, a smiling and mischievous young man with a fine sense of humour. He enjoyed activities, social events and outings with his family but also liked just lazing around and relaxing. He had a particularly close relationship with his sister.
- **Warren Cox** aged 30, a happy and contented young man, who was usually quiet but had a great sense of humour and love for everyone. His parents, with whom he lived, described him as very fit.
- **Emma Kemp** aged 26, described by her mother as a 'party animal' who was caring, friendly and sociable and liked dancing, bowling, television and computers. She was lively and active and could understand people who used simple direct language.

- **Edward Hughes** aged 61, who was a quiet, private man who spent much of his life in care. He had been settled in a care home for some time, where he enjoyed the ordinary routines of daily living.
- **Martin Ryan** aged 43, described by his family as a charming, strong and energetic man who took time to get to know people but lived happily in his care home.
- **Tom Wakefield** aged 20, a sociable young man who liked music – particularly Robbie Williams, Blue and Jools Holland. He also enjoyed barbecues and football matches.

All of these people died between 2003 and 2005, in circumstances which Mencap alleged amounted to institutional discrimination. We have undertaken detailed separate investigations into what happened to each one of them. This Overview draws out overarching themes and lessons and makes general recommendations, in addition to the specific recommendations arising from the individual investigations.

We have not upheld all the complaints, but the very nature of our thorough and impartial investigations serves only to heighten the sense of outrage at the treatment received by most of the people involved.

In one case we concluded that the death of the person concerned occurred as a consequence of the service failure and maladministration identified. In another case the Health Service Ombudsman concluded that it was likely the death of the person could have been avoided, had the care and treatment provided not fallen so far below the relevant standard. In two cases, although we upheld complaints of service failure and maladministration, we could not conclude that the person's death was avoidable. Mencap have asked us to say that, whether the death could have been

avoided or not, this should not detract from the unacceptable standard of care and treatment that was experienced in those cases. We agree and have no difficulty in doing so.

In four of the six cases we upheld the complaint that the person concerned was treated less favourably, in some aspects of their care and treatment, and in the services of some of the bodies about which complaints were made, for reasons related to their learning disabilities. We also found in four of the six cases that the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality.

We believe these outcomes are a shocking indictment of services which profess to value individuals and to personalise services according to individual need.

## Role of the Ombudsmen

The Health Service Ombudsman is empowered to carry out independent investigations into complaints made by, or on behalf of, people who have suffered injustice or hardship because of poor treatment or service provided by the NHS. The Local Government Ombudsman has a similar remit in respect of services provided by councils, which include social care. We usually investigate only after the complaint has already been reviewed by the relevant public body and, currently in the case of complaints about NHS bodies, by the Healthcare Commission as well. Our investigations include consideration of the way in which complaints about services have been handled during earlier stages of the process, and the reasonableness of decisions and actions taken in the light of the law and of good practice in existence at the time of the actions concerned.

Both Ombudsmen look thoroughly at all the circumstances surrounding a complaint and try to resolve it in a way which is fair to all concerned. Where the complaint is justified we look to the public bodies involved to provide an appropriate and proportionate remedy for the injustice or hardship suffered by complainants.

Our approach uses the following *Principles of Good Administration*:<sup>1</sup>

- Getting it right
- Being customer focused
- Being open and accountable
- Acting fairly and proportionately
- Putting things right
- Seeking continuous improvement.

These Principles, and the outcomes which they provide, are of great relevance to the cases under consideration and are reflected in the individual reports for each person. Above all we have been concerned, in recognising that we cannot in these situations put things right, to secure positive remedies for the families concerned, when we have upheld complaints.

In 2007 a Regulatory Reform Order amended our legislation to give new powers to the Ombudsmen to work together more effectively in investigating and reporting on complaints which cross our respective jurisdictions. These new powers have been relevant in three of the six cases we have investigated. It has enabled us to produce joint investigation reports in those three cases and this joint Overview.

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<sup>1</sup> *Principles of Good Administration* is available at [www.ombudsman.org.uk](http://www.ombudsman.org.uk)

## Relevant policy and good practice guidance

Each of the individual investigation reports sets out in detail the relevant legal, policy and administrative framework for the NHS, for social care services commissioned or provided by councils in the three reports where this is relevant, and for arrangements for co-operation between the two. The individual reports also describe the relevant standards and guidance, including professional standards, which were in existence between 2003 and 2005, at the time when these deaths occurred.

Of particular relevance to all of these cases is the guidance issued by the Chief Inspector of Social Services in 2001 concerning the provision and planning of services for people with learning disabilities.

### ***HSC 2001/016 and LAC (2001) 23: Valuing People: A New Strategy for Learning Disability for the 21st Century: implementation***

This document required councils and primary care trusts to have in place by April 2002 a quality framework to improve service quality amongst all agencies with particular attention to people with complex needs. Its intention was that *'All public services will treat people with learning disabilities as individuals, with respect for their dignity'*. Funding was provided that year to help healthcare providers develop appropriate skills, especially in primary and secondary care. Objectives included:

- *'2.2 All public services will treat people with learning disabilities as individuals with respect for their dignity and challenge discrimination on all grounds including disability.'*
- *4.4 Making sure that all agencies work in partnership with carers, recognising that carers themselves have needs which must be met.'*

- *5.2 Enabling mainstream NHS services, with support from specialist learning disability staff, to meet the general and specialist health needs of people with learning disabilities.'*
- *5.16 Carers should be treated as full partners by all agencies involved.'*

Other documents set out the requirement to assess an individual's health and social care needs and to draw up plans to meet those needs, to focus on the fundamentals of good nursing care, to benchmark practice in this area, to establish principles of good practice in discharging people from hospital, and to involve individuals and their families at every stage in the planning of care.

In addition to this, both the General Medical Council and the Nursing and Midwifery Council set out professional standards on how doctors and nurses should approach their work. Of particular relevance to most of our investigations are:

- Paragraphs 5 and 36 of the General Medical Council's *Good Medical Practice 2001*, which say:
  5. *'The investigation and treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age or social or economic status to prejudice the treatment you give.'*
  36. *Healthcare is increasingly provided by multi-disciplinary teams. Working in a team does not change your personal accountability for your professional conduct and the care you provide.'*

And:

- The Nursing and Midwifery Council's *Code of Professional Conduct*, published in April 2002, which says:
  - 1 'You are personally accountable for your practice. This means that you are answerable for your actions and omissions regardless of advice or directions from another professional.
  - 2.4 You must promote the interests of patients and clients. This includes helping individuals and groups gain access to health and social care, information and support relevant to their needs.
  - 4.1 The team includes the patient or client, the patient or client's family, informal carers and health and social care professionals in the NHS, voluntary and independent sectors.
  - 4.2 You are expected to work co-operatively within teams ... You must communicate effectively and share your knowledge, skills and expertise with other members of the team as required for the benefit of patients and clients.'

None of the above is intended solely for specialists in working with people with learning disabilities. Instead, it sets standards for the quality of services to be provided for everyone. The statements are fundamental to the values of the professions and should underlie the behaviour and actions of individuals at all times. One of the most distressing features of our investigations has been the evidence in some cases that these fundamental principles were not being consistently upheld to the extreme detriment of the individuals concerned.

*Following a stroke in November 2005, Mr Ryan was admitted to a busy general ward run by a Hospital Trust. Although prevailing policy and guidelines did not require trusts to have a specialist stroke unit (and this Trust did not have such a unit) the guidelines did require trusts to organise stroke services so that patients were admitted under the care of a specialist team for acute care and rehabilitation. At the time Mr Ryan was admitted, services at the Trust for stroke patients were fragmented and fell short of professional and national expectations for stroke care set out in policy and guidelines.*

*There was no special team of experts skilled in management of the needs of stroke patients, for example doctors, nurses, dieticians and speech and language therapists, who could identify and meet Mr Ryan's basic needs, including his nutritional needs.*

*Neither the Consultant nor the Ward Sister provided effective clinical leadership, either for their professional group or the ward team as a whole. Despite speech and language therapy assessments that Mr Ryan would need alternative feeding (such as feeding him by a tube through his nose or abdominal wall into his stomach), the medical team did not make a decision about alternative feeding until Mr Ryan had been in hospital for 18 days. Soon after that, Mr Ryan became too ill to undergo the procedure to insert a feeding tube.*

*Mr Ryan died 26 days after admission.*

## Treating people as individuals

The *Disability Discrimination Act 1995* makes it unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified. It is also unlawful for service providers to fail to make reasonable adjustments for people with disabilities, where the existence of a physical barrier, practice, policy or procedure makes it impossible or unreasonably difficult for a person with a disability to use the service provided, unless such a failure is justified.

Equality for people with disabilities does not mean treating them in the same way as everyone else. Sometimes alternative methods of making services available to them have to be found in order to achieve equality in the outcomes for them. The focus is on those outcomes.

In many of the organisations whose actions we investigated it did not appear that this level of understanding of the need to make reasonable adjustments had become embedded, even at the most senior levels, despite the legislation and the extensive guidance available. Our investigations uncovered a lack of understanding of how to make reasonable adjustments in practice, which suggests there may be a need for further training on the practical implementation of the *Disability Discrimination Act 1995*.

Valuing People explained that the Government's intention was that:

*'all public services will treat people with learning disabilities as individuals with respect for their dignity.'*

The objective was to:

*'enable people with learning disabilities to access health [and social care] services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.'*

The *Human Rights Act 1998* came into force in England in October 2000. It was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. It requires public authorities to act in a way which is compatible with the Convention.

Of particular relevance to the delivery by a public authority of health and social care for people with disabilities are the following rights contained in the Convention:

Article 2 The right to life.

Article 3 The prohibition of torture or inhuman or degrading treatment.

Article 14 The prohibition of discrimination.

When the UK Government introduced the *Human Rights Act 1998*, it said that its intention was to do more than require government and public authorities to comply with the *European Convention on Human Rights*. It wanted instead to create a new 'human rights culture' among public authorities and among the public at large.

A key component of that human rights culture is the observance of the core human rights principles of fairness, respect, equality, dignity and autonomy for all.

Despite the fact that ten years have elapsed since the introduction of the *Human Rights Act 1998*, our investigation of these complaints demonstrates that an underlying culture which values human rights was not in place in the experience of most of these people. The lack of respect for these principles spread across many organisations. The absence of understanding of individual needs, empathy for the situation in which individuals were placed, and a basic concern for them as people, led to prolonged suffering and inappropriate care. This happened in a context within which professionals pride themselves on caring for others.

*When Mr Hughes, following an operation, was transferred to a ward, the nurses made entirely inadequate attempts to assess his needs, or plan or deliver care for him. Mr Hughes was medically fit to be discharged but it was not safe to discharge him. The Trust's staff failed to enact even the most basic principles of good discharge as set out in the prevailing local and national policies. They did not engage with community staff to ensure that a multi-agency plan was in place. This service failure was at least in part for disability related reasons.*

In the investigations which we have undertaken we have found several examples of very poor service which have resulted in shocking outcomes for the people concerned. Sir Jonathan Michael's report, *Healthcare for All*, highlights the important effect of professional misperceptions, in which illness is overlooked and its symptoms attributed to the disability of the person concerned, despite information from carers to the contrary. We have found evidence of this in some of our investigations. On one occasion it appeared that some professionals were seeking to move someone, whose needs they found difficult to address, out of their service with no regard for the interests of the person concerned.

We were shocked that such events should have occurred and that on these occasions, and possibly on a much wider basis, the policy intentions of government set out in the *Human Rights Act 1998*, the *Disability Discrimination Act 1995* and in *Valuing People* were frustrated and appear not to have been understood. Or, if understood, they were not regarded as important enough to be put into practice. Taken together, they set out an inspirational culture which underlies everyday practice and places a value on the life of every human being.

While we are concerned here with the experience of a number of people with learning disabilities, we are well aware that there may be other vulnerable groups who are similarly affected and who would equally benefit from a change in culture. Such a change will come about only through strong leadership at all levels in the Department of Health, the NHS and local government. We make recommendations to the organisations concerned designed to focus on the understanding and practical implementation of values stated and restated, over several years, and to the regulators of those bodies to ensure that this time lessons are genuinely learnt and change occurs.

**Table 1: Overview of upheld complaints**

Body complained about	Decisions on upheld complaint
Buckinghamshire Hospitals NHS Trust	<ul style="list-style-type: none"> <li>• Inadequate care and treatment including inadequate attempts to assess, plan and deliver care by nursing staff and inadequate discharge arrangements which were unsafe.</li> <li>• These failures were for disability related reasons.</li> <li>• In some areas the Trust failed to live up to human rights principles of dignity and equality.</li> <li>• Failure to inform patient’s family of significant events in his care.</li> <li>• Poor complaint handling.</li> </ul>
Gloucestershire County Council	<ul style="list-style-type: none"> <li>• Arrangements for transition from residential school to adult care fell significantly below a reasonable standard.</li> <li>• Some of this maladministration was for disability related reasons.</li> <li>• The Council failed to live up to human rights principles of dignity and equality.</li> <li>• Poor complaint handling.</li> </ul>
Cheltenham and Tewkesbury Primary Care Trust (now Gloucestershire Primary Care Trust)	<ul style="list-style-type: none"> <li>• Shortcomings in fulfilling of responsibilities with regard to planning for the health needs of people with profound and multiple learning disabilities.</li> <li>• This service failure was for disability related reasons.</li> <li>• The PCT failed to live up to human rights principles of dignity and equality.</li> <li>• Poor complaint handling.</li> </ul>

<p>Gloucestershire Partnership NHS Foundation Trust (now 2gether NHS Foundation Trust for Gloucestershire)</p>	<ul style="list-style-type: none"> <li>• Service failure in care and treatment including nursing care and arrangements for discharge to an adult care home.</li> <li>• Some of this service failure was for disability related reasons.</li> <li>• The Trust failed to live up to human rights principles of dignity and equality.</li> <li>• Poor complaint handling.</li> </ul>
<p>Gloucestershire Hospitals NHS Foundation Trust</p>	<ul style="list-style-type: none"> <li>• Failures in care and treatment including the co-ordination and supervision of care, poor record keeping, inadequate observations, failure to properly report and record highly significant incidents, failures in nursing care, poor care planning, failures in communications with the patient’s family about prognosis and imminent death.</li> <li>• Many of the failures in care and treatment were for disability related reasons.</li> <li>• The Trust failed to live up to human rights principles of dignity and equality.</li> </ul>
<p>Kingston Hospital NHS Trust</p>	<ul style="list-style-type: none"> <li>• Had service failure not occurred it is likely the patient’s death could have been avoided.</li> <li>• Service failure in care and treatment including failure in stroke care, clinical leadership, communication and multidisciplinary working and a failure to feed the patient.</li> <li>• In many respects the service failure occurred for disability related reasons.</li> <li>• The Trust failed to live up to human rights principles of dignity, equality and autonomy.</li> <li>• Poor complaint handling.</li> </ul>



London Borough of Havering	<ul style="list-style-type: none"> <li>• Contributed to public service failure which resulted in an avoidable death.</li> <li>• Failure to provide and/or secure an acceptable standard of care and consequently the care home resident's safety was put at risk.</li> <li>• Less favourable treatment for reasons related to disability.</li> <li>• The Council failed to live up to human rights principles of dignity equality and autonomy.</li> <li>• Poor complaint handling.</li> </ul>
Barking, Havering and Redbridge Hospitals NHS Trust	<ul style="list-style-type: none"> <li>• Contributed to public service failure which resulted in an avoidable death.</li> <li>• Service failure in care and treatment including failures in pain management, post-operative monitoring, discharge arrangements and nursing care.</li> <li>• Some of these service failures were for disability related reasons.</li> <li>• The Trust failed to live up to human rights principles of dignity equality and autonomy.</li> <li>• Poor complaint handling.</li> </ul>
Royal Berkshire NHS Foundation Trust	<ul style="list-style-type: none"> <li>• Poor complaint handling.</li> </ul>
Healthcare Commission	<ul style="list-style-type: none"> <li>• Poor complaint handling.</li> </ul>

### Doing the basics well – an issue of leadership

The individual investigation reports for each of the people concerned set out the standards of practice to be observed across a range of everyday functions in health and social care. Such guidance is issued on a regular basis and covers matters such as communication, record keeping, partnership working, working with carers, transition

and discharge planning, and the use of advocates among others. Some might say there are too many good practice documents to enable them to be assimilated, but they set out a broad and consistent approach which should be familiar to all professionals across health and social care, not just to those who specialise in working with people with disabilities. In fact, the standards in place for normal professional practice across all areas will, if observed consistently, offer many of

the safeguards essential to ensuring that the needs of people who are vulnerable for any reason are addressed, and appropriate adjustments made for their care.

Again, on many occasions in the lives of these people, basic policy, standards and guidance were not observed, adjustments were not made, and services were not co-ordinated. There did not appear to be any understanding of the impact that this failure in service was having, nor any empathy for the suffering caused. Above all, what was evident was a lack of leadership. In some situations it appeared that no one had a real grasp of what was happening. No one took responsibility for sorting out organisational difficulties, which were impacting adversely upon standards of care. No one took a proactive approach in owning and resolving problems by making reasonable adjustments and seeking urgent solutions. It is this aspect of the quality of the service they experienced that Mencap described as ‘indifference’, and it is unacceptable.

The poor practice which was evident in many situations across these investigations covered a wide range of day-to-day care and administration and did not always amount to service failure or maladministration. In this Overview we highlight some of the most prominent issues which had significant impacts on the care given to individuals, but this short section is by no means a definitive list of examples. We commend the full investigation reports to readers wishing to gain an understanding of the various complex factors which led to failure to offer good care to very vulnerable individuals. It is this complexity across widely varying situations which itself requires strong leadership to maintain a focus on the experience of and outcomes for people with learning disabilities, particularly when they are unable to communicate their own needs.

- **Communication** – it is clear that professionals who were not specialists in learning disabilities were not always familiar with legislation and guidance, which had been in existence for some years, and did not have it at the forefront of their minds. This raises questions which were not part of our investigations about how information is disseminated within organisations and the training and support available to assist implementation. However, there is another highly relevant issue concerning the passing of information accurately between professionals, and between professionals and the family, and then acting upon it.

*Mr Ryan himself was unable to communicate his needs. There was evidence that various professionals, including the community team and the speech and language therapists, were very concerned about Mr Ryan and tried to raise their concerns, particularly about nutrition, with the medical and nursing teams. But they could not make themselves heard and nothing happened to help Mr Ryan. Nobody took any action to feed him.*

- **Partnership working and co-ordination** – in some of the cases we have investigated there was clear evidence that professionals were not working together to make use of the skills and expertise of different disciplines in the interests of the individual. The example above concerning Mr Ryan demonstrates this in a multidisciplinary health team but, sadly, this was even more evident on occasions across the boundaries of health and social care. Guidance on transition planning for children moving into adult services, and in discharge planning for those leaving hospitals, is intended to ensure that the needs of individuals at a time of change and risk are fully assessed, resources are appropriately targeted and plans are in place to meet those needs, but in situations in which individuals were at greatest risk this co-ordination and planning was entirely absent. It was not clear that in these complex situations a designated professional had been appointed formally as co-ordinator to ensure effective planning and implementation.

*Tom Wakefield spent much of his early life in a residential school but at the age of 19, when he should have moved to suitable adult accommodation, no appropriate place had been found or commissioned for him. He remained at the school where his behaviour and health deteriorated. There was no proactive planning for Tom's future needs between the Council and the Primary Care Trust and no formal co-ordinated transition plan.*

- **Relationships with families and carers** – in 2001, as part of the supporting documents for Valuing People, the Department of Health published *Family Matters*, a report highlighting the perspective of family carers for people with learning disabilities. It acknowledges:

*'Families have an important and unique contribution to the discussion of the future direction of services for men and women with learning disabilities. They are the only people who will have a continuous relationship with the person with a learning disability from childhood to adulthood. This contribution needs to be acknowledged, valued, listened to and acted upon.'*

However, they also state that: *'in many services a culture has developed that sees families as a problem and difficult to work with ... The reality is that services need to find constructive and positive ways to work with families in the best interest of people with learning disabilities'*.

In some of the situations which we considered, the importance of listening to family members, recognising their particular knowledge of the person concerned, and often their ability to communicate and to understand responses, was not acknowledged. Families, and on occasions residential care workers, were not treated as part of the team. Valuable contributions, which only they were able to make, were lost. This led them to feel excluded and ignored and greatly added to their distress.

- **Following routine procedures** – there are many documents which set out standard good practice and processes, some of which we have quoted in this Overview, which would have improved the experience of and outcomes for these people, and are in fact designed to support the professional management of complex situations. However, it appeared in our investigations that it was in exactly these situations that standards and guidance were not followed, significantly increasing the risk to vulnerable individuals. We have already described the impact for Tom Wakefield of the lack of transition planning, and for Mr Hughes of the lack of a proper discharge plan.

- **Quality of management** is important in ensuring that routine good practice and established procedures happen on a regular and consistent basis, and in taking ownership and responsibility for the needs of individuals. Part of this management is an understanding of personal accountability in taking a proactive and sustained approach to addressing poor practice, and challenging inadequate systems. We found a few examples of people who had indeed tried to do this but who appeared either to give up easily in the face of an unresponsive system or resistance from others, or had no senior support for their efforts. We have already described how the attempts of the community team and speech and language therapists to raise their concerns about Mr Ryan were not heard.
- **Advocacy** – a final issue in identifying the basics which need to be done consistently well is notable for its absence in all of our investigations. The strategy set out in Valuing People in 2001 included investment of significant amounts of money in the following years to develop advocacy services to support people with learning disabilities. We have seen no evidence of the use or availability of independent advocates for any of the people involved in these six cases until the stage at which Mencap became involved. While parents and families undoubtedly advocated strongly on behalf of their family members, it is possible that independent advocates might have provided the people concerned and their families with additional support, or even have affected some of the outcomes. We have no way of knowing whether this is the case, but the use of independent advocates could have provided an additional safeguard for the rights of a very vulnerable group of people. We cannot speculate on the reasons why they did not have this opportunity.

We asked ourselves what would change the attitudes and culture which resulted, in these cases, in a failure to follow basic good practice. More guidance will not help since detailed and appropriate guidance has been in existence for many years. Reminders and refreshers for staff across all disciplines, perhaps coupled with the lessons learnt from these investigations, may be helpful, and the implementation of good management processes would also assist. Above all, changes in this area depend on strong leadership, at all levels in organisations, from people who recognise the hallmarks of good quality services in everyday practice and have a real empathy for and understanding of the situations of others – particularly those who cannot easily communicate, and are prepared to challenge consistently the acceptance of poor outcomes. The focus must always be on the best possible outcomes for individuals. Current standards in place for normal professional practice will, if observed, offer many of the safeguards essential to ensuring that the needs of people with learning disabilities are addressed. The investigation reports show that basic standards and guidance in a range of general services, such as care planning, nutrition and pain management, were often not observed and that this disproportionately disadvantaged and discriminated against the people concerned. There is nothing ‘specialist’ about this.

## Complaint handling

Most of the complaints which we considered had been reviewed first by the NHS or council complaints systems. The families told us that their experiences of these systems had left them drained and demoralised and with a feeling of hopelessness.

They gave repeated examples of failures to understand their complaints, with little effort made to clarify matters with them, confused and fragmented systems, poor investigations with little rigorous testing of evidence, defensive explanations, a failure to address the heart of the complaint and a reluctance to offer apologies. Our investigations generally confirmed this picture.

Complaints against NHS bodies at the time of these events followed a second stage review process by the Healthcare Commission. The families who asked the Healthcare Commission to review their complaints said they had hoped that the Healthcare Commission's review would give them the explanations they sought. In practice, they experienced many of the same problems of delay, lack of contact, poor specification of complaints and a lack of clarity about the process that they had experienced at the first stage of the process. Clinical advice was not always appropriately sourced, explanations were inadequate and the families remained unclear as to what had changed as a result of their complaints. Again, our investigations generally confirmed this picture.

For the most part the NHS bodies and the councils concerned, and the Healthcare Commission, have subsequently acknowledged and apologised for the failings in their complaint handling and have provided information on improvements they have made to their services and to their complaint handling arrangements. We have included this information in the individual investigation reports.

Nonetheless, it remains the case that poor complaint handling compounded the distress which resulted from the failures in service experienced by the families of those who died. Even in one case where the complaint of service failure was not upheld, poor complaint handling added to the distress of losing a much loved family member. In most cases, the distress to families could have been reduced by effective investigation and empathetic and timely responses to complaints. These families should not have had to wait so long and fight so hard for the explanations and apologies to which they were entitled.

The White Paper *Our Health, Our Care, Our Say*, published in January 2006, made a commitment to implement a single comprehensive complaints process across health and social care, focused on resolving complaints locally with a more personal and comprehensive approach.

From 1 April 2009 changes introduced by the *Health and Social Care Act 2008* will remove the Healthcare Commission as the second tier complaint handler and the Ombudsmen will provide the second and final tier of the new system across health and adult social care. The changes in the system provide an excellent opportunity for health and social organisations to review their systems and to put in place good arrangements for the future handling of complaints.

## Remedy

Our investigations found that in some of the cases there was unremedied injustice which we concluded had resulted from the maladministration and service failure we identified. Table 2 below gives an overview of the injustice we found.

### Table 2: Overview of injustice found

- One avoidable death and one death which was likely to have been avoidable.
- Unnecessary distress and suffering for the aggrieved.
- Unnecessary distress and suffering for the families of the aggrieved, in particular about those failings which occurred for disability related reasons.
- Distress at unanswered questions of what difference would have been made if there had been no service failure or maladministration. Would the person concerned have lived longer? Could there have been some improved enjoyment in the last period of their life?
- Distress compounded by poor complaint handling leaving questions unanswered.
- Distress arising from a failure to live up to human rights principles.

Table 3 gives an overview of the remedies which were provided by the councils and NHS bodies concerned prior to our investigations.

### Table 3: Overview of remedy provided prior to the Ombudsmen's investigations

- Senior level personal apology and offer of meetings.
- Offer to involve family in planning services.
- Actions to address failings and to minimise risk of reoccurrence; action plan notified at Board level and to the regulator.
- Commitment to learn lessons from the investigations, and to work openly and collaboratively with local and central bodies.
- Identification of lessons learnt.

The summary investigation reports which follow detail our findings in relation to the public bodies concerned and set out the remedies we have recommended and secured for the injustice we found. They include apologies and explanations to the families, financial compensation and extensive action plans to ensure that others do not experience similar injustice in future.

### Table 4: Overview of remedy secured by the Ombudsmen

- Further personal apologies and offers of meetings.
- Public apologies through the published investigation reports.
- Financial compensation for distress ranging from £5,000 to £40,000.

## Conclusion and recommendations

Many of the issues highlighted by our investigations have been evidenced by previous inquiries, yet people with learning disabilities continue to live with them day by day. We do not extrapolate from these cases to suggest that all health and social care in respect of people with learning disabilities is poor. Nevertheless, the recurrent nature of the complaints across different agencies leads us to the view that understanding of the issues is at best patchy and at worst an indictment of our society.

In writing this Overview we have been motivated by the desire to bring positive change from the experiences of these people and their families, which could in itself provide some redress for all those concerned. We are not looking to '*make this a priority for 2009*', but to change underlying attitudes and behaviour on a lasting basis. We do not underestimate the challenges involved.

We have made individual recommendations to address the specific unremedied injustice we have found in the cases where we have upheld the complaints (and for the most part these individual recommendations have been accepted by the public bodies concerned).

However, the findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities.

We have thought long and hard about what general recommendations we could properly and usefully make in the light of our investigation findings and the themes and issues we have identified in this Overview. We are Ombudsmen, not regulators and we do not seek to usurp their role. Nonetheless, we are committed to ensuring that the learning

from complaints investigated by us is fed back to those responsible for the design and delivery of public services so that they can use that feedback to improve those services.

We see no point in repeating the detailed recommendations of Sir Jonathan Michael's Independent Inquiry into Access to Healthcare for People with Learning Disabilities, *Healthcare for All*, although we do not disagree with those recommendations.

We welcome the simplified complaint handling arrangements for health and social care which are being introduced from 1 April 2009 and therefore make no specific recommendations for improvements in the complaint handling system.

We have not found any shortage of policy and good practice guidance on the planning and provision of health and social care services for people with learning disabilities; on making reasonable adjustments in order to comply with the requirements of the *Disability Discrimination Act 1995*; or on observing the core human rights principles of fairness, respect, equality, dignity and autonomy for all. We have noted the very recent publication by the Department of Health of *Valuing People Now: a new three-year strategy for people with learning disabilities*. So we make no recommendations for further guidance.

Nonetheless, we are still left with an underlying concern that similar failures to those identified in the investigations will occur again – and indeed may be occurring today in services provided or commissioned by NHS bodies and councils across the country. We believe it is legitimate, in the light of the very serious findings of our investigations, to ask all NHS bodies and councils with social services responsibilities to satisfy themselves that is not the case.

As we have said above, we have concluded that the findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities. This is not a question that we, as Ombudsmen with a very specific remit, can or should answer but it is, we suggest, a question which those responsible for commissioning and providing health and social care services should ask themselves; which those responsible for the regulation of health and social care services should ensure is addressed in their regulatory frameworks and performance monitoring regimes; and about which the Department of Health should properly be concerned. Our recommendations are therefore addressed to the leaders of those bodies.

**We recommend:**

**First, that all NHS and social care organisations in England** should review urgently:

- the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas;

and

- the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities;

and should report accordingly to those responsible for the governance of those organisations within 12 months of the publication of this report.

**Secondly, that those responsible for the regulation of health and social care services (specifically the Care Quality Commission, Monitor and the Equality and Human Rights Commission)** should satisfy themselves, individually and jointly, that the approach taken in their regulatory frameworks and performance monitoring regimes provides effective assurance that health and social care organisations are meeting their statutory and regulatory requirements in relation to the provision of services to people with learning disabilities; and that they should report accordingly to their respective Boards within 12 months of the publication of this report.

**Thirdly, that the Department of Health** should promote and support the implementation of these recommendations, monitor progress against them and publish a progress report within 18 months of the publication of this report.



Ann Abraham  
**Parliamentary and Health Service Ombudsman**



Jerry White  
**Local Government Ombudsman**

March 2009





# Summary investigation reports



## Summary report of a joint investigation by the Health Service Ombudsman and the Local Government Ombudsman of a complaint made by Mencap on behalf of Mr Allan Cannon and Mrs Anne Handley in relation to their late son, Mr Mark Cannon.

### Complainants:

Mr Allan Cannon and Mrs Anne Handley

### Aggrieved:

Mr Mark Cannon (late son of Mr Allan Cannon and Mrs Anne Handley)

### Representative:

Mencap

### Complaint against:

London Borough of Havering (the Council)  
Barking, Havering and Redbridge Hospitals  
NHS Trust (the Trust)  
The New Medical Centre, Romford (the Practice)  
Healthcare Commission

## Introduction

This complaint was investigated jointly by the Local Government Ombudsman for England and the Health Service Ombudsman for England in accordance with the powers conferred by amendments to their legislation due to *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007*. With the consent of the complainants, Mr Allan Cannon and Mrs Anne Handley, the two Ombudsmen agreed to work together because the health and social care issues were so closely linked. A co-ordinated response, consisting of a joint investigation leading to a joint conclusion and proposed remedy in one report, seemed the most appropriate way forward.

## Background

Mr Cannon was a 30 year old man with severe learning disabilities. He also suffered from epilepsy. He had very little speech but was able to communicate with his family and he was particularly close to his sister. He was able to walk unaided but often needed support when he was feeling unsteady on his feet. Mr Cannon was smiling and 'mischievous' with a fine sense of humour. He enjoyed participating in activities, social events and outings with his family and carers, but he also liked lazing around and relaxing in an easy chair or bean bag. Mr Cannon lived at home with his mother, stepfather and sister. He attended a day centre five days a week with occasional stays at the Grange (the Care Home) owned by the Council.

In June 2003 Mr Cannon was at the Care Home and he broke his thigh bone, in circumstances which remain unclear. He was admitted to the Trust, the broken bone was repaired and he was discharged to his mother's home. However, four days later his GP arranged for him to be readmitted to the Trust because he was in pain and it was difficult to persuade him to eat or drink. After about a week, Mr Cannon was discharged again.

In early August 2003 Mr Cannon's GP made a home visit, diagnosed an infection and prescribed antibiotics. Despite this treatment, Mr Cannon's condition deteriorated and a few days later he was taken to the Accident and Emergency Department (A&E) at the Trust. He was admitted to a medical admission ward but he deteriorated further and was transferred to the Intensive Therapy Unit (the ITU). A couple of days later his condition had stabilised and he was transferred to the High Dependency Unit (the HDU). However, Mr Cannon collapsed, suffered a cardiac arrest and returned to the ITU. Around a fortnight later, almost three weeks after he had been admitted

as an emergency, Mr Cannon's family agreed with doctors that there was no hope of recovery and Mr Cannon died.

The Coroner found that Mr Cannon's broken leg was caused by a fall and that his death was as a result of bronchopneumonia. He recorded a verdict of accidental death.

## The complaint

Mr Cannon's parents complained that their son should not have died. They said that if staff at the Care Home, the Trust and the Practice had acted differently, he would have survived. They believed their son had been treated less favourably for reasons related to his learning disabilities.

Mr Cannon's parents were also dissatisfied with the way their complaint against the NHS had been handled by the Trust and the Healthcare Commission, and with the way the circumstances of Mr Cannon's injury had been investigated by the Council. They felt the NHS and Council complaints processes had failed them, and they asked for answers to their questions about the service provided for their son.

## What should have happened

The staff who looked after Mr Cannon should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework, and the professional standards relevant to the events in question.

In Mr Cannon's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard.

Mr Cannon's care should have been organised within the legal and policy framework for integrated health and social care as set out in key documents including the *National Health Service and Community Care Act 1990*, the *National Assistance Act 1948* and the *Care Standards Act 2000*.

In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies. Mr Cannon's care and treatment at the Trust should have met national and professional standards regarding nursing care and discharge arrangements.

The responses to Mr Cannon's parents' complaint about the Trust should have followed the procedures set out in the *Directions* (1996 and subsequent amendments) produced by the Secretary of State for Health, and the Healthcare Commission should have reviewed that complaint in line with the *National Health Service (Complaints) Regulations 2004*. The complaint about the Council should have been handled in line with the *Complaints Procedure Directions 1990*.

## How the Ombudsmen investigated

The investigator met Mr Cannon's parents to gain a full understanding of their complaint. It was important to carefully consider their recollections and views. Evidence about what happened to Mr Cannon and how his parents' complaints about NHS and Council services were handled was considered. Enquiries were also made of the Coroner who conducted the inquest into Mr Cannon's death. All the bodies complained about provided additional information in response to specific enquiries.

Several professional advisers provided expert clinical advice to the Ombudsmen. They were: an A&E nurse; a community nurse; an orthopaedic nurse; a learning disability nurse; an A&E consultant; an ICU consultant; an orthopaedic consultant; and a GP.

Mr Cannon's parents, their representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

## What the Ombudsmen found and concluded

### The Local Government Ombudsman's investigation of the complaint against the Council

Mr Cannon broke his leg when he was in respite care at the Care Home. His parents complained that their son was provided with inadequate care by the Council and this led to his injury and death. They said the Council failed to keep their son safe as a result of poor planning, poor supervision, weak management and inadequate staffing. They

also said the Council repeatedly failed to properly investigate the circumstances of Mr Cannon's injury or take responsibility for the part their failings played in his injury and subsequent death.

The Local Government Ombudsman concluded that the Council failed to provide and/or secure an acceptable standard of care for Mr Cannon and, as a result, his safety was put at risk. That failure constitutes maladministration.

The Local Government Ombudsman also concluded that there was maladministration in the way the Council investigated Mr Cannon's parents' complaint. He found complaint handling during the early stages of the complaints process was extremely confusing, the complaints were poorly considered, responses were unsympathetic and the whole process was unreasonably delayed.

Therefore, the Local Government Ombudsman upheld the complaint against the Council.

### The Health Service Ombudsman's investigation of the complaint against the Trust

Mr Cannon was admitted to the Trust three times between June and August 2003. During the first admission he underwent surgery to repair his broken leg. Subsequent admissions were because his condition deteriorated while he was at home.

Mr Cannon's parents complained that on each occasion that Mr Cannon was admitted the Trust failed to provide him with adequate care and treatment or to plan and put in place proper arrangements for his discharge. They were happy with his care in the ITU but they said failings elsewhere at the Trust led to a decline in his condition and his death. They were also dissatisfied with the way their complaint was handled.

The Health Service Ombudsman found failings in key aspects of the care and treatment provided for Mr Cannon.

- Management of Mr Cannon's pain was inadequate. His urgent need for pain relief was not met and assessment and planning for ongoing pain management was not of a reasonable standard. This failure meant Mr Cannon was left in severe pain and great distress for prolonged periods of time.
- Assessment, observation, monitoring and recording of Mr Cannon's condition was inadequate particularly during his three admissions to A&E, during the days immediately following his operation and when he was admitted to a ward on his third admission.
- Management of Mr Cannon's epilepsy was inadequate because his seizures and medication levels were not properly monitored and his medication was not always given as prescribed. This failure may have increased the frequency of Mr Cannon's seizures and increased his agitation.
- On two occasions discharge arrangements did not meet the standards set out in national guidelines. Mr Cannon was discharged without due concern for his safety and community healthcare providers were not fully aware of his condition or the level of support he would need. Staff did not properly consider his needs and his mother was left to care for him and arrange help as best she could.
- On one occasion junior doctors made a decision that Mr Cannon should not be resuscitated if he collapsed. Their decision was not appropriate and did not conform with legal and professional guidance.

The Health Service Ombudsman found shortcomings in the way in which the Trust handled Mr Cannon's parents' complaint. For instance, the Trust failed to properly investigate the complaint and failed to take opportunities to offer full explanations and appropriate apologies.

The Health Service Ombudsman concluded there was service failure in the care and treatment provided for Mr Cannon by the Trust and that this was at least in part for disability related reasons. She also found maladministration in the way the Trust handled his parents' complaint.

The Trust told the Health Service Ombudsman about actions it had taken subsequently to address the failures in the service provided for Mr Cannon.

The Health Service Ombudsman concluded that, had the Trust provided appropriate and reasonable care and treatment, according to prevailing standards and guidance, it is likely Mr Cannon's suffering would have been less and it is possible that he would have survived. Furthermore, his family would have suffered less anxiety and distress. These findings represented unremedied injustice.

Therefore, the Health Service Ombudsman upheld the complaint against the Trust.

### The Health Service Ombudsman's investigation of the complaint against the Practice

Mr Cannon's parents had not previously complained about the Practice, but to ensure they had a full picture of their son's care and treatment during the final months of his life, the Health Service Ombudsman used her discretion to investigate their complaint.

Mr Cannon's parents complained that the Practice failed to provide their son with adequate care and that more could have been done to diagnose his illness following his discharge from hospital. In particular, Mr Cannon's parents believed that a GP who examined their son only a few days before he was readmitted had not acted properly and should have done more to help him.

The Health Service Ombudsman did find some shortcomings in the actions of the GP who visited Mr Cannon prior to his final admission to hospital. However, she decided that these shortcomings did not amount to service failure.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Practice.

### The Health Service Ombudsman's investigation of the complaint against the Healthcare Commission

Mr Cannon's parents were dissatisfied with the way their complaint was handled by the Healthcare Commission.

The Health Service Ombudsman found maladministration in the way the Healthcare Commission reviewed Mr Cannon's parents' complaint against the Trust because it was not based on appropriate or adequate clinical advice. This meant its decision was unreliable and unsafe. Furthermore, the Healthcare Commission's review did not cover key aspects of Mr Cannon's parents' complaint and the report of the review contained significant factual inaccuracies. The Health Service Ombudsman concluded the Healthcare Commission's response was superficial, incomplete and not evidence-based. Mr Cannon's parents were denied a proper independent review of their complaint against the Trust and this caused them unnecessary uncertainty and distress.

Therefore, the Health Service Ombudsman upheld the complaint against the Healthcare Commission.

### Was Mr Cannon treated less favourably for reasons related to his learning disabilities?

The Health Service Ombudsman concluded that failures in the care and treatment provided for Mr Cannon by the Trust were in part for reasons related to his learning disabilities. Staff did not make reasonable adjustments to the way in which they organised and delivered care to meet his complex needs. She concluded that in some significant respects the service failures at the Trust were for disability related reasons.

The Local Government Ombudsman concluded that some of the failures by the Council represented failure to make reasonable adjustments to meet Mr Cannon's needs, and resulted in him being treated less favourably for reasons related to his learning disabilities.

The Ombudsmen concluded that there was no evidence of any positive intention to humiliate or debase Mr Cannon. Nevertheless, by omitting to provide and/or secure proper care for Mr Cannon, public services failed to have due regard to his dignity and status as a person, and the need to observe the principle of equality.

### Was Mr Cannon's death avoidable?

The Ombudsmen considered Mr Cannon's death could not be attributed to one specific incident or action. That said, they concluded that the Council and the Trust had failed Mr Cannon. The injury suffered by Mr Cannon might well have been avoided. In any event he should not have died as a consequence of that injury. On that basis, the Ombudsmen found that Mr Cannon's



death arose in consequence of service failure and maladministration they identified. Therefore, they concluded his death was avoidable.

### **The Ombudsmen's recommendations**

The Ombudsmen recommended that Mr Cannon's parents should receive apologies and compensation totalling £40,000 from the bodies against which complaints were upheld. The compensation was in recognition of the injustice suffered in consequence of service failure and maladministration identified.

In response to these recommendations the Trust acknowledged its failings and apologised to Mr Cannon's parents. It also agreed to pay its share of the compensation recommended. The Healthcare Commission agreed to apologise to Mr Cannon's parents. The Council did not accept the recommendations.

### **The complainant's response**

Mr Cannon's parents welcomed the Ombudsmen's report, saying it was *'tough and hard hitting'*. Nevertheless, they were particularly disappointed that the Health Service Ombudsman did not uphold their complaint against the Practice because they believed their son did not receive a reasonable standard of care from the GPs there. Mr Cannon's father, although welcoming the Health Service Ombudsman's findings regarding the Trust, expressed continuing concerns about specific aspects of the care and treatment it provided for his son.

## Summary report of an investigation by the Health Service Ombudsman of a complaint made by Mencap on behalf of Mr and Mrs Cox in relation to their late son, Mr Warren Cox.

### Complainants:

Mr and Mrs Cox

### Aggrieved:

Mr Warren Cox (Mr and Mrs Cox's late son)

### Representative:

Mencap

### Complaint against:

Harold Road Surgery (the Surgery)

A GP employed by South East Health Ltd  
(the Out of Hours GP)

East Sussex Hospitals NHS Trust (the Trust)  
Healthcare Commission

## Background

Mr Warren Cox was a 30 year old man with severe learning disabilities. His parents described him as a very happy and contented young person with a great sense of humour and a love for everyone. He lived at home with his parents who were his carers. Mr Cox had very little speech, but he could make himself understood to his family.

In September 2004 Mr Cox became unwell with abdominal pain. He had difficulty sleeping and had a bad epileptic seizure. His parents contacted their local Surgery, and the GPs who visited Mr Cox and spoke to his parents on the telephone diagnosed a viral infection. Around 1.30am on 25 September 2004 Mr Cox's parents became increasingly anxious about their son because his abdomen was very swollen and they telephoned the Out of Hours GP. He visited and said Mr Cox

should go to hospital for an X-ray. Mr Cox's parents were reluctant to take Mr Cox to hospital at that time of night because they were worried they would have to wait until the X-ray department opened and this would make it hard for them to care for their son properly. Subsequently, Mr Cox's parents telephoned the Out of Hours GP again and he arranged for an ambulance to take Mr Cox to hospital urgently.

At the Trust an intestinal obstruction was diagnosed. Various examinations and tests were performed and Mr Cox had an X-ray of his abdomen. Shortly after he returned from the X-ray department, around 90 minutes after he reached the Trust, Mr Cox vomited and unexpectedly his heart stopped and he stopped breathing. Sadly, attempts to resuscitate him were unsuccessful.

A post mortem showed that Mr Cox had died from inhaling vomit into his lungs and that his bowel had stopped working due to inflammation of the lining of his abdomen.

## The complaint

Mr Cox's parents complained that their son should not have died. They said that if the GPs from the Surgery, the Out of Hours GP and staff at the Trust had acted differently and with more urgency, he would have survived. They believed their son had been treated less favourably for reasons related to his learning disabilities.

Mr Cox's parents were also dissatisfied with the way their complaint had been handled by the Surgery, the Trust and the Healthcare Commission. They felt the NHS complaints process had failed them and they had not had answers to their questions about the service provided for their son.

## What should have happened

The NHS staff who looked after Mr Cox should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Mr Cox's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard. In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies.

The responses to Mr Cox's parents' complaint should have followed the *National Health Service (Complaints) Regulations 2004*.

## How the Health Service Ombudsman investigated

The investigator met Mr Cox's parents to gain a full understanding of their complaint. It was important to carefully consider their recollections and views. Evidence about what happened to Mr Cox and how his parents' complaint had been handled was considered. Further enquiries were made of the Surgery, the Out of Hours GP and the Trust.

Several professional advisers provided expert clinical advice to the Health Service Ombudsman. They were: two GPs; a consultant gastroenterologist; a consultant surgeon; an accident and emergency consultant; a hospital nurse; and a learning disability nurse.

Mr Cox's parents, their representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

## What the Health Service Ombudsman found and concluded

### The investigation of the complaint against the Surgery

Mr Cox's parents complained that GPs at the Surgery failed to diagnose their son's condition and failed to carry out further investigations when it was clear he was in pain and distress. They said the GPs did not listen to them when they expressed concern about Mr Cox's condition and when they suggested he had appendicitis. They believed the GPs treated their son less favourably for reasons related to his learning disabilities. Mr Cox's parents were also dissatisfied with the way the Surgery handled their complaint.

The Health Service Ombudsman was advised that diagnosing acute appendicitis is very difficult, especially when a person is unable to communicate the detail about their symptoms. Also, she was advised that although the GPs did not reach a definitive diagnosis this did not necessarily mean their actions were unreasonable. She found that, although the GPs could have considered more proactive management, they were not at fault for

taking a conservative approach to Mr Cox's care and treatment. The Health Service Ombudsman found that, in the circumstances, the GPs acted reasonably in their responses to Mr Cox's parents' concerns about their son and in their examinations of him.

The Health Service Ombudsman concluded that no one could say for certain whether different or more urgent action by the GPs would have resulted in a different outcome for Mr Cox. However, she found no evidence of service failure by the GPs and no evidence that they treated Mr Cox less favourably for reasons related to his learning disabilities. Also, she found no maladministration in the way the Surgery handled Mr Cox's parents' complaint.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Surgery.

### The investigation of the complaint against the Out of Hours GP

Mr Cox's parents had not previously complained to the Out of Hours GP. However, the Health Service Ombudsman exercised her discretion and accepted their complaint for investigation because it was important to consider the whole story about Mr Cox's care and treatment.

Mr Cox's parents complained that the Out of Hours GP who saw their son on the night he died did not tell them how seriously ill he was and delayed calling an ambulance. They believed that, had he acted more urgently, their son might not have died. They said the Out of Hours GP did not listen to what they had to say and treated their son less favourably for reasons related to his learning disabilities.

The Health Service Ombudsman found that the Out of Hours GP provided a good standard of care, took appropriate note of Mr Cox's parents' concerns and acted promptly and appropriately when he heard that Mr Cox had deteriorated.

Mr Cox's parents thought the ambulance took too long to arrive. However, the Health Service Ombudsman found that the Out of Hours GP had called for an urgent ambulance immediately after he had spoken to them for the second time and the ambulance had arrived within half an hour. Furthermore, it was clear that the Out of Hours GP could not have predicted Mr Cox's rapid deterioration and, therefore, his actions were appropriate in the circumstances. The Health Service Ombudsman found no evidence that the Out of Hours GP treated Mr Cox less favourably for reasons related to his learning disabilities.

The Health Service Ombudsman found no evidence of service failure by the Out of Hours GP and, therefore, she did not uphold the complaint against him.

### The investigation of the complaint against the Trust

Mr Cox's parents complained that their son should have been treated with greater urgency when he reached the Trust. They were dissatisfied with specific aspects of his care and treatment, including the actions of doctors, nurses and a radiographer. Mr Cox's parents felt strongly that inappropriate action by the staff meant they were denied the opportunity of being with their son when he died. They said he had received less favourable treatment for reasons related to his learning disabilities. They were also dissatisfied with the way the Trust handled their complaint.

The Health Service Ombudsman found that doctors and nurses at the Trust had acted reasonably in the way they assessed Mr Cox. Staff performed appropriate examinations, arranged appropriate tests and investigations, and instigated appropriate treatment. She found staff could not have predicted that Mr Cox's heart would stop and he would stop breathing because there was no indication that he would collapse so suddenly. Also, in the circumstances, staff acted appropriately and in line with professional guidelines in asking Mr Cox's parents to leave the area where he was being resuscitated.

The Health Service Ombudsman found no reason to believe that Mr Cox would have survived if different or quicker treatment had been provided by staff at the Trust. She identified some areas where the care and treatment provided could have been better, for example the management of pain and communication with Mr Cox's family, but found the overall standard of care and treatment was in line with prevailing standards. She found no evidence that staff at the Trust treated Mr Cox less favourably for reasons related to his learning disabilities. Furthermore, she found no maladministration in the way the Trust handled Mr Cox's parents' complaint.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Trust.

### The investigation of the complaint against the Healthcare Commission

Mr Cox's parents were dissatisfied with the way their complaint was handled by the Healthcare Commission.

The Health Service Ombudsman found failings in the way the Healthcare Commission reviewed Mr Cox's parents' complaint. She concluded that these failings amounted to maladministration

which led to an injustice because the Healthcare Commission had denied Mr Cox's parents a proper independent review of their complaint and unreasonably delayed resolution of the complaint.

The Health Service Ombudsman upheld the complaint and recommended that the Healthcare Commission should apologise to Mr Cox's parents for the failings identified. The Healthcare Commission accepted this recommendation.

### Was Mr Cox treated less favourably for reasons related to his learning disabilities and was his death avoidable?

The Health Service Ombudsman found no evidence that Mr Cox was treated less favourably by any of the bodies complained about for reasons related to his learning disabilities. She found no service failure or maladministration relating to the care and treatment Mr Cox received from any of the bodies complained about. On that basis she found that Mr Cox's death did not arise in consequence of any service failure or maladministration. Therefore, she could not conclude that his death was avoidable.

The Health Service Ombudsman said that in reaching her conclusions she had seen nothing in any of the evidence which suggested that Mr Cox's parents were in any way to blame for the death of their son. She said she had no doubt that at all times they acted in what they understood and believed to be his best interests.

### The complainants' response

Mr Cox's parents were dissatisfied with the outcome of the investigation. They expressed their strong belief that the actions of the GPs at the Surgery led to delay in diagnosing their son's condition and that the Out of Hours GP failed him.

## Summary report of an investigation by the Health Service Ombudsman of a complaint made by Mencap on behalf of Mrs Jane Kemp in relation to her late daughter, Miss Emma Kemp.

### Complainant:

Mrs Jane Kemp

### Aggrieved:

Miss Emma Kemp (Mrs Kemp's late daughter)

### Representative:

Mencap

### Complaint against:

NEWDOC GP out of hours service  
Falkland Surgery  
Eastfield House Surgery  
Royal Berkshire NHS Foundation Trust (the Trust)  
Healthcare Commission

## Background

Miss Kemp was a 26 year old woman with severe learning disabilities who lived in a residential care home. Mrs Kemp described her daughter as a *'party animal'* who was caring and friendly and loved dressing nicely to go out with her family and friends. She had many interests including dancing, bowling, television and computers. Mrs Kemp said there was not a day in the week when her daughter was not doing something. She was lively, active and always up early, eager to go out. Miss Kemp could understand what people said to her as long as they used simple direct language and she liked talking to people about her activities. She regularly spent time with her mother and grandparents.

In late April 2004 Miss Kemp became unwell and over the following month she was seen by several GPs and community nurses. In late May 2004 she was admitted as an emergency to the Trust and a

doctor found a previously unnoticed lump in her groin. Over the next two weeks she underwent various tests before she was discharged to her mother's home. In mid-June 2004 Mrs Kemp was told by two of the Trust's cancer specialists (Consultants R and S) that the lump was a non Hodgkin's lymphoma (a malignant tumour of the lymph system, which is the system that helps the body fight infection). Within days Miss Kemp was readmitted to the Trust because her GP was concerned she was not eating or drinking properly.

Mrs Kemp was dissatisfied with the care and treatment her daughter was receiving at the Trust and she instructed solicitors to ensure the Trust's actions were in Miss Kemp's best interests. Mrs Kemp was told by Consultant R that the likelihood of successful treatment of Miss Kemp's cancer was less than 10%. A second opinion was obtained from a third consultant, Consultant T, which confirmed Consultant R's view. Mrs Kemp then agreed with the consultants' proposal that chemotherapy was not in her daughter's best interests. At the end of June 2004 Miss Kemp was transferred to a specialist facility for palliative care (care which focuses on controlling symptoms, such as pain and discomfort, rather than cure). She died there in July 2004.

## The complaint

Mrs Kemp complained that her daughter should have received cancer treatment and that she should not have died. She said the GPs should have diagnosed her condition earlier and staff at the Trust did not act in her best interests when planning and delivering care and treatment. She believed her daughter had been treated less favourably for reasons related to her learning disabilities.

Mrs Kemp was also dissatisfied with the way her complaint had been handled by the Trust and the Healthcare Commission. She felt the NHS complaints process had failed her and she wanted answers to her questions about the service provided for her daughter.

### What should have happened

The NHS staff who looked after Miss Kemp should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Miss Kemp's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard.

In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies. Miss Kemp's care and treatment should have met national and professional standards regarding management of cancer patients, general nursing care and discharge arrangements as well as the Trust's own discharge and consent policies. In addition, NHS staff caring for Miss Kemp should have acted in accordance with the law and professional standards for managing patients who lack capacity to consent to investigations and treatment.

The responses to Mrs Kemp's complaint should have followed the *National Health Service (Complaints) Regulations 2004*.

### How the Health Service Ombudsman investigated

The investigator met Mrs Kemp to gain a full understanding of her complaint. It was important to carefully consider her recollections and views. Evidence about what happened to Miss Kemp and how her mother's complaint had been handled was considered. The Trust also provided additional information in response to specific enquiries and investigators met key Trust staff.

Several professional advisers provided expert clinical advice to the Health Service Ombudsman. They were: a professor of oncology; a hospital nurse; a learning disability nurse; and a GP.

Mrs Kemp, her representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

### What the Health Service Ombudsman found and concluded

#### The investigation of the complaint against the GPs

Mrs Kemp had not previously complained about the GPs. However, the Health Service Ombudsman exercised her discretion and accepted the complaint for investigation because it was important to consider the whole story about Miss Kemp's care and treatment.

Mrs Kemp complained that the various GPs who saw her daughter in the month before her cancer was detected did not recognise that Miss Kemp's symptoms meant she was seriously ill. She said they should have admitted Miss Kemp to hospital for investigation and their inaction resulted in delayed diagnosis and treatment.

The Health Service Ombudsman found that the GPs had no reason to refer Miss Kemp to hospital sooner or to suspect she had cancer. She concluded that there was no reason to criticise the service provided by the GPs. Their actions were in line with national and professional standards and they made reasonable adjustments in their practice with regard to Miss Kemp's learning disabilities. There was no evidence that they treated her less favourably with regard to her learning disabilities.

Therefore, the Health Service Ombudsman did not uphold the complaint against the GPs.

### The investigation of the complaint against the Trust

Mrs Kemp was dissatisfied with the organisation of investigations, with nutrition, hydration, pain relief and discharge planning, and with the standard of accommodation and facilities. Mrs Kemp said her daughter's condition had deteriorated and she became critically ill because of the poor care she had received and because staff did not act in her best interests.

The Health Service Ombudsman found that the time taken to investigate and diagnose Miss Kemp's cancer was reasonable and during a biopsy of the lump and a CT scan key staff tried to adapt their practice to meet her needs. She found that on the whole, tests and examinations were carried out in a reasonable way and best interest principles were appropriately applied.

The Health Service Ombudsman found that more could have been done to meet Miss Kemp's nutrition, hydration and pain relief needs. For example, Trust staff could have made more effective use of the knowledge of Miss Kemp's family and carers to help them assess her pain. However, the Health Service Ombudsman found no evidence that at any point during either admission to the Trust Miss Kemp's condition was seriously compromised by lack of fluid or food. Neither did she find that her need for pain relief was ignored or that she was denied pain relief.

Miss Kemp was discharged from hospital to her mother's home after her first admission when preliminary tests to establish the nature of the lump in her groin had been completed. The Health Service Ombudsman found shortcomings in the Trust's approach to managing Miss Kemp's discharge. However, staff did take some action to try and ensure she was safely discharged. On balance, the Health Service Ombudsman did not conclude that discharge arrangements fell significantly below a reasonable standard in the circumstances.

The Health Service Ombudsman found that when Miss Kemp was admitted to the Trust on the second occasion the standard of accommodation and facilities was not ideal. No single room was available on the cancer ward. However, a single room was found close by the specialist ward and in the circumstances the Health Service Ombudsman did not consider this was unreasonable.

Mrs Kemp's key complaint was that the decision not to treat her daughter's cancer was made solely because Miss Kemp had learning disabilities. Miss Kemp had a high grade B cell lymphoma for which the usual treatment would be a series of cycles of specialist chemotherapy known as R-CHOP. This involves giving four different drugs intravenously over a period of about six months.



The treatment can have serious side-effects, including infection.

During the course of the investigation it became clear that even eminent experts in cancer treatment held different views about whether or not treating Miss Kemp's cancer was in her best interests. However, it was not for the Health Service Ombudsman to have a clinical opinion about whether or not Miss Kemp should have received treatment for her cancer. The question she asked was whether or not Miss Kemp received a reasonable standard of care and treatment.

The Health Service Ombudsman found that Consultants R and T did act in line with relevant ethical, legal and professional guidance on how they should act when a patient lacks the capacity to consent to treatment. She found they consulted with a wide range of colleagues, weighed up the risks and benefits of treatment and involved Mrs Kemp in their decision. She also found that in the circumstances the decision taken by Consultants R and T was not unreasonable.

The Health Service Ombudsman found no evidence that in making their decision Consultants R and T treated Miss Kemp less favourably with regard to her learning disabilities. That is not to say that if Miss Kemp had not had learning disabilities the decision in relation to her best interests would have been the same. Rather, that they considered the challenges that existed as a result of her learning disabilities and the adjustments that could reasonably be made to address those challenges and concluded that the risk of harm and distress that was likely to be caused by the treatment outweighed the benefit that was likely to be obtained. In different circumstances those assessments of risk and benefit might well have been different, but these were the circumstances that Consultants R and T were faced with in Miss Kemp's case.

The Health Service Ombudsman found no service failure in the care and treatment provided for Miss Kemp by the Trust. Therefore, she did not uphold this aspect of the complaint against the Trust.

### The investigation of complaint handling by the Trust

Mrs Kemp was dissatisfied with the way the Trust handled her complaint and the Health Service Ombudsman found the Trust failed to comply fully with the applicable regulations. In particular, the Trust's actions did not accord with principles of good administration and it did not provide an appropriate or adequate remedy.

The Health Service Ombudsman concluded these failings amounted to maladministration but that this did not occur for disability related reasons. She upheld this aspect of Mrs Kemp's complaint but made no recommendation for further remedy because the Trust had apologised and taken appropriate action to address the failings she identified.

### The investigation of the complaint against the Healthcare Commission

Mrs Kemp was dissatisfied with the way the Healthcare Commission reviewed her complaint. She said the review took too long and did not provide her with the answers she sought.

The Healthcare Commission reviewed this complaint twice because Mrs Kemp was dissatisfied with the first review. The Health Service Ombudsman found that the Healthcare Commission's first review was flawed because it did not take advice from a suitably qualified clinician. This rendered its decision unreliable

and unsafe and was maladministration. However, overall the Healthcare Commission's second review was reasonable and in line with the applicable standard. The Health Service Ombudsman did not find maladministration with regard to delay. She concluded that any injustice arising from the maladministration relating to the Healthcare Commission's first review was remedied by the second review and there was no service failure in the Healthcare Commission's complaint handling.

Therefore, she did not uphold the complaint against the Healthcare Commission.

### Was Miss Kemp treated less favourably for reasons related to her learning disabilities?

The Health Service Ombudsman found no evidence that Miss Kemp was treated less favourably by the GPs or the Trust for reasons related to her learning disabilities.

### Was Miss Kemp's death avoidable?

The Health Service Ombudsman found no service failure or maladministration relating to the decision not to treat Miss Kemp's cancer. On that basis, her finding was that Miss Kemp's death did not arise in consequence of any service failure or maladministration. Therefore, she did not conclude that Miss Kemp's death was avoidable. It will never be known whether Miss Kemp would have survived had she received chemotherapy, or whether the intensive treatment which this involved or the side-effects of that treatment would in fact have hastened her death, but that was not the subject of the Health Service Ombudsman's investigation.

### The complainant's response

Mrs Kemp was dissatisfied with the outcome of the investigation. Mrs Kemp said she strongly believed that Miss Kemp did not receive a reasonable standard of care, that she should have been treated with chemotherapy and that the decision not to treat her cancer was for reasons related to her learning disabilities.

## Summary report of a joint investigation by the Health Service Ombudsman and the Local Government Ombudsman of a complaint made by Mencap on behalf of Mrs Iris Keohane in relation to her late brother, Mr Edward Hughes.

### Complainant:

Mrs Iris Keohane

### Aggrieved:

Mr Edward Hughes (Mrs Keohane's late brother)

### Representative:

Mencap

### Complaint against:

Buckinghamshire Hospitals NHS Trust (the Trust)  
Tower House Surgery (the Surgery)  
Buckinghamshire County Council (the Council)  
Healthcare Commission

## Introduction

This complaint was investigated jointly by the Local Government Ombudsman for England and the Health Service Ombudsman for England in accordance with the powers conferred by amendments to their legislation due to *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007*. With the consent of the complainant, Mrs Keohane, the two Ombudsmen agreed to work together because the health and social care issues were so closely linked. A co-ordinated response, consisting of a joint investigation leading to a joint conclusion and proposed remedy in one report, seemed the most appropriate way forward.

## Background

Mr Hughes was a 61 year old man with severe learning disabilities who had lived in care for most of his adult life. For many years he had lived at a care home in High Wycombe (the Care Home) which was managed by the Council. Mrs Keohane told us her brother had been born in difficult circumstances during World War II and that as a result he suffered damage to his brain at birth. He also suffered from dementia, schizophrenia and heart problems. His verbal communication was limited to a few words and his behaviour could be challenging.

In May 2004 Mr Hughes was admitted to the Trust because he could not pass urine. He had an operation on his prostate but deteriorated after the surgery and was admitted to the Intensive Care Unit (the ICU). After nine days in the ICU he was transferred to a ward and two days later he was discharged to the Care Home. Staff at the Care Home were concerned about him and the following day they asked a GP to visit. The GP decided Mr Hughes did not need to be readmitted to hospital. Later that day Mr Hughes suddenly collapsed and he was taken to the Accident and Emergency Department (A&E) at the Trust, but he could not be resuscitated and died.

The Coroner found that Mr Hughes had died because he had been aspirating (inhaling fluids and solids which should have passed into his stomach) over a period of time and that he had also suffered an acute episode of aspiration.

## The complaint

Mrs Keohane complained to the Ombudsmen that her brother should not have died. She said that if the Trust, the GP and the Care Home staff had acted differently, he would have survived. She believed her brother had been treated less favourably for reasons related to his learning disabilities.

Mrs Keohane was also dissatisfied with the way her complaint had been handled by the Surgery, the Trust and the Healthcare Commission. She felt the NHS complaints process had failed her and she asked the Ombudsmen to find answers to her questions about the service provided for her brother.

## What should have happened

The staff who looked after Mr Hughes should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Mr Hughes' case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard.

In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies. Mr Hughes' care and treatment at the Trust should have met national and professional standards regarding nursing care and discharge arrangements and the Trust's own discharge policy.

The responses to Mrs Keohane's complaint about NHS services should have followed the *National Health Service (Complaints) Regulations 2004*.

## How the Ombudsmen investigated

The investigator spoke to Mrs Keohane to gain a full understanding of her complaint. It was important to carefully consider her recollections and views. Evidence about what happened to Mr Hughes, how his sister's complaint about NHS services had been handled, and the internal investigations conducted by the Trust and the Council were considered. These bodies provided additional information in response to specific enquiries. Enquiries were also made of the Coroner who conducted the inquest into Mr Hughes' death.

Several professional advisers provided expert clinical advice to the Ombudsmen. They were: a professor of cardiology; a surgical consultant; a consultant anaesthetist with experience of work in ICU; a GP; a speech and language therapist; a hospital nurse; and a learning disability nurse.

Mrs Keohane, her representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

## What the Ombudsmen found and concluded

### The Health Service Ombudsman's investigation of the complaint against the Trust

Mrs Keohane was satisfied with the care and treatment her brother received before he left the ICU at the Trust. She complained about the service provided for Mr Hughes from the time he left the ICU to the time he was discharged two days later. In particular, she said staff on the ward did not take sufficient account of his needs as a person with learning disabilities and his discharge was premature and poorly planned. Mrs Keohane said her brother was '*pushed out*' from the Trust because staff '*did not want him there because he was more difficult*'. Mrs Keohane also complained that Trust staff did not communicate properly with her about her brother's condition and that the Trust's response to her complaint was inadequate.

The Health Service Ombudsman found that Mr Hughes was assessed thoroughly and appropriately by doctors who put in place an appropriate plan for management of his medical care, in particular his heart problems. She also found the Trust's speech and language therapists acted reasonably when assessing Mr Hughes' ability to swallow.

However, the Health Service Ombudsman found nurses on the ward made entirely inadequate attempts to assess Mr Hughes' needs or plan or deliver care for him. Nurses seemed to have little idea of how to look after Mr Hughes or how to make reasonable adjustments so they could manage his needs. They did not act in accordance with professional standards.

Mr Hughes was medically fit to be discharged because he no longer needed specialist medical care and because a plan to manage his heart condition had been put in place by Trust doctors. However, the Health Service Ombudsman found it was not safe to discharge him. She found the team responsible for ensuring Mr Hughes was safely discharged (including nurses, doctors and therapists) failed to enact even the most basic principles of good discharge as set out in the prevailing local and national policies. She was critical of the failure of Trust staff to engage with community staff to ensure that a multi-agency plan was in place for Mr Hughes' discharge. She found that in this respect, neither doctors nor nurses acted in accordance with professional standards.

The Health Service Ombudsman found that when Mr Hughes was in the ICU, Trust doctors had told his family that they thought he had suffered a heart attack. However, she found no evidence that staff communicated with his family after he left the ICU. They did not inform his family, as they should have done, that he had fallen on the night before he was discharged or even that he was due to be discharged.

The Health Service Ombudsman concluded that the Trust failed to: provide a reasonable standard of nursing care; make reasonable adjustments to meet Mr Hughes' needs; discharge him safely; or communicate adequately with his family. She also concluded that this service failure was at least in part for disability related reasons.

The Health Service Ombudsman found many shortcomings in the way in which the Trust handled Mrs Keohane's complaint. For instance, the Trust failed to: recognise or address the most serious issues complained about; conduct an appropriate investigation; or acknowledge and apologise for poor care and treatment. She concluded that this was maladministration.

The Trust informed the Health Service Ombudsman of actions it had taken to address shortcomings in its care and treatment of Mr Hughes and its handling of Mrs Keohane's complaint. It also offered further apologies for failings identified during the investigation. The Health Service Ombudsman found these actions were appropriate and reasonable. However, she also concluded that Mrs Keohane still had reason to be aggrieved by the failings in the Trust's care and treatment of her brother, and in particular those failings which occurred for disability related reasons. Furthermore, partly due to failings at the Trust, Mrs Keohane had to wait four years for answers to her questions which flowed from the maladministration and service failure identified. These findings represented unremedied injustice.

Therefore, the Health Service Ombudsman upheld the complaint against the Trust.

### The Health Service Ombudsman's investigation of the complaint against the Surgery

After around three weeks in the Trust, including a period in the ICU, Mr Hughes was discharged to the Care Home at short notice without an agreed discharge plan to guide staff caring for him in the community.

Mrs Keohane complained that the GP did not respond quickly enough to a request from Care Home staff to visit Mr Hughes on the day he died. She said the GP did not examine her brother properly and should have admitted him to hospital. She said the GP treated Mr Hughes less favourably for reasons related to his learning disabilities. She was also dissatisfied with the way the Surgery handled her complaint.

The Health Service Ombudsman appreciated why Mrs Keohane found it difficult to accept that the GP examined Mr Hughes properly and made reasonable decisions about his care and treatment when, later that day, he collapsed and died. However, she found no reason to criticise the GP. She found no evidence of service failure by the Surgery and no evidence that Mr Hughes was treated less favourably for reasons related to his learning disabilities. Furthermore, she found no evidence of maladministration in the way the Surgery handled Mrs Keohane's complaint.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Surgery.

### The Local Government Ombudsman's investigation of the complaint against the Council

Mrs Keohane did not complain to the Local Government Ombudsman about the actions of staff at the Care Home until October 2007. By this time the NHS components of the complaint had already been accepted for investigation by the Health Service Ombudsman. Therefore, with the aim of providing a timely integrated response, the Local Government Ombudsman decided he would exercise his discretion and accept the case for investigation.

Mrs Keohane complained about the care and treatment provided by staff at the Care Home when Mr Hughes was discharged and when he collapsed. In particular, she wanted to know whether appropriate arrangements were made for her brother's dietary needs.

The Local Government Ombudsman's review of different sources of evidence showed the story about what had happened to Mr Hughes after his last meal had become distorted over time and he was able to set the record straight on this point. Evidence clearly showed that Mr Hughes' evening meal had been prepared broadly in line with imprecise instructions given by the Trust and that he had collapsed and vomited around 20 minutes after eating his meal. The Local Government Ombudsman found no evidence that the actions of Care Home staff in preparing this meal and other drinks and meals had any influence on Mr Hughes' subsequent collapse and death.

The Local Government Ombudsman was concerned to find that Care Home staff did not have up-to-date first aid training which would have helped them respond appropriately when Mr Hughes collapsed. However, he was persuaded that they acted reasonably in the circumstances and he found no evidence of maladministration.

Therefore, the Local Government Ombudsman did not uphold the complaint against the Council.

### The Health Service Ombudsman's investigation of the complaint against the Healthcare Commission

Mrs Keohane was dissatisfied with the way her complaint was handled by the Healthcare Commission.

The Health Service Ombudsman found maladministration in the way the Healthcare Commission reviewed Mrs Keohane's complaint against the Trust because the Healthcare Commission made no effort to follow up its recommendations to the Trust. Furthermore, it took too long to review the complaint and did not keep Mrs Keohane updated on progress. This

resulted in an injustice to Mrs Keohane in that she did not receive a proper review of her complaint. Therefore, the Health Service Ombudsman upheld this aspect of the complaint against the Healthcare Commission. However, she found no maladministration in the way the Healthcare Commission handled the review of Mrs Keohane's complaint against the Surgery and, therefore, she did not uphold this aspect of her complaint.

### Was Mr Hughes treated less favourably for reasons related to his learning disabilities? The Health Service Ombudsman's conclusion

The Health Service Ombudsman concluded that failures in the Trust's care and treatment of Mr Hughes were in part for reasons related to his learning disabilities. Staff did not make reasonable adjustments to meet his complex needs. His behaviour, which was linked to his impairment, made him difficult to manage and staff discharged him unsafely.

The Health Service Ombudsman also concluded that the Trust's actions and omissions constituted a failure to live up to human rights principles, especially those of dignity and equality. By discharging Mr Hughes prematurely and without sufficient regard to his care, the Trust failed to have due regard to the need to safeguard his dignity and wellbeing in his future care by the Care Home, and to the observance of the principle of equality in the delivery of his care. There was no evidence of any positive intention to humiliate or debase Mr Hughes. Nevertheless, the standard of service provided did raise the question of whether the Trust's actions constituted a failure to respect Mr Hughes' dignity. In these respects, the Trust's service failure touched upon and demonstrated inadequate respect for Mr Hughes' status as a person.

## Was Mr Hughes' death avoidable?

Mrs Keohane asked whether the Ombudsmen could find any additional information about the reason why Mr Hughes collapsed and died. The Ombudsmen were clear that it was not possible to establish beyond doubt why Mr Hughes collapsed. They found no evidence which pointed directly to a cause for his collapse. There was no post mortem evidence which showed that he collapsed due to any of the most common causes of collapse for a person of his age. That said, in the light of the advice from the advisers, it seemed possible that he collapsed due to a sudden change in his heart rhythm which led to the other events associated with his death. The advisers said the likelihood that Mr Hughes would survive such an event, even in hospital, would have been low.

The Ombudsmen did not conclude that Mr Hughes' death occurred in consequence of any maladministration or service failure which they found during the investigation and, therefore, they did not conclude that his death was avoidable.

## The Health Service Ombudsman's recommendations

The Health Service Ombudsman recommended that Mrs Keohane should receive an apology and compensation of £10,000 from the Trust and an apology from the Healthcare Commission. The compensation was in recognition of the injustice suffered in consequence of the service failure and maladministration identified.

In response to these recommendations the Trust acknowledged its failings, apologised to Mrs Keohane and offered information about improvements in service since Mr Hughes' death. It also agreed to pay the compensation recommended. The Healthcare Commission agreed to apologise to Mrs Keohane.

## The complainant's response

Mrs Keohane said trying to find out what had happened to her brother had been a '*long, frustrating and distressing time*'. She said the investigation was thorough and at last enabled her family to have a better understanding of what happened to Mr Hughes. She said it was a comfort to her to have the story clarified and presented so clearly. She also found comfort in the information provided about the standard of care in the Care Home.

However, Mrs Keohane did not accept the advisers' suggestion about the reason for her brother's collapse, or the conclusion that there was no service failure by the GP. Mrs Keohane said she strongly believed that Mr Hughes was prematurely discharged from the Trust and the GP should have readmitted him.



## Summary report of an investigation by the Health Service Ombudsman of a complaint made by Mencap on behalf of Mrs Vera Ryan in relation to her late son, Mr Martin Ryan.

### Complainant:

Mrs Vera Ryan

### Aggrieved:

Mr Martin Ryan (Mrs Ryan's late son)

### Representative:

Mencap

### Complaint against:

Kingston Hospital NHS Trust (the Trust)

## Background

Mr Ryan was a 43 year old man with severe learning disabilities, Down's syndrome and epilepsy who lived in a residential care home. Mr Ryan's family described him as a charming, strong and energetic man who, before his stroke, was living happily with his carers. They said it took Mr Ryan a while to get to know people and it took people a while to get to know him. They thought this was probably because he could not communicate verbally and because his behaviour was different.

In November 2005 Mr Ryan suffered a stroke and was admitted to a general ward at the Trust. Over the following weeks his care and treatment was the responsibility of a multidisciplinary team including doctors, nurses, physiotherapists and speech and language therapists. For most of the time he was in hospital, carers from his residential home were with him and he was visited occasionally by specialist community nurses. However, throughout his stay he was given no nutrition. The primary causes of

his death were recorded on his death certificate as pneumonia and a stroke.

## The complaint

Mr Ryan's mother accepted that the Trust had acknowledged many failings in its care of her son and that it had taken action to try and remedy those failings. However, she remained dissatisfied and complained to the Health Service Ombudsman that her son should not have died. She said that if staff at the Trust had acted differently, he would have survived. In particular, she said she had thought her son would be *'in good hands'* at the Trust. Instead he had *'starved to death'*. She believed her son had been treated less favourably for reasons related to his learning disabilities.

Mrs Ryan was also dissatisfied with the way her complaint had been handled by the Trust. She felt the NHS complaints process had failed her and she asked the Health Service Ombudsman to find out the answers to her questions about the service provided for her son.

## What should have happened

The NHS staff who looked after Mr Ryan should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Mr Ryan's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998* and *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) were especially relevant to the overall standard. In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies.

Mr Ryan's care and treatment should have met the prevailing specific national and professional standards for management of stroke patients, especially the *National Clinical Guidelines for Stroke* (1st edition 2000 and 2nd edition 2004) issued by the Royal College of Physicians and the *National Service Framework for Older People* (2001). These documents set out expectations including: standards for developing specialist stroke units; guidelines for testing and investigating stroke patients; and requirements for multidisciplinary working. By April 2004 the government required all hospitals caring for stroke patients to have developed a specialised stroke service. Furthermore, Mr Ryan's care should have met the Trust's own standards, in particular its Eating and Drinking Policy.

The responses to Mrs Ryan's complaint should have followed the *National Health Service (Complaints) Regulations 2004*.

### How the Health Service Ombudsman investigated

The investigator met Mr Ryan's family to gain a full understanding of Mrs Ryan's complaint. It was important to carefully consider their recollections and views. Evidence about what happened to Mr Ryan and how his mother's complaint had been handled was considered. The Trust also provided additional information in response to specific enquiries.

Several professional advisers provided expert clinical advice to the Health Service Ombudsman. They were: a consultant physician specialising in stroke care; a speech and language therapist; a hospital nurse; and two learning disability nurses.

Mr Ryan's family, their representative and others involved in the events complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

### What the Health Service Ombudsman found and concluded

The basic facts about Mr Ryan's stay at the Trust were revealed by the Trust's internal inquiry. However, Mrs Ryan asked the Health Service Ombudsman to look further into two specific aspects of her son's clinical care – the failure to feed him and the failures in communication between different members of Trust staff. In particular, she wanted to know whether malnutrition had led to her son's death. The Trust had told Mrs Ryan that the failures in her son's care were not for disability related reasons and that he had not died from malnutrition and starvation.

The Health Service Ombudsman found that the key failings in Mr Ryan's care and treatment could be grouped into three main areas: failings in stroke care; failings in clinical leadership; and failings in communication and multidisciplinary team working.

#### Stroke care

The Trust had not responded to national and professional recommendations about stroke care. Although prevailing policy and guidelines did not require trusts to have a specialist stroke unit (and this Trust did not have such a unit) the guidelines

did require trusts to organise stroke services so that patients were admitted under the care of a specialist team for acute care and rehabilitation. The Health Service Ombudsman found that at the time Mr Ryan was admitted, services at the Trust for stroke patients were fragmented and fell short of professional and national expectations for stroke care set out in policy and guidelines. There was no special team of experts skilled in management of the needs of stroke patients, for example doctors, nurses, dieticians and speech and language therapists, who could identify and meet Mr Ryan's basic needs, including his nutritional needs.

### Clinical leadership

The Health Service Ombudsman found that neither the Consultant nor the Ward Sister provided effective clinical leadership, either for their professional group or the ward team as a whole. Neither of the lead professionals had set up effective systems of organising care and treatment. Nursing shift patterns did not encourage continuity of care and medical cover was fragmented with no effective arrangements at weekends. Neither lead professional recognised that the basic standard of care which doctors and nurses in their charge were providing for a very ill man was inadequate.

Mr Ryan could not swallow due to his stroke and the Health Service Ombudsman found that the medical team, under the leadership of the Consultant, was primarily responsible for deciding on a plan for feeding Mr Ryan. Despite speech and language therapy assessments that Mr Ryan would need alternative feeding (such as feeding him by a tube through his nose or abdominal wall into his stomach), the medical team did not make a decision about alternative feeding until Mr Ryan had been in hospital for 18 days. Soon after that, Mr Ryan became too ill to undergo the procedure to insert a feeding tube.

The Health Service Ombudsman found that the Ward Sister did not take the lead, as she should have done, in monitoring and managing Mr Ryan's condition. She did not put in place arrangements to guide or support members of her nursing team in caring for Mr Ryan's needs. It was clear she was not aware of failings in her team: for example, assessments were poor, care plans were inadequate and the delivery and evaluation of nursing care was below a reasonable standard in the circumstances. There was no evidence of nursing actions aimed at meeting Mr Ryan's nutritional needs.

### Communication and multidisciplinary team working

National, professional and local policy and guidelines stressed the importance of multidisciplinary team working in stroke care. However, poor communication and team working between professionals meant the approach to Mr Ryan's care, including his nutrition, was fragmented, unplanned and ineffective. For instance, there were no multidisciplinary team meetings. This meant there was no forum for professionals involved in Mr Ryan's care and treatment, such as the community nurses, the speech and language therapists and the physiotherapists, to discuss integrated plans for his care.

There was evidence that various professionals, including the community team and the speech and language therapists, were very concerned about Mr Ryan and tried to raise their concerns, particularly about nutrition, with the medical and nursing teams. But they could not make themselves heard and nothing happened to help Mr Ryan. Nobody took any action to feed him.

## Malnutrition and starvation

Mrs Ryan believed her son '*starved to death*'. He was not fed for 26 days and it is an indisputable fact that people need food to live and that without sufficient food people weaken and die.

The Health Service Ombudsman was advised that Mr Ryan had suffered a significant stroke. However, she was also advised that had he been cared for in a Trust where stroke services were organised according to policy and guidelines, he would have had a better chance of survival, albeit with long-term mental and physical problems. However, the Health Service Ombudsman's medical adviser said that prolonged starvation would have made it less likely that Mr Ryan would have survived because he would have been more susceptible to infection and less able to combat infection when it occurred.

The Health Service Ombudsman concluded that she could not say for certain whether Mr Ryan would have survived if he had been fed. However, what she did say was that the failure to feed him for 26 days undoubtedly placed him at considerable risk of harm. She said that although it was impossible to prove that malnutrition and starvation contributed to or caused Mr Ryan's death, it was likely that the failure to feed him for a prolonged period was one of a number of failings which led to his death.

The Health Service Ombudsman concluded that the Trust's failures in its arrangements for stroke patients, clinical leadership, communication, multidisciplinary working and nutritional care were service failure which was at least in part for disability related reasons.

## Complaint handling

Mrs Ryan was dissatisfied with the way her complaint was handled by the Trust and she believed her complaint had not been properly dealt with for reasons related to her son's learning disabilities.

The Health Service Ombudsman found shortcomings in the way the Trust handled Mrs Ryan's complaint. For instance, the Trust failed to recognise the seriousness of the matters complained about, failed to investigate properly and failed to provide appropriate responses which were accurate and consistent. She concluded that the Trust's complaint handling was maladministrative but that the failings in complaint handling were not for disability related reasons.

### Was Mr Ryan treated less favourably for reasons related to his learning disabilities?

The Health Service Ombudsman concluded that the failings in care and treatment could not be separated from the fact that Trust staff did not attempt to make any reasonable adjustments, as they should have done, to the way in which they organised and delivered care and treatment to meet Mr Ryan's complex needs. She concluded, therefore, that in some significant respects the Trust's service failures were for disability related reasons.

The Health Service Ombudsman also concluded that the Trust's actions and omissions constituted a failure to live up to human rights principles, especially those of dignity, equality and autonomy. By failing to care properly for Mr Ryan, in particular by not feeding him, the Trust failed to have due regard to his status as a person, to the need to avoid the infringement of his dignity and wellbeing

that would arise from a lack of attention to his needs, in particular his need for food, and to observance of the principle of equality in the way these rights were to be protected. There was no evidence of any positive intention to humiliate or debase Mr Ryan. Nevertheless, the standard of service did at the very least constitute a failure to respect Mr Ryan's human dignity.

### Was Mr Ryan's death avoidable?

In considering whether to make a finding about avoidable death the Health Service Ombudsman assessed whether the injustice complained about (in this case Mr Ryan's death) arose in consequence of the service failure or maladministration she had identified. She concluded that it was impossible to say for certain whether Mr Ryan would have survived if he had been fed. However, while she could not categorically say that Mr Ryan died because he was not fed, she was not persuaded that the Trust could categorically say that this was not the reason for his death.

The Health Service Ombudsman concluded that, had the care and treatment Mr Ryan received not fallen so far below the relevant standard, it is likely that his death could have been avoided.

### Injustice

The Trust put forward evidence about changes which had occurred since Mr Ryan was a patient there, and the Health Service Ombudsman found the Trust had taken reasonable action to address the shortcomings identified by its own inquiry and service failure and maladministration identified in her investigation. That said, Mr Ryan's parents still had reason to be aggrieved by the failings in the Trust's care and treatment of their son and, in

particular, those failings which the Health Service Ombudsman concluded occurred for disability related reasons. Furthermore, they should not have had to wait for an investigation by the Health Service Ombudsman to fully establish the facts about the service provided for their son. Partly due to failings at the Trust, Mr Ryan's parents had to wait over two years for answers to their questions. These findings represent unremedied injustice.

Moreover, in discovering that their son's death could probably have been avoided, had the care and treatment not fallen so far below the relevant standard, Mr Ryan's parents suffered an injustice which can never be remedied.

Therefore, the Health Service Ombudsman upheld Mrs Ryan's complaint against the Trust.

### Recommendation

The Health Service Ombudsman recommended Mr Ryan's parents should receive apologies and compensation of £40,000 from the Trust. This compensation was in recognition of the injustice suffered in consequence of the service failure and maladministration identified.

In response to the recommendations the Trust's Chief Executive acknowledged the failings, apologised to Mr Ryan's parents and agreed to pay the compensation.

## The complainant's response

Mr Ryan's family and Mencap have said the outcome of the investigation is that *'justice has been done'* because the Health Service Ombudsman's report exposes the very serious failures that led to Mr Ryan's death. They also welcomed the conclusions that some of the failures in care and treatment were for disability related reasons. They said they believe the report will have a positive impact on future care of people with learning disabilities. They welcomed action by the Trust aimed at preventing a similar occurrence. In particular, they have said that the report shows how *'proper care, using multidisciplinary working, personalised care planning and good communication within teams and with families and carers would greatly improve the outcome for people with a learning disability in our hospitals'*.

## Summary report of a joint investigation by the Health Service Ombudsman and the Local Government Ombudsman of a complaint made by Mencap on behalf of Mr and Mrs Wakefield in relation to their late son, Mr Tom Wakefield.

### Complainants:

Mr and Mrs Wakefield

### Aggrieved:

Mr Tom Wakefield (Mr and Mrs Wakefield's late son)

### Representative:

Mencap

### Complaint against:

West Street Surgery (the Surgery)  
Gloucestershire County Council (the Council)  
Cheltenham and Tewkesbury Primary Care Trust –  
now Gloucestershire Primary Care Trust (the PCT)  
Gloucestershire Partnership NHS Foundation  
Trust – now 2gether NHS Foundation Trust for  
Gloucestershire (the Partnership Trust)  
Gloucestershire Hospitals NHS Foundation Trust  
(the Acute Trust)  
Healthcare Commission

## Introduction

This complaint was investigated jointly by the Local Government Ombudsman for England and the Health Service Ombudsman for England in accordance with the powers conferred by amendments to their legislation due to *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007*. With the consent of the complainants, Tom's parents, the two Ombudsmen agreed to work together because the health and social care issues were so closely linked. A co-ordinated response, consisting of a joint investigation leading to a joint conclusion and

proposed remedy in one report, seemed the most appropriate way forward.

## Background

Tom Wakefield was a sociable young man with profound and multiple learning disabilities and kypho-scoliosis (progressive curvature of the spine which caused problems with his posture). Since he was an infant he had had gastrointestinal problems for which he had undergone surgery as a child. Tom's posture and gastrointestinal problems gave him pain which appeared to have been well controlled by medication until 2001. He could understand speech and was able to communicate using facial, hand and arm movements. He had a history of self-harming behaviour.

From the age of 6 years Tom attended Penhurst School (the Residential School). In July 2003, when he was 19 years old, he should have been transferred to suitable adult accommodation, but no place had been found for him so he remained at the Residential School. His behaviour and health deteriorated and the school felt unable to accommodate him. In November 2003 he was admitted to an NHS Assessment Unit managed by the Partnership Trust, where he spent 3 months until he moved to an adult care home. By that point his health had deteriorated further and in April 2004, shortly after moving to the Care Home, he was admitted to the Acute Trust where he died a few weeks later, aged 20. His death certificate records the causes of his death as aspiration pneumonia, reflux oesophagitis, scoliosis and cerebral palsy.

## The complaint

Tom's parents complained to the Ombudsmen that their son should not have died. They said that if staff at the Surgery, the Council, the Partnership Trust, the PCT and the Acute Trust had acted differently, he would have survived. They believed their son had suffered unnecessarily and had been treated less favourably for reasons related to his learning disabilities.

Tom's parents were also dissatisfied with the way their complaint about NHS services had been handled by the Surgery, the Partnership Trust, the PCT and the Healthcare Commission. They were also dissatisfied with the way the planning and provision of their son's care had been investigated by the Council. They felt the NHS and Council complaints processes had failed them and they asked the Ombudsmen to find out the answers to their questions about the service provided for their son.

## What should have happened

The staff who looked after Tom should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Tom's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard.

Tom's care should have been organised within the legal and policy framework for integrated health and social care as set out in key documents including the *National Health Service and Community Care Act 1990* and the *Care Standards Act 2000*.

In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies. Tom's care and treatment at the Partnership Trust and the Acute Trust should have met national and professional standards regarding nursing care and discharge arrangements.

The responses to Tom's parents' complaint about NHS services should have followed the *National Health Service (Complaints) Regulations 2004* and their complaint about the Council should have been handled in line with the *Complaints Procedure Directions 1990*.

## How the Ombudsmen investigated

The investigator met Tom's parents to gain a full understanding of their complaint. It was important to carefully consider their recollections and views. Evidence about what happened to Tom and how his parents' complaints about NHS and Council services were handled was considered. The bodies complained about provided additional information in response to specific enquiries, and specific clinical staff involved with Tom's care were contacted.

Several professional advisers provided expert clinical advice to the Ombudsmen. They were: a hospital nurse; a learning disability nurse; two consultant gastroenterologists; a consultant psychiatrist; a professor of pharmacy; and a GP.



Tom's parents, their representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

## What the Ombudsmen found and concluded

### The Health Service Ombudsman's investigation of the complaint against the Surgery

Tom's parents complained that the care and treatment provided by the Surgery was inadequate. In particular, they said the Surgery failed to deal appropriately with their son's pain and weight loss and failed to act on medical advice from a hospice to refer him for an endoscopy (an examination of the gullet and stomach using a telescopic instrument) and prescribe morphine for his pain. Tom's parents were also dissatisfied with the way the Surgery handled their complaint.

The Health Service Ombudsman could appreciate why Tom's parents found it difficult to accept that the Surgery offered reasonable care and treatment to their son during his last years at the Residential School, given that it appears he was in pain and losing weight at this time. However, she found that the care and treatment provided by the Surgery, including the management of Tom's pain and weight loss, and the decision not to refer him for an endoscopy did not fall significantly below a reasonable standard in the circumstances.

The Health Service Ombudsman found no evidence of service failure by the Surgery and no evidence that Tom was treated less favourably by the Surgery for reasons related to his learning disabilities.

Furthermore, she found no maladministration in the way the Surgery handled Tom's parents' complaint.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Surgery.

### The Local Government Ombudsman's investigation of the complaint against the Council

Tom was still living in the Residential School when he was 19 years old and should have been living in adult accommodation.

Tom's parents complained that the Council had failed to plan for, or commission, new provision for their son or to deal appropriately with his transition into adult accommodation. They said a Social Worker failed to pass on information about an offer of a suitable permanent placement for Tom. They also said the Council failed to investigate their concerns adequately or respond properly to their complaint.

The Local Government Ombudsman found that the Council's arrangements for Tom's transition to adult accommodation fell significantly below a reasonable standard in the circumstances. He found there was no commissioning strategy in place, there were gaps in plans for people with profound and multiple learning disabilities and challenging behaviour, and transition arrangements, including communication, had been poor. He also found that in relation to finding a placement for Tom, Social Services did not work on a person-centred basis. Rather, they worked in an unplanned and unstructured way. They failed to liaise or communicate properly with colleagues and Tom's family about a potentially suitable placement which became available. Furthermore, the Council did not respond appropriately to Tom's parents'

complaint or provide adequate reassurances about changes in practice. The Local Government Ombudsman concluded that these failures in service provision and complaint handling amounted to maladministration.

The Local Government Ombudsman said it will never be known if, had appropriate arrangements been in place, Tom would have lived longer or if he could have had more enjoyment from his life in his last year. He found that the Council's actions contributed to the injustice suffered by Tom and his family and concluded that some of the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons.

Therefore, the Local Government Ombudsman upheld the complaint against the Council.

### The Health Service Ombudsman's investigation of the complaint against the PCT

Tom's parents complained that the PCT failed to liaise appropriately with the Council in planning their son's transition to adult accommodation and did not provide a reasonable response to their complaint.

The Health Service Ombudsman found there were shortcomings in the way the PCT fulfilled its responsibilities with regard to planning for the health needs of people with profound and multiple learning disabilities. She concluded that these shortcomings amounted to service failure which was for disability related reasons.

She also found maladministration in the way the PCT handled Tom's parents' complaint.

The Health Service Ombudsman recognised the Council had lead responsibility for planning for Tom's transition to adult care and took into account improvements the PCT had made since the events complained about. Nonetheless, she concluded that it was impossible to know what difference it would have made to Tom and his family in terms of his transition to adult accommodation if the PCT had fulfilled its responsibilities in this regard. This unanswered question was an injustice which remained a cause of distress for Tom's parents. Furthermore, maladministration in the way the PCT handled Tom's parents' complaint led to further delay and distress for them.

Therefore, the Health Service Ombudsman upheld the complaint against the PCT.

### The Health Service Ombudsman's investigation of the complaint against the Partnership Trust

The Residential School decided it could no longer care for Tom because he was an adult and because his behaviour was becoming more challenging. The Residential School served Tom with notice to leave the home where he had lived for 13 years and the Partnership Trust arranged for him to be admitted to an Assessment Unit.

Tom's parents complained that their son's admission to the Assessment Unit was inappropriate. They said his care and treatment there was inadequate, he was at risk because the environment was poor and his discharge to the Care Home was badly managed. They were also dissatisfied with the way the Partnership Trust handled their complaint.

The Health Service Ombudsman found that it had been appropriate for Tom to go to the Assessment Unit for assessment for an onward placement.

However, she found that the environment was not suitable for Tom's needs and the care and treatment he received fell significantly below a reasonable standard in the circumstances. In particular, a good plan was developed for Tom's care, but this was not implemented. Furthermore, the standard of nursing care was poor and the way in which Tom was discharged to the Care Home was not in line with national guidelines on discharge. The Health Service Ombudsman concluded there was service failure in the care and treatment provided for Tom at this time which was at least in part for disability related reasons.

The Health Service Ombudsman found shortcomings in the way the complaint was handled, for example, some aspects were inadequately investigated and the approach and tone of some responses was inappropriate. She concluded that, overall, these shortcomings amounted to maladministration.

The Partnership Trust told the Health Service Ombudsman about actions it had taken to improve services for people with learning disabilities. However, at the time Tom needed help from the Partnership Trust he did not receive a reasonable standard of service. We cannot know whether the outcome for Tom would have been different had he been provided with better medical treatment and social and nursing care. This service failure contributed to the injustice of unnecessary distress and suffering for Tom and his family. Moreover, partly due to failings in the Partnership Trust's complaint handling, Tom's parents had to wait four years to learn the truth about his care and treatment in the Assessment Unit. This undoubtedly contributed to their distress which remained an unremedied injustice.

Therefore, the Health Service Ombudsman upheld the complaint against the Partnership Trust.

## The Health Service Ombudsman's investigation of the complaint against the Acute Trust

Tom's condition was already deteriorating when he moved from the Assessment Unit to the Adult Care Home. It was soon after this move that he became so ill that he was admitted to the Acute Trust.

Tom's parents had not previously complained about the Acute Trust, but to ensure they had a full picture of their son's care and treatment during the final months of his life, the Health Service Ombudsman used her discretion to investigate their complaint. They complained that Tom's care and treatment at the Acute Trust, particularly pain management, hydration and nutrition, were inadequate.

It was clear that given Tom's complex health needs, poor nutritional state and disabilities, providing him with appropriate care and treatment represented a significant challenge for the Acute Trust. Tom's condition had deteriorated to a point where his recovery was unlikely.

Nonetheless, the Health Service Ombudsman found significant failings in the care and treatment the Acute Trust provided. In particular: medical co-ordination and supervision of his care fell below prevailing standards; nursing assessments, planning and interventions were inadequate; arrangements for managing Tom's medication were inadequate; incident recording and reporting were poor; and it seemed Tom's parents were not made fully aware of his prognosis. The Health Service Ombudsman found that staff did not act in line with prevailing professional standards and they did not know how to make reasonable adjustments in their practice to meet Tom's needs. This was service failure for disability related reasons.

This service failure contributed to the injustice of unnecessary distress and suffering for Tom and was an unremedied injustice.

Therefore, the Health Service Ombudsman upheld the complaint against the Acute Trust.

### The Health Service Ombudsman's investigation of the complaint against the Healthcare Commission

Tom's parents were dissatisfied with the way their complaint was handled by the Healthcare Commission.

The Health Service Ombudsman found maladministration in the way the Healthcare Commission reviewed Tom's parents' complaint. The Healthcare Commission did not look at the NHS services as a whole and failed to address significant aspects of the complaint. Also, the clinical advice it obtained was inappropriate and inadequate which meant its decisions were unreliable and unsafe. Furthermore, the Health Service Ombudsman found the Healthcare Commission did not explain its decision adequately and did not keep in touch with Tom's parents during the review. These shortcomings resulted in an injustice to Tom's parents in that they did not receive the standard of review to which they were entitled and their experience fell far short of their reasonable expectations.

Therefore, the Health Service Ombudsman upheld the complaint against the Healthcare Commission.

### Was Tom treated less favourably for reasons related to his learning disabilities?

From the evidence she received the Health Service Ombudsman concluded that the failings in the service provided for Tom by the PCT, the Partnership Trust and the Acute Trust were at least in part for disability related reasons. Similarly, the Local Government Ombudsman's consideration of the actions of the Council led him to conclude that the maladministration he found had been for disability related reasons.

The Ombudsmen concluded that the service failure and maladministration identified at the different organisations constituted a failure to live up to human rights principles, especially those of dignity and equality. They also concluded that there was no positive intention to humiliate or debase Tom. However, they considered the standard of service he received did raise the question of whether the actions of the Council, the PCT, the Partnership Trust and the Acute Trust constituted a failure to respect Tom's dignity. Maladministration and service failure touched upon and showed inadequate respect for Tom's status as a person.

Furthermore, the Health Service Ombudsman concluded that service failure by the Partnership Trust and the Acute Trust resulted in unnecessary suffering for Tom in the final months of his life.

### Was Tom's death avoidable?

Tom's parents said that had Tom received appropriate and reasonable service from the bodies they complained about his death could have been avoided. They said they accepted Tom had a life-limiting illness but not that his condition was life-threatening. They said doctors did not give them any indication their son was likely to die.

The Ombudsmen found there was public service failure by the Council and NHS bodies and that those combined failures resulted in significant unremedied injustice for Tom and his parents. Tom's parents will never know if, had appropriate arrangements been in place for their son's transition to adult care, his life would have been longer or if he could have had some extra enjoyment in his last year of life.

However, on balance the Ombudsmen could not say that Tom's death was in consequence of the service failure or maladministration we identified. Rather, they saw evidence that Tom's condition had been declining for many years and that this decline began before the events complained about. Therefore, they could not conclude that Tom's death was avoidable.

### The Ombudsmen's recommendations

The Ombudsmen recommended that Tom's parents should receive apologies and compensation totalling £30,000 from the various bodies against which complaints were upheld. This compensation was in recognition of the injustice suffered in consequence of service failure and maladministration identified.

In response to these recommendations all of the bodies acknowledged their failings, apologised to Tom's parents and offered information about improvements in service since Tom's death. They also agreed to pay the compensation recommended. The Healthcare Commission agreed to apologise to Tom's parents.

### The complainants' response

Tom's parents were dissatisfied with the outcome of some aspects of the investigation. In particular, they disagreed with the Health Service Ombudsman's decision not to uphold their complaint against the Surgery. They said they believed that the *'actions of the GP were pivotal'* to what happened to Tom. Furthermore, they strongly disagree with the decision regarding avoidable death. They believe Tom's death was avoidable and they do not accept that their son was at the end of his life.

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