Local Government
OMBUDSMAN

Parliamentary
and Health Service
Ombudsman

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

## Part seven: the complaint made by Mr and Mrs Wakefield

HC 203-VII

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# Section 1: introduction and summary

1 This is the final report of our joint investigation into Mr and Mrs Wakefield's complaint against West Street Surgery (the Surgery), Cheltenham and Tewkesbury Primary Care Trust, now the Gloucestershire Primary Care Trust (the PCT)[1], Gloucestershire County Council (the Council), Gloucestershire Partnership NHS Foundation Trust (the Partnership Trust)[2], Gloucestershire Hospitals NHS Foundation Trust (the Acute Trust) and the Healthcare Commission. This report contains our findings, conclusions and recommendations with regard to their areas of concern.

## The complaint

2 Tom Wakefield was a sociable young man with profound and multiple learning disabilities. He could understand speech and was able to communicate in a variety of ways. He used self-harming behaviour (tearing his face and scalp) to communicate and as a means of getting what he wanted. His school records describe him as having a happy smile and liking simple humour. He enjoyed people-watching and going on outings, including going to the pub. He also liked time by himself. His mother said that until 2001 Tom had been well and had a good appetite. She described him as being big and strong, '*a meat and two veg person*'.

3 Tom's gastrointestinal problems began when he was young. At six months he had repeated haematemeses (vomiting blood). An endoscopy when he was 15 months old revealed severe oesophageal ulceration. He had operations to correct a hiatus hernia (when the upper part of the stomach pushes up into the opening in the diaphragm through which the gullet passes) and a pyloroplasty (when the opening between the stomach and the intestine is widened to help the stomach empty more quickly). He continued to suffer from oesophageal reflux, a condition that allows the stomach's contents to flow upwards, causing irritation to the oesophagus. It can also sometimes cause aspiration (where stomach contents are inhaled into the lungs). Tom's scoliosis led to postural problems which, combined with his oesophageal reflux and ulceration, gave him pain. However, it appears that until 2001 his pain was well controlled by standard medication.

4 From the age of six Tom attended Penhurst School. While at school his health needs were the responsibility of a team of professionals including school nurses, a speech and language therapist and a GP. Tom should have transferred in July 2003, when he was 19 years old, to suitable adult accommodation. In this period of transition planning, a social worker and representatives of the Community Learning Disability Team were also involved in his care. Because the Council had not found a place for Tom by the date he was due to transfer, it was agreed that he could remain at the school until he was 20 years old.

5 From 2002 Tom's health deteriorated and from early 2003 he was displaying increasing signs of distress and was losing weight. The school thought his behaviour resulted primarily from his unhappiness with his environment. His parents were convinced that his behaviour represented his attempts to communicate pain. From March 2003 Tom was reviewed regularly at a hospice for children and adolescents by consultants with expertise in pain management and in children's medicine. His GP tried unsuccessfully to obtain psychologist or psychiatrist input to help assess Tom's behaviour.

1 Cheltenham and Tewkesbury PCT, Cotswold and Vale and West Gloucestershire PCT merged in 2006 to form Gloucestershire PCT

2 Services now provided by ²gether Foundation Trust for Gloucestershire

6 In the autumn of 2003 Tom's health and behaviour deteriorated further and the school felt that it was no longer able to cope with his needs. On 3 October 2003 he was given six weeks' notice to leave.

7 On 20 November 2003 Tom was admitted to an NHS in-patient unit, the Windrush Unit, part of the Partnership Trust. The Windrush Unit served a dual purpose and housed a number of people on a longer-term basis as well as providing an assessment service. The Partnership Trust had recognised that the quality of the environment at the Windrush Unit was poor and the Unit has since closed. When Tom was there the longer-stay patients were being resettled in other accommodation. The usual length of stay for assessment patients was about 12 weeks. Tom was there for just under 14 weeks before permanent accommodation became available towards the end of February 2004. During this period he continued to lose weight and his health and behaviour worsened. In January 2004 he sustained an injury to his ear which became infected and had to be drained under anaesthetic.

8 At the end of February 2004 Tom moved to Prospect Place, an adult care home.

9 On 2 March 2004 Tom was admitted to a hospital (an event which is not the subject of this complaint) suffering from severe constipation and was discharged within a few days. In April 2004 he was admitted to the Acute Trust. He was found to have an ulcerated oesophagus and an impaired swallow reflex. During this admission a percutaneous endoscopic gastrostomy (PEG) was performed to allow a feeding tube to be passed directly into his stomach.

10 Tom died on 25 May 2004. His death certificate records the cause of death as aspiration pneumonia, reflux oesophagitis, scoliosis and cerebral palsy.

11 Mr and Mrs Wakefield told the Ombudsmen that they spent over a year trying to persuade NHS organisations and the Council to listen to their concerns about their son. Despite their efforts, they feel that in the last months of his life he was in pain and did not receive the care and support he needed. Throughout this period they felt they were not listened to.

12 Three years after Tom's death, his parents say all they have are six separate sets of responses. They still do not have a full account of his care and treatment. Nor do they consider that they have confirmation that organisations have really understood and reflected on what happened to Tom and his family. They believe the bodies concerned have failed to acknowledge the extent of their failings, and have not taken sufficiently robust action to prevent a recurrence.

13 Mr and Mrs Wakefield have given permission for Mencap to act as their representative.

## The overarching complaint

14 Tom's parents believe their son's death was avoidable, that he suffered unnecessarily and that he received less favourable treatment for reasons related to his learning disabilities. We have called these aspects of the complaint 'the overarching complaint'.

## Complaint against the Surgery

15 Mr and Mrs Wakefield complain that:

**Complaint (a):** the care and treatment provided by the Surgery was inadequate. In particular, they consider that the Surgery failed to deal adequately with their son's pain and weight loss and failed to act upon medical advice to refer him for an endoscopy (examination of the gullet and stomach using a telescopic instrument). They consider that had his weight and pain been better managed, and had the endoscopy been performed, the course of events might have been different.

**Complaint (b):** the Surgery did not provide a reasonable response to their complaint.

## Complaint against the Council

16 Mr and Mrs Wakefield complain that:

**Complaint (c):** the Council failed to plan for, or commission, new provision for their son, or to deal appropriately with his transition into adult accommodation. In particular, they are concerned about the failure by his social worker to pass on information regarding the offer in October 2003 of a suitable permanent placement. They also complain about the way the Council responded to their complaints about Tom's transition to adult care. Although their complaint was investigated at Stage 2 of the Council's complaints procedure, Tom's parents consider that they have not had an adequate response and remain uncertain of the actions taken by the Council in the light of its investigation.

## Complaint against the PCT

17 Mr and Mrs Wakefield complain that:

**Complaint (d):** the PCT failed to liaise appropriately with the Council in planning for their son's transition into adult accommodation.

**Complaint (e):** the PCT did not provide a reasonable response to their complaint.

## Complaint against the Partnership Trust

18 Mr and Mrs Wakefield complain that:

**Complaint (f):** their son's admission to the Windrush Unit was inappropriate. They also complain that while at the Unit he received inadequate care and treatment (including specific failures to investigate an injury to his ear), that he was generally at risk and he was in a poor physical environment. They also complain that his discharge from the Windrush Unit was badly managed.

**Complaint (g):** the Partnership Trust did not provide a reasonable response to their complaint.

## Complaint against the Acute Trust

19 Mr and Mrs Wakefield complain that:

**Complaint (h):** the care and treatment provided for their son, particularly with regard to pain management, hydration and nutrition, from his admission in April 2004 until his death the following month was inadequate.

## Complaint against the Healthcare Commission

20 Mr and Mrs Wakefield complain about:

**Complaint (i):** the way the Healthcare Commission handled their complaint, including the time taken to respond.

21 Mr and Mrs Wakefield hope the Ombudsmen's investigation will provide the answers they seek and that their hurt and suffering will be acknowledged. They have said they are aware that nothing will bring Tom back, but they hope other families would benefit from changes brought about as a result of their complaint. They do not want others to go through the same experiences as them and their son.

# The Ombudsmen's remit, jurisdiction and powers

## General remit of the Health Service Ombudsman

22 By virtue of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints against the NHS in England. In the exercise of her wide discretion she may investigate complaints about NHS bodies such as trusts, family health service providers such as GPs, and independent persons (individuals or bodies) providing a service on behalf of the NHS.

23 When considering complaints against an NHS body, she may look at whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by the body, a failure by the body to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the body.

24 Failure or maladministration may arise from action of the body itself, a person employed by or acting on behalf of the body, or a person to whom the body has delegated any functions.

25 When considering complaints against GPs, she may look at whether a complainant has suffered injustice or hardship in consequence of action taken by the GP in connection with the services the GP has undertaken with the NHS to provide. Again, such action may have been taken by the GP himself or herself, by someone employed by or acting on behalf of the GP or by a person to whom the GP has delegated any functions.

26 The Health Service Ombudsman may carry out an investigation in any manner which, to her, seems appropriate in the circumstances of the case and in particular may make such enquiries and obtain such information from such persons as she thinks fit.

27 If the Health Service Ombudsman finds that service failure or maladministration has resulted in an injustice, she will uphold the complaint. If the resulting injustice is unremedied, in line with her *Principles for Remedy*, she may recommend redress to remedy any injustice she has found.

## Remit over the Healthcare Commission

28 By operation of section 3(1E) of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints about injustice or hardship in consequence of maladministration by any person exercising an NHS complaints function. As the Healthcare Commission is the second stage of the NHS complaints procedure set out in the *National Health Service (Complaints) Regulations 2004*, it is within the Health Service Ombudsman's remit.

## Health Service Ombudsman - premature complaints

29 Section 4(5) of the *Health Service Commissioners Act 1993* states that the Health Service Ombudsman generally may not investigate any complaint until the NHS complaints procedure has been invoked and exhausted, and this is the approach taken by the Ombudsman in the majority of NHS complaints made to her.

30 However, section 4(5) makes it clear that if, in the particular circumstances of any case, the Health Service Ombudsman considers it is not reasonable to expect the complainant to have followed the NHS route, she may accept the case for investigation notwithstanding that the complaint has not been dealt with under the NHS complaints procedure. This is a matter for the Health Service Ombudsman's discretion after proper consideration of the facts of each case.

31 In this instance, Tom's parents had not previously complained to the Acute Trust. Nevertheless, they had asked the Healthcare Commission to consider their son's care while in the Acute Trust but this had not happened. They explained that they had become exhausted by the complaints process and had lacked the energy to pursue matters further. They had, however, remained concerned about the care provided to their son while he was a patient at the Acute Trust and feel that without an investigation of his care while he was there they will still not fully understand what happened to him. Taking these matters into account, the Health Service Ombudsman exercised her discretion to investigate the complaint against the Acute Trust under the provisions of the Act which governs her work.

## General remit of the Local Government Ombudsman

32 Under the *Local Government Act 1974 Part III*, the Local Government Ombudsman has wide discretion to investigate complaints of injustice arising from maladministration by local authorities (local councils) and certain other public bodies. He may investigate complaints about most council matters, including Social Services and the provision of social care.

33 If the Local Government Ombudsman finds that maladministration has resulted in an injustice, he will uphold the complaint. If the resulting injustice is unremedied, he may recommend redress to remedy any injustice he has found.

## Powers to investigate and report jointly

34 *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007* clarified the powers of the Health Service Ombudsman and the Local Government Ombudsman, with the consent of the complainant, to share information, carry out joint investigations and produce joint reports in respect of complaints which fell within the remit of both Ombudsmen.

35 In this case, the Health Service Ombudsman and the Local Government Ombudsman 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 the production of a joint conclusion and proposed remedy in one report seemed the most appropriate way forward.

## The investigation

36 During the investigation, our investigator met Mr and Mrs Wakefield and their representative to ensure we had a full understanding of their complaint. The investigator also examined relevant documentation including: Tom's health records from the Surgery, the Partnership Trust and the Acute Trust; the complaint files relating to the attempted local resolution of the complaints by all the bodies complained about; and the complaint files from the Healthcare Commission. Health records were also obtained from a hospice (the Hospice), which Tom attended for assessment in 2003, and the former Medical Director of the Hospice (the Hospice's Medical Director) responded to our specific enquiries. Further comments and information have been provided by the GP, the Partnership Trust, the Acute Trust, the PCT and the Council. In addition, our investigative staff met staff from the Partnership Trust and the Acute Trust.

37 We obtained specialist advice from a number of our professional advisers (the Professional Advisers): Dr I Barrison and Dr R Barry, two consultant gastroenterologists (the First Gastroenterology Adviser and the Second Gastroenterology Adviser); Dr E Ward, a GP (the GP Adviser); Dr N Evans, a consultant psychiatrist (the Psychiatry Adviser); Ms C McFarlane, a senior acute nurse (the Nursing Adviser); Ms N Trenowden, a learning disability nurse (the Learning Disability Nursing Adviser); and Professor C Butler, a professor of pharmacy (the Pharmacy Adviser).

38 The Professional Advisers are specialists in their field and in their roles as advisers to the Ombudsmen they are completely independent of any NHS body and the Healthcare Commission. Their role is to help the Ombudsmen and their investigative staff understand the clinical aspects of the complaint.

39 In this report we have not referred to all the information examined in the course of our investigation, but we are satisfied that nothing significant to the complaint or our findings has been overlooked.

## Our decisions

40 Having considered all the available evidence related to Mr and Mrs Wakefield's complaint, including their recollections and their response to our draft report, and taken account of the clinical advice we have received, we have reached the following decisions.

## Complaint against the Surgery

41 The Health Service Ombudsman finds 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. She finds the failings she identified **do not amount to service failure**. She finds **no maladministration** in the way the Surgery handled Mr and Mrs Wakefield's complaint. She **does not uphold** the complaint against the Surgery.

## Complaint against the Council

42 The Local Government Ombudsman finds that the Council's arrangements for Tom's transition to adult accommodation fell significantly below a reasonable standard. This was **maladministration** which contributed to the **injustice** suffered by Tom and his family. It will never be known if, had everything been in place, his life would have been longer or if he could have had some improved enjoyment of his life in his last year. The Local Government Ombudsman has concluded that some of the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons. He **upholds** the complaint about the provision of facilities for Tom and his transition to adult accommodation. The Local Government Ombudsman also finds that Mr and Mrs Wakefield were not provided with an adequate response to their complaint, nor have they received adequate assurance about actions taken subsequently. This was **maladministration** which would have compounded the distress caused to them. He **upholds** the complaint about complaint handling.

## Complaint against the PCT

43 The Health Service Ombudsman finds that 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. This was **service failure**. She recognises that the Council had lead responsibility for planning for transition to adult care, but concludes nonetheless that it is 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 to people with profound and multiple learning disabilities. This unanswered question remains a cause of distress for Tom's parents which has yet to be acknowledged and is an **unremedied injustice**. The Health Service Ombudsman also concludes that the service failure by the PCT was for disability related reasons. She finds **maladministration** in the way the PCT handled Mr and Mrs Wakefield's complaint. Given the **unremedied injustice** resulting from service failure she **upholds** the complaint against the PCT.

## Complaint against the Partnership Trust

44 The Health Service Ombudsman finds that the admission to the Windrush Unit was appropriate. She also finds that, whilst the Partnership Trust made a reasonable assessment of Tom's needs, the plans set out for him were not implemented. He was not provided with reasonable nursing care. The arrangements for his discharge to his adult care home were inadequate. This **service failure** by the Partnership Trust contributed to the **injustice** of unnecessary distress and suffering for Tom and his family. The Health Service Ombudsman concludes that some of the service failures by

the Partnership Trust in terms of managing his discharge and his care and treatment were for disability related reasons. She also concludes that the Partnership Trust's acts and omissions constituted a failure to live up to human rights principles of dignity and equality. In addition, she finds **maladministration** in the way the Partnership Trust handled Mr and Mrs Wakefield's complaint. She **upholds** the complaint against the Partnership Trust.

## Complaint against the Acute Trust

45 The Health Service Ombudsman finds that the nursing and medical care provided by the Acute Trust fell below a reasonable standard. This **service failure** by the Acute Trust contributed to the **injustice** of unnecessary distress and suffering for Tom and his family. The Health Service Ombudsman concludes that some of the service failures by the Acute Trust in terms of care and treatment were for disability related reasons. She also concludes that the Trust's acts and omissions constituted a failure to live up to human rights principles of dignity and equality. She **upholds** the complaint against the Acute Trust.

## Complaint against the Healthcare Commission

46 The Health Service Ombudsman finds **maladministration** in the way the Healthcare Commission handled Mr and Mrs Wakefield's complaints, which led to the **injustice** that they were denied a reasonable review of their complaints. She **upholds** the complaint against the Healthcare Commission.

## The overarching complaint

47 The Health Service Ombudsman concludes that some of the service failures by the Partnership Trust in terms of managing Tom's discharge, and by both the Partnership Trust and the Acute Trust in terms of his care and treatment, were for disability related reasons. She also concludes that the Trusts' acts and omissions constituted a failure to live up to human rights principles of dignity and equality. She also concludes that the service failure by the PCT was for disability related reasons. The Local Government Ombudsman concludes that some of the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons.

48 The Ombudsmen conclude that there was **service failure** by most, although not all, of the bodies complained about. That service failure resulted in **unremedied injustice** for Tom's parents. They 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 more enjoyable in his last year. **Service failure** by NHS bodies and **maladministration** by the Council have resulted in the **unremedied injustice** of unnecessary distress and suffering for Tom's family. Poor complaint handling has compounded their distress.

49 We conclude that **maladministration** by the Council and **service failure** by the PCT, the Partnership Trust and the Acute Trust resulted in unnecessary suffering for Tom in the final months of his life. The resulting distress for his family is an injustice which remains unremedied.

50 We have not found that Tom died in consequence of the maladministration or service failure we identified and, therefore, we cannot say that his death was avoidable.

51 In this report we explain the detailed reasons for our decisions and comment on the particular areas where Mr and Mrs Wakefield have expressed concerns to the Ombudsmen.

# Section 2: the basis for our determination of the complaints

## Introduction

52 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, the Ombudsmen generally begin by comparing what actually happened with what should have happened.

53 So, in addition to establishing the facts that are relevant to the complaint, we also need to establish a clear understanding of the standards, both of general application and which are specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those bodies and individuals whose actions are the subject of the complaint. We call this establishing the overall standard.

54 The overall standard has two components: the general standard which is derived from general principles of good administration and, where applicable, of public law; and the specific standards which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

55 Having established the overall standard we then assess the facts in accordance with the standard. Specifically, we assess whether or not an act or omission on the part of the body or individual complained about constitutes a departure from the applicable standard.

56 If so, we then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

57 The overall standard which we have applied to this investigation is set out below.

## The general standard

### Principles of Good Administration

58 Since it was established the Office of the Parliamentary and Health Service Ombudsman has developed and applied certain principles of good administration in determining complaints of service failure and maladministration. In March 2007 the Parliamentary and Health Service Ombudsman published these established principles in codified form in a document entitled *Principles of Good Administration*.

59 The document organises the established principles of good administration into six Principles. These Principles are:

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

60 We have taken all of these Principles into account in our consideration of Mr and Mrs Wakefield's complaint and therefore set out below in greater detail what the *Principles of Good Administration* says under these headings:[3]

[3] *Principles of Good Administration* is available at www.ombudsman.org.uk

'*Getting it right*' means:

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

'*Being customer focused*' means:

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

'*Being open and accountable*' means:

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.
- Stating criteria for decision making and giving reasons for decisions.
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for actions.

'*Acting fairly and proportionately*' means:

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

'*Putting things right*' means:

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

'*Seeking continuous improvement*' means:

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

## Principles for Remedy

61 In October 2007 the Parliamentary and Health Service Ombudsman published a document entitled *Principles for Remedy*.[4]

62 This document sets out the Principles that we consider should guide how public bodies provide remedies for injustice or hardship resulting from their service failure or maladministration. It sets out how we think public bodies should put things right when they have gone wrong. It also confirms our own approach to recommending remedies. The *Principles for Remedy* flows from, and should be read with, the *Principles of Good Administration*. Providing fair and proportionate remedies is an integral part of good administration and good service, so the same principles apply.

63 We have taken the *Principles for Remedy* into account in our consideration of Mr and Mrs Wakefield's complaints.

# The specific standards

## Disability discrimination

### Legal framework

***Disability Discrimination Act 1995***

64 The sections of the *Disability Discrimination Act 1995* most relevant to the provision of services in this complaint were brought into force in 1996 and 1999 respectively. Although other parts of the *Disability Discrimination Act 1995* were brought into force in 2004 and further provisions added by the *Disability Discrimination Act 2005*, these changes either post-date or are not directly relevant to the subject matter of this complaint.

65 Since December 1996 it has been 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.

66 Since October 1999 it has in addition been unlawful for service providers to fail to comply with the duty to make reasonable adjustments for disabled people where the existence of a practice, policy or procedure makes it impossible or unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

67 It has also been unlawful since October 1999 for service providers to fail to comply with the duty to make reasonable adjustments so as to provide a reasonable alternative method of making the service in question available to disabled people where the existence of a physical feature makes it impossible or

[4] *Principles for Remedy* is available at www.ombudsman.org.uk

unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

68 Since October 1999 it has been unlawful for service providers to fail to comply with the duty to take reasonable steps to provide auxiliary aids or services to enable or facilitate the use by disabled people of services that the service provider provides, unless that would necessitate a permanent alteration to the physical fabric of a building or unless such failure is justified.

## Policy aims

69 The *Disability Discrimination Act 1995* recognises that the disabling effect of physical and mental impairment will depend upon how far the physical and social environment creates obstacles to disabled people's enjoyment of the same goods, services and facilities as the rest of the public.

70 The key policy aim behind the legislation is to ensure that as far as reasonably possible disabled people enjoy access not just to the same services, but to the same standard of service, as other members of the public. In other words, those who provide services to the public, whether in a private or public capacity, are to do whatever they reasonably can to eradicate any disadvantage that exists for a reason related to a person's physical or mental impairment.

71 The critical component of disability rights policy is therefore the obligation to make '*reasonable adjustments*', which shapes the '*positive accent*' of the *Disability Discrimination Act 1995*. This obligation recognises that very often equality for disabled people requires not the same treatment as everyone else but different treatment. The House of Lords made explicit what this means in a case (*Archibald v Fife Council*, [2004] UKHL 32, judgment of Baroness Hale), which although arising from the *Part 2* employment provisions of the *Disability Discrimination Act 1995*, has bearing on the *Part 3* service provisions also:

> *'The 1995 Act, however, does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated in the same way. It expects reasonable adjustments to be made to cater for the special needs of disabled people. It necessarily entails an element of more favourable treatment.'*

72 As the Court of Appeal has also explained, specifically in respect of the *Part 3* service provisions of the *Disability Discrimination Act 1995* (*Roads v Central Trains* [2004] EWCA Civ 1451, judgment of Sedley LJ), the aim is to ensure '*access to a service as close as it is possible to get to the standard offered to the public at large*'.

## Policy and administrative guidance

**Disability Rights Commission Codes of Practice**

73 Between April 2000 and October 2007 the Disability Rights Commission had responsibility for the enforcement and promotion of disability rights in Britain. In that capacity, and by virtue of the provisions of the *Disability Rights Commission Act 1999*, it had a duty to prepare statutory codes of practice on the law. These statutory codes of practice, although not legally binding, are to be taken into account by courts and tribunals in determining any issue to which their provisions are relevant.

74 Before the establishment of the Disability Rights Commission in April 2000, the relevant Secretary of State, on the advice of the National Disability Council, published a statutory code of practice on the duties of service providers under *Part 3* of the *Disability Discrimination Act 1995* entitled *Code of Practice: Goods, Facilities, Services and Premises* (1999), itself a revision of an earlier code of practice published in 1996.

75 On its establishment in 2000 the Disability Rights Commission consulted on a further revised code of practice, which came into force on 27 May 2002 as the *Disability Discrimination Code of Practice (Goods, Facilities, Services and Premises)*. The revised code of practice not only updated the previous codes but anticipated the changes to the law that were due to come into effect in 2004, in particular with respect to the duty to remove obstructive physical features.

76 The 2002 code made it clear that a service provider's duty to make reasonable adjustments is a duty owed to disabled people at large and that the duty is '*anticipatory*':

> *'Service providers should not wait until a disabled person wants to use a service which they provide before they give consideration to their duty to make reasonable adjustments. They should be thinking now about the accessibility of their services to disabled people. Service providers should be planning continually for the reasonable adjustments they need to make, whether or not they already have disabled customers. They should anticipate the requirements of disabled people and the adjustments that may have to be made for them.'*

77 It also drew attention to the pragmatic strain of the *Disability Discrimination Act 1995*. For example, in respect of the forthcoming '*physical features*' duty, the code says:

> *'The Act does not require a service provider to adopt one way of meeting its obligations rather than another. The focus of the Act is on results. Where there is a physical barrier, the service provider's aim should be to make its services accessible to disabled people. What is important is that this aim is achieved, rather than how it is achieved.'*

***Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001)**

78 In 2001 the Department of Health published a White Paper, explicitly shaped by the relevant legislation (including the *Disability Discrimination Act 1995* and the *Human Rights Act 1998*), with a foreword written by the then Prime Minister, outlining the Government's future strategy and objectives for achieving improvements in the lives of people with learning disabilities.

79 The White Paper identified four key principles that it wanted to promote: legal and civil rights (including rights to education, to vote, to have a family and to express opinions); independence; choice; and inclusion (in the sense of being part of mainstream society and being integrated into the local community).

80 As the White Paper explained, the intention was that '*All public services will treat people with learning disabilities as individuals, with respect for their dignity*'.

81 The fifth stated objective of the Government was to '*enable people with learning disabilities to access health services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary*'.

82 The Department of Health also published in 2001 two circulars aimed jointly at the health service and local authorities, focusing on the implementation of Valuing People and including detailed arrangements for the establishment of Learning Disability Partnership Boards: *HSC 2001/016* and *LAC (2001) 23*.

83 The Department of Health has published a series of reports to help the NHS meet its duties under the *Disability Discrimination Act 1995*.

***Signposts for success in commissioning and providing health services for people with learning disabilities* (1998)**

84 This was published by the Department of Health and was the result of extensive consultation undertaken with people with learning disabilities, carers and professionals with the aim of informing good practice. It was targeted at the whole NHS and emphasises the need for shared values and responsibilities, respecting individual rights, good quality information and effective training and development. It also encourages the use of personal health records. The accompanying executive letter *EL (98)3* informs chief executives of the availability of the guidance.

***Doubly Disabled: Equality for disabled people in the new NHS – access to services* (1999)**

85 This Department of Health report, also aimed at the whole NHS, contains a specific section on learning disability. It provides guidance for managers with specific responsibility for advising on access for disabled patients to services and employment. It also provides information for all staff on general disability issues. The accompanying circular *HSC 1999/093* emphasises the purpose of the document saying:

> '*... it will be essential for service providers to ensure that they have taken reasonable steps to ensure that services are not impossible or unreasonably difficult for disabled people to use.*'

***Once a Day: A Primary Care Handbook for people with learning disabilities* (1999)**

86 This was issued jointly by the Department of Health and the Royal College of General Practitioners, and was specifically aimed at primary care services. It draws attention to the interface between primary care and general hospital services and sets out actions which healthcare providers should take to facilitate equal access to health services for people with learning disabilities. The overall purpose of the handbook was described in the accompanying circular *HSC 1999/103* which says:

> '*The purpose of this guidance, for GPs and primary care teams, is to enhance their understanding, improve their practice and promote their partnerships with other agencies and NHS services.*'

### In practice

87 The practical effect of the legal, policy and administrative framework on disability discrimination is to require public authorities to make their services accessible to disabled people. To achieve this objective they must take all reasonable steps to ensure that the design and delivery of services do not place disabled people at a disadvantage in their enjoyment of the benefits provided by those services.

88 Failure to meet this standard will mean not only that there is maladministration or service failure, but that there is maladministration or service failure for a disability related reason. This does not require a deliberate intention to treat disabled people less favourably. It will be enough that the public authority has not taken the steps needed, without good reason.

89 To be confident that it has met the standard, a public authority will need to show that it has planned its services effectively, for example, by taking account of the views of disabled people themselves and by conducting the risk assessments needed to avoid false assumptions; that it has the ability to be flexible, for example, by making reasonable adjustments to its policies, practices and procedures, whenever necessary; and by reviewing arrangements regularly, not just when an individual disabled person presents a new challenge to service delivery.

90 It should also be noted that a failure to meet the standard might occur even when the service in question has been specially designed to meet the needs of disabled people. This might be because, for example, the service design meets the needs of some disabled people but not others, or because good design has not been translated into good practice.

91 It is not for the Ombudsmen to make findings of law. It is, however, the role of the Ombudsmen to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsmen will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving disabled people, such considerations are so integral to good administration and service delivery that it is impossible to ignore them.

## Human rights

### Legal framework

***Human Rights Act 1998***

92 The *Human Rights Act 1998* came into force in England in October 2000. The *Human Rights Act 1998* was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. To that extent, the *Human Rights Act 1998* did not so much create new substantive rights for UK citizens but rather established new arrangements for the domestic enforcement of those existing substantive rights.

93 It requires public authorities (that is, bodies which exercise public functions) to act in a way that is compatible with the *European Convention on Human Rights*; it requires the courts to interpret statute and common law in accordance with the *European Convention on Human Rights* and to interpret legislation compatibly with the *European Convention on Human Rights* wherever possible; and it

requires the sponsors of new legislation to make declarations when introducing a Bill in Parliament as to the compatibility of that legislation with the *European Convention on Human Rights*.

94 Of particular relevance to the delivery of healthcare to disabled people by a public authority are the following rights contained in the *European Convention on Human Rights*:

| | |
|---|---|
| Article 2 | Right to life |
| Article 3 | Prohibition of torture, or inhuman or degrading treatment |
| Article 14 | Prohibition of discrimination. |

## Policy aims

95 When the UK Government introduced the *Human Rights Act 1998*, it said 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.

96 A key component of that human rights culture is observance of the core human rights principles of Fairness, Respect, Equality, Dignity and Autonomy for all. These are the principles that lie behind the *Human Rights Act 1998*, the *European Convention on Human Rights* and human rights case law, both in the UK and in Strasbourg.

97 These principles are not new. As the Minister of State for Health Services remarked in her foreword to *Human Rights in Healthcare – A Framework for Local Action* (2007):

> *'The Human Rights Act supports the incorporation of these principles into our law, in order to embed them into all public services. These principles are as relevant now as they were over 50 years ago when UK public servants helped draft the European Convention on Human Rights.'*

98 The policy implications for the healthcare services are also apparent as one aspect of that aim of using human rights to improve service delivery. As the Minister of State also observed:

> *'Quite simply we cannot hope to improve people's health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people's lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.'*

99 At the time of the introduction of the *Human Rights Act 1998* in October 2000, the importance of human rights for disabled people was recognised. Writing in the Disability Rights Commission's publication of September 2000 entitled *The Impact of the Human Rights Act on Disabled People*, the then Chair of the Disability Rights Commission noted that:

> *'The Human Rights Act has particular significance for disabled people ... The withdrawal or restriction of medical services, the abuse and degrading treatment of disabled people in institutional care, and prejudiced judgements about the parenting ability of disabled people are just some of the areas where the Human Rights Act may help disabled people live fully and freely, on equal terms with non-disabled people.'*

### In practice

100 The practical effect of the legal, policy and administrative framework on human rights is to create an obligation on public authorities not only to promote and protect the positive legal rights contained in the *Human Rights Act 1998* and other applicable human rights instruments but to have regard to the practical application of the human rights principles of Fairness, Respect, Equality, Dignity and Autonomy in everything they do.

101 Failure to meet this standard will not only mean that the individual has been denied the full enjoyment of his or her rights; it will also mean that there has been maladministration or service failure.

102 To be confident that it has met the requisite standard, a public authority will need to show that it has taken account of relevant human rights principles not only in its design of services but in their implementation. It will, for example, need to show that it has made decisions that are fair (including by giving those affected by decisions a chance to have their say, by avoiding blanket policies, by acting proportionately and by giving clear reasons); that it has treated everyone with respect (including by avoiding unnecessary embarrassment or humiliation, by enabling individuals to make their own choices so far as practicable, and by having due regard to the individual's enjoyment of physical and mental wellbeing); that it has made genuine efforts to achieve equality (including by avoiding unjustifiable discrimination, by taking reasonable steps to enable a person to enjoy participation in the processes that affect them, by enabling a person to express their own personal identity and by actively recognising and responding appropriately to difference); that it has preserved human dignity (including by taking reasonable steps to protect a person's life and wellbeing, by avoiding treatment that causes unnecessary mental or physical harm, and by avoiding treatment that is humiliating or undignified); and that it has promoted individual autonomy (including by taking reasonable steps to ensure that a person can live independently).

103 It is not for the Ombudsmen to make findings of law. It is, however, the role of the Ombudsmen to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsmen will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving health and social care, such considerations are so integral to the assessment of good administration and good service delivery that it is impossible to ignore them.

## Health and social care

### Legal framework

***National Health Service Act 1977***

104 The *National Health Service Act 1977* made it a duty for the NHS to promote services to improve health. Section 1 of the Act confers a duty on the Secretary of State to secure improvements in the physical and mental health of the population. Section 22 creates a duty of co-operation between NHS bodies and local authorities in exercising their respective functions.

***National Health Service and Community Care Act 1990***

105 The *National Health Service and Community Care Act 1990* clarified that local authorities have a duty to assess the individual community care needs of any person who, in their view, requires services and then have to decide what services should be provided. The Act also required health authorities to assist in the assessment of need in cases where the person appeared to require the services of the NHS.

***Health Act 1999***

106 The *Health Act 1999* enabled the establishment of primary care trusts and described their functions.

***Care Standards Act 2000***

107 The main purpose of the Act was to reform the regulatory system for care services in England and Wales. For the first time, local authorities were to be required to meet the same standards as independent sector providers. In England the Act provided for an independent National Care Standards Commission to undertake a regulatory function to ensure that standards were met.

**The Care Homes regulations, amended 2003, incorporating National Minimum Standards for Social Care**

108 These regulations and standards form the basis of the regulatory framework established under the *Care Standards Act 2000* for the conduct of care homes and were drafted following consultation with service users, providers and regulators. The regulations contain a statement of national minimum standards published by the Secretary of State under section 23(1) of the *Care Standards Act 2000* applicable to care homes (as defined by section 3 of that Act) which provide accommodation, together with nursing or personal care, for adults (aged 18-65). Standard 2 of the National Minimum Standards Care Homes Regulations (*Care Homes for Adults (18-65)*), states:

> *'2.1 New service users are admitted only on the basis of a full assessment undertaken by people competent to do so, involving the prospective service user, using an appropriate communication method and with an independent advocate as appropriate.*
>
> *'2.2 For individuals referred through Care Management, the registered manager obtains a summary of the single Care Management (health and social services) assessment – integrated with the Care Programme Approach (CPA) for people with mental health problems – and a copy of the single Care Plan.'*

***Community Care (Delayed Discharges etc) Act 2003***

109 The *Community Care (Delayed Discharges etc) Act 2003* placed a duty upon local authorities to enable timely, well planned discharges from hospital for people who had a need for social care. It required the NHS to alert social services departments to patients who may need social care support to enable discharge from hospital.

## Policy aims

110 By the end of the 1990s the Government had become concerned about a number of failures in social care and in the co-ordination of care across health and social services. Accordingly, further legislation (which built on early legislation) was introduced to underline the requirement for proper assessment of needs and planning of health and social care for whole communities and for individuals. The Government also introduced legislation

to raise the quality, safety and consistency of services provided to people with complex health and social care needs and to ensure that people with complex needs were discharged from hospital safely and without unnecessary delay.

## Policy and administrative guidance

***Governing the NHS: A Guide for NHS Boards***

111 This document was issued jointly by the Department of Health and the NHS Appointments Commission in 2003 and summarises the main functions of primary care trusts as being to:

- identify the health needs of the population
- maintain an effective public health function
- work to improve the health of the community
- lead local planning
- secure the provision of a full range of services
- manage and develop primary healthcare services
- develop and improve local services
- lead the integration of health and social care
- deliver services within their remit.

***Moving into the Mainstream, the report of a national inspection of services for adults with learning disabilities***

112 This report was issued to local authorities by the Chief Inspector of the Social Services Inspectorate (SSI) in 1998 and set out best practice guidance for local authorities about the planning and provision 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**

113 Valuing People drew on the legislation and guidance described above and clarified how it was to be applied to people with learning disabilities. *HSC 2001/016* and *LAC (2001) 23* circulars laid out specifically what was expected of the NHS and local authorities. Local authorities would, by October 2001, have established learning disability partnership boards that would develop integrated plans and services for people with learning disabilities, taking account of the health needs of the population, resources and service users' and carers' views. Councils were expected to take the lead role with the learning disability partnership boards for ensuring appropriate plans were drawn up and provision was made for people with learning disabilities to whom councils had a duty of care. Primary care trusts would be the lead NHS organisations on the partnership board and would take account of the partnership board's plans in exercising their duties to assess the health needs of people with learning disabilities and in commissioning an appropriate range of services. The partnership boards would, by 2002, have a framework in place for planning services to address the needs of young people making the transition to adult services and would take action to ensure that people with learning disabilities could obtain fair benefit from mainstream policy. A quality framework would be in place by April 2002 to improve service quality amongst all agencies, with particular attention for people with complex needs such as those with profound and multiple learning disabilities.

114 By winter 2002 people with learning disabilities who made substantial and long-term use of publicly funded services were to have a named person to act as their service co-ordinator. This person was to pay particular attention to achieving effective organisation and monitoring of services provided by all agencies. A health facilitator was to be available to help people to access the healthcare they needed and to help healthcare providers develop appropriate skills – especially in primary and secondary care.

***LAC (2003) 13, Fair access to care services: guidance on eligibility criteria for adult social care***

115 In this circular the Department of Health reminded councils of their duties under section 47 of the *NHS and Community Care Act 1990* and said that they should develop strategies to fill gaps and improve the range, accessibility and effectiveness of adult social care services. It says that prior to admission to adult care, a care plan should be developed and agreed with the individual. There should be a written record of a care plan that should encompass, as a minimum, a note of eligible needs, the preferred outcome of service provision, contingency plans to manage emergency changes and a review date.

116 The *National service framework for mental health: modern standards and service models* (the National Service Framework for Mental Health) (Department of Health, 1999) reiterated the importance of the Care Programme Approach (CPA) as a means for systematically assessing an individual's health and social care and for drawing up plans to address those needs. The CPA required close working between health and social services and the involvement of users and carers. It stressed the need for anticipatory planning to enable better decision making at times of change and to try to avoid crisis.

117 In *Making a Difference: strengthening the nursing, midwifery and health visiting contribution to health and healthcare* (Making a Difference), issued in 1999 by the Department of Health, the Chief Nursing Officer identified a need to focus on the fundamentals of nursing care. This led to the development of a set of benchmarking tools known as *The Essence of Care: Patient-focused benchmarking for health care practitioners* (the Essence of Care), (Department of Health, 2001). At the time of this complaint benchmarking tools were available for eight areas including:

- Food and nutrition
- Personal hygiene and mouth care
- Continence and bladder and bowel care
- Record keeping
- Safety of patients with mental health needs
- Privacy and dignity
- Communication.

NHS trusts were expected to develop and implement local policies that ensured compliance with the benchmark standards.

118 In January 2003 the Department of Health published comprehensive guidelines about discharging patients from hospital called *Discharge from hospital: pathway, process and practice* (Discharge from Hospital). The lengthy guidelines are in the form of a workbook and include principles for good practice as well as introducing a range of tools to assist professionals involved in the discharge process. Amongst other things, it expects organisations

to have arrangements to ensure that people can be safely transported home or to another setting and that relevant information, such as discharge summaries and care plans, transfer on a timely basis. Amongst the document's '*key messages*' are:

> *'Ensure individuals and their carers are actively engaged in the planning and delivery of their care.*
>
> *'...*
>
> *'Agree, operate and performance manage a joint discharge policy that facilitates effective multidisciplinary working at ward level and between organisations.*
>
> *'On admission, identify those individuals who may have additional health, social and/or housing needs to be met before they can leave hospital and target them for extra support.*
>
> *'...*
>
> *'Consider how an integrated discharge planning team can be developed to provide specialist discharge planning support to the patient and multidisciplinary team.'*

119 Appendices 5.6 and 5.7 of the guidelines specifically address the needs of people with learning disabilities, mental health problems or dementia. The importance of meeting the special needs of these groups of patients by effective multidisciplinary and multi-agency working is threaded through the guidance.

## Professional standards

### The General Medical Council

120 The General Medical Council (the body responsible for professional regulation of doctors) publishes *Good Medical Practice* (Good Medical Practice), which contains general guidance on how doctors should approach their work. This booklet is clear that it represents standards which the General Medical Council expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of their work. Key sections of the booklet current at the time of this complaint are set out at Annex A.

121 Paragraph 5 of Good Medical Practice, 2001, says:

> *'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 arrange.'*

### The Nursing and Midwifery Council

122 The Nursing and Midwifery Council (the body responsible for professional regulation of nurses) publishes a booklet, *The Nursing and Midwifery Council code of professional conduct* (the Code of Conduct), which contains general and specific guidance on how nurses should approach their work. The booklet represents the standards which the Nursing and Midwifery Council expects nurses to meet.

123 Paragraph 1 of the Code of Conduct current in 2004 said:

> *'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.*
>
> *'You have a duty of care to your patients and clients, who are entitled to receive safe and competent care.'*

124 Paragraph 2 of the Code of Conduct said:

> *'As a registered nurse, midwife or health visitor, you must respect the patient or client as an individual.*
>
> *'...*
>
> *'You are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.'*

125 Paragraph 4 of the Code of Conduct emphasised the importance of teamwork and communication. It said:

> *'As a registered nurse, midwife or health visitor, you must co-operate with others in a team.*
>
> *'The team includes the patient or client, the patient's or client's family, informal carers and health and social care professionals in the National Health Service, independent and voluntary sectors.*
>
> *'You are expected to work co-operatively within teams and to respect the skills, expertise and contributions of your colleagues. You must treat them fairly and without discrimination.*
>
> *'You must communicate effectively and share your knowledge, skill and expertise with other members of the team as required for the benefit of patients and clients.*
>
> *'Health care records are a tool of communication within the team. You must ensure that the health care record for the patient or client is an accurate account of treatment, care planning and delivery.'*

## Complaint handling

### Council complaint handling

126 The *NHS and Community Care Act 1990* imposes on Social Services authorities a statutory duty to provide a complaints procedure. Statutory guidance has been issued by the Department of Health and authorities must have regard to it when managing complaints about their service. The statutory complaints process applicable to this complaint was that contained within the *Complaints Procedure Directions 1990* (these have now been superseded by *The Council Social Services Complaints (England) Regulations 2006* and associated guidance, for complaints made after August 2006).

127 The 1990 Directions established a three-part process consisting of a first, informal, stage aimed at resolving the complaint at a local level, but which progressed to the formal second stage if the complainant remained dissatisfied.

The matter was considered at the second stage by the designated complaints officer and an investigator might be appointed. If the complainant remained dissatisfied at the end of this stage of the process, he or she had the right to request an independent review by a panel set up by the council to review the stage 2 investigation. The panel did not carry out a fresh investigation, nor could it consider any aspect of the complaint that had not already been considered at an earlier stage. The panel had no power to make binding findings, but could make recommendations to the council to resolve the complaint. If the council rejected the findings it had to provide reasons for doing so.

## NHS complaint handling

128 Prior to 2004 complaint handling in the NHS was subject to various Directions which required NHS trusts to have written procedures for dealing with complaints within their organisation (known as local resolution) and to operate the second element of the complaints procedure (independent review). Complaints against primary care providers were dealt with at the local level under practice-based complaints procedures required under the provider's terms of service.

129 However, on 30 July 2004 the *NHS (Complaints) Regulations 2004* (the Regulations) came into force, and created the procedure applicable to this complaint. These Regulations made detailed provision for the handling of complaints at local level by NHS bodies complained about and, if the complainant was dissatisfied with this local resolution, for the complaint to be given further consideration by the Healthcare Commission. Complaints against primary care providers continue to be dealt with at the local level by practice-based complaints procedures, but likewise move to the Healthcare Commission for the second stage of the process.

*Complaints against NHS bodies*

130 The Regulations (Regulation 3(2)) emphasise that complaint handling arrangements by NHS bodies at the local level must ensure that complaints are dealt with speedily and efficiently and that complainants are treated courteously and sympathetically and, as far as possible, involved in decisions about how their complaints are handled. The guidance issued by the Department of Health to support the Regulations emphasises that the procedures should be open, fair, flexible and conciliatory and encourage communication on all sides, with the primary objective being to resolve the complaint satisfactorily while being fair to all parties.

131 *Part II* of the Regulations (Regulations 3 to 13) sets out the statutory requirements for NHS bodies managing complaints at the local level and deals with such matters as who may make complaints, when they may be made and the matters which may be complained about. A dedicated complaints manager must be identified along with a senior person in the organisation to take responsibility for the local complaints process and for complying with the Regulations. Regulation 13 states that the response to the complaint, which must be signed by the Chief Executive where possible, must be sent to the complainant within 20 working days from when the complaint was made, unless the complainant agrees to a longer period. That response must also inform complainants of their right to refer the complaint to the Healthcare Commission.

*Complaints against GPs*

132 Guidance to GPs is found in the 1996 *Practice-based Complaints Procedures. Guidance for general practices*. This is intended to be a good practice guide and sets out a model for a practice-based complaint procedure with sample resource leaflets and suggested forms. It is not intended to be prescriptive, so the only mandatory part of the guidance is that relating to the national criteria. These criteria, found in paragraph 3.1, are:

- Practice-based procedures should be managed by the practice.
- One person should be nominated to administer the procedure.
- The procedure must be in writing and must be publicised (and should include details of how to complain further).
- Complaints should normally be acknowledged within two working days and an explanation normally provided within ten working days.

133 The aim of the practice-based complaints procedure is to make the process more accessible, speedier and fairer to everyone and to try to resolve most complaints at practice level. Detailed procedures are expected to be workable, flexible and 'user-friendly' for patients and practices alike.

## Complaint handling by the Healthcare Commission

134 Complainants who are dissatisfied with the outcome of their complaint may ask the Healthcare Commission to consider the complaint, and *Part III* of the Regulations (Regulations 14 to 19) sets out the statutory requirements on the Healthcare Commission when considering complaints at this second level.

135 Regulation 16 states that the Healthcare Commission must assess the nature and substance of the complaint and decide as soon as it is reasonably practicable how it should be dealt with '*having regard to*' a number of matters including the views of the complainant and the body or person complained against and any other relevant circumstances. There is a wide range of options available to the Healthcare Commission for dealing with the complaint, apart from investigating it, including taking no further action, referring the matter back to the body or person complained about with recommendations as to action to resolve the complaint, and referring the matter to a health regulatory body.

136 If the Healthcare Commission does decide to investigate, it must send the proposed terms of reference to the complainant and the body or person complained about (and any other body with an interest in the complaint) for comment. Once the investigation begins, the Healthcare Commission has a wide discretion in deciding how it will conduct the investigation (Regulation 17) and this may include taking such advice as seems to it to be required, and requesting (not demanding) the production of such information and documents as it considers necessary to enable it properly to consider the complaint. The Healthcare Commission has established its own internal standards for the handling of complaints and although, for example, the Regulations do not specify the type of advice to be taken the Healthcare Commission has acknowledged the need to seek appropriate guidance from a clinical adviser with relevant experience and expertise. Likewise, although the Regulations set no specific timescales for it to complete the investigatory process (Regulation 19 merely requires it to prepare a written report of its investigation '*as soon as is reasonably practicable*'), the

Healthcare Commission has said that it aims in the majority of cases to take no longer than six months to complete the process.

137 The report produced by the Healthcare Commission at the end of its investigation must summarise the nature and substance of the complaint, describe its investigations and summarise its conclusions, including any findings of fact, its opinion on the findings and the reasons for its opinion, and recommend what action should be taken and by whom to resolve the complaint or otherwise.

# Section 3: the investigation

## Background

138 We have outlined the background to the complaint in Section 1 of this report. We say more about the key events associated with each aspect of the complaint in the relevant sections which follow.

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

### Complaint (a): care and treatment

139 Tom's parents complain about the care and treatment provided for their son by the Surgery. In particular, they consider the Surgery failed to deal adequately with his pain and weight loss and failed to act upon advice to refer him for an endoscopy which they say was made by a consultant at the Hospice. They believe that if their son's weight and pain had been better managed, and the endoscopy had been performed, the course of events might have been different.

#### Key events

140 Penhurst School's healthcare record dated February 2003 says that Tom's bouts of agitation had become more frequent since the beginning of that year and on 5 March 2003, following Mr and Mrs Wakefield's request, the GP wrote to the Hospice about the management of his pain.

141 On 10 March 2003 the Hospice's Medical Director wrote to Tom's parents (with a copy to the GP) saying that their son was probably experiencing background pain from several different sources. He thought that the most likely source was musculoskeletal and that the secondary source was probably his bowels but his gastro-oesophageal reflux was not considered a significant problem at that point. The letter described a stepwise process for testing out different strategies for managing the pain.

142 On 14 July 2003 the Hospice's Medical Director agreed with Tom's parents that clonazepam (a drug used to control muscle spasms and seizures) should be added to the existing prescription of benzodiazepines (drugs used to help relieve muscle spasms). A follow-up letter to Mr and Mrs Wakefield noted that oral morphine had been tried, without success.

143 On 8 August 2003 the Manager of the Vicarage (a respite placement used during school holidays) wrote to Tom's social worker after he had stayed there from 27 July to 4 August 2003. He noted that there had been:

> *'... a marked deterioration since Tom's last stay with us in October 2002. He had lost a considerable amount of weight, was having suppositories or enemas to manage his constipation, and was prescribed more medication for pain relief and muscle spasms.'*

144 He went on to note:

> *'It was obvious from the outset that Tom's needs were more complex e.g. pressure care treatment needed more frequently, methods to be found which would ease/reduce Tom's muscle spasms and aches.'*

145 On 12 August 2003 Tom's social worker noted there was a disagreement between Mrs Wakefield and Penhurst School regarding the prescription for clonazepam. Mrs Wakefield wanted the drug to be used and gradually increased in line with

the Hospice's Medical Director's advice, but the school was reluctant to agree to this because they felt that Tom's behaviour reflected his frustration about being at school rather than his pain. Later the GP said that he had discussed Tom's medication with the Hospice's Medical Director and it had been agreed to increase the dosage of diazepam (another benzodiazepine) instead.

146 In August 2003 the GP decided to ask the Community Learning Disability Team to become involved in Tom's case because he thought this might be helpful in obtaining adult accommodation for him. He wrote a detailed report to the Community Learning Disability Team which referred to Tom's medical history, behavioural problems, gastrointestinal problems and the difficulty of obtaining psychological support. He also described the problem of managing Tom's pain saying:

> *'It is very difficult to accurately assess Tom's pain and in addition to this he is extremely sensitive to pain killers. When we increased the dose of pain killers he went into severe constipation and required admission to hospital for bowel clearance. We are therefore not in a position to use Morphine or strong pain killers for this reason.'*

147 In the report the GP said:

> *'I can predict that Tom will need significantly more medical input in his care in the future than he has required up until now. I would be most grateful if we could strongly consider his medical needs when considering a suitable placement in the near future.'*

148 In September 2003 the GP referred Tom to a newly opened part of the Hospice, so his pain could be assessed while he was an in-patient. The Hospice notes include the following entry:

> *'Phoned* [Tom's GP] *who will arrange upper GI Ix* [gastrointestinal investigation].*'*

149 On 26 September 2003 the Deputy Medical Director of the Hospice wrote to the GP following the assessment. She noted that Tom had had a couple of significant episodes of more severe pain, both of which occurred shortly after meals. She said:

> *'These observations suggest an upper gastrointestinal cause for some of Tom's pain, possibly oesophagitis, oesophageal stenosis or peptic ulcer. We note his past history of pyloric stenosis. As the Hospice's Medical Director discussed, we have initially increased his Omeprazole to 40mg daily, and added in Domperidone 10mg tds* [three times a day] *as a trial* [these are both drugs for controlling acid reflux]. *I gather you are going to consider referral for possible endoscopy to clarify diagnosis.'*

150 An unsigned file note in Tom's health record, dated 17 October 2003 (which the GP thought was made by the school nurse) and titled '*review with* [doctor at the Hospice]', says, '*endoscopy ruled out as thought to be impractical*'.

151 A note for this date in the Hospice health record says:

*'Tom came in for appointment*
*Pain still a problem.*
*Discussed options*
*– GI = would not consider surgery for upper GI problem. Already on maximum drug Px* [prescription]. *Therefore no point in proceeding.'*

152 Tom started receiving morphine in October 2003 when he was in respite care. On 14 November 2003 Mr and Mrs Wakefield contacted the GP about a prescription of morphine by the Hospice's Medical Director. Subsequently, morphine was administered either by the nurses from Penhurst School or, if they were unavailable, by nurses from the Surgery.

153 On 19 November 2003 a speech and language therapist noted that Tom's eating and drinking skills were being compromised by deteriorating health and posture, and were causing concern. The therapist noted that although his swallow was strong he got some '*pooling*' and often had to swallow repeatedly to clear any debris. She also noted that he was becoming distressed during meals, possibly due to pain associated with the movement of food through his digestive system.

154 On 20 November 2003 Tom was admitted to the Windrush Unit.

### Mrs Wakefield's recollections and views

155 Mrs Wakefield said that from 2001 her son's self-harming behaviour had increased. She could understand that his strong personality and his history of self-harming might have led the school to believe that the deterioration in his behaviour was not a response to pain. She said the school staff had strongly indicated to her that he was displaying bad temper because he was bored at school. However, from 2002 his behaviour was much more extreme and it went on for too long for it to be explained as an expression of frustration about still being at school. She said he would wake up from sleep screaming and could only be calmed by being moved to his chair. With hindsight she thought the change in position was reducing the extent of the acid reflux he had been experiencing. She said there were other signs that indicated that he was in pain – he would be tense, sweating and pale. She explained that her son was showing signs of experiencing pain in his sleep and the pain appeared to come in spasms and would wake him up. She described the state of his scalp as '*mute testimony*' to his distress.

156 Mrs Wakefield said she had spoken to her son's GP about pain and the need to investigate its cause on many occasions on the telephone and during the GP's regular visits to Penhurst School. She had raised her concern with staff at the school and the GP that the pain was caused by acid reflux, and was told that this could not be the case because he was on medication. She was concerned that the GP might not have seen her son unless staff had indicated that he should be seen. Mrs Wakefield explained that, in 2003 because of her concerns about her son's pain, she decided to contact the GP direct, as it was clear to her that something was very wrong with him. She said that initially the GP had dismissed her request that her son should be assessed at the Hospice. She said the GP had not thought it appropriate because he was not terminally ill. Mrs Wakefield thought that the GP's view was coloured by the school's view. However, the GP had agreed to the referral.

157 Mrs Wakefield recalled that the doctors at the Hospice had no difficulty in communicating with her son. The consultant there had informed her that his joints were on the point of dislocating which no one had mentioned to her before. Mrs Wakefield recalled that the consultant was also clear that her son was experiencing bouts of severe gastric pain and that this needed to be investigated. She said he had recommended an endoscopy and had indicated that he was surprised that one had not been carried out before. He also recommended morphine for pain relief.

158 Mrs Wakefield said the GP had been reluctant to prescribe morphine. She believed that this was partly because of his concern about the constipating effects of the drug, which she could understand, but she thought that it also stemmed to some extent from personally held views about prescribing controlled drugs.

159 Mrs Wakefield said that in the months before he left school her son's appetite had declined and he had lost a lot of weight. Mrs Wakefield recalled that significant weight loss had been identified while he was in a respite placement, but this observation did not appear to have been acted on. Mrs Wakefield said she discussed her concerns about this with the GP. She had been told that there would be no point in 'tube feeding' because he would have pulled the tube out. Mrs Wakefield explained that because she thought that the GP was referring to nasogastric feeding she had not disagreed with him. She did not realise at the time that the GP was referring to feeding via a percutaneous endoscopic gastrostomy (PEG), which would allow a feeding tube to be passed directly into Tom's stomach or, indeed, that this had been an option.

160 Mrs Wakefield recalled that it had been suggested to her that if her son was receiving morphine, it would have been harder to place him in permanent adult accommodation, although she had subsequently found out that this was not the case. She had concluded that his medical care was being compromised by the Council's need to keep her son at the school as long as possible.

### The Surgery's position

161 The Surgery's position is set out in the GP's letter of 6 January 2003 in which he responded to Mr and Mrs Wakefield's complaint. In that letter the GP described the actions he had taken and the rationale for those actions. He explained his reluctance to prescribe morphine because of its potential side-effects and problems of storing controlled drugs at the school. He also explained the risks for Tom of undergoing an endoscopy.

### The Surgery's response to the Health Service Ombudsman's enquiries

162 My investigator made enquiries of the Surgery and the GP provided further detailed information about Tom's care and treatment. He said he had no special training in the field of learning disabilities although he provided a full GP service to all the children at Penhurst School. He saw every child several times a year for formal review and he had a low threshold for seeing them.

163 The GP recalled that Tom had been very badly afflicted with constipation and that he had spent a lot of time trying to address this condition. He said that in 2003 the symptoms of indigestion were '*fairly well under control*'.

164 The GP said:

> *'At no time did I discount the possibility of arranging an endoscopy but in view of the profound behavioural and physical disabilities suffered by Thomas, I felt it was imperative that the potential benefits of carrying out this procedure significantly outweighed the very considerable possible risks. It is important also to note that Tom's feeding problems were intermittent and often related to those who were involved in the feeding and that the problems experienced whilst he was an inpatient at* [the Hospice] *may well have been because he was in an unfamiliar environment and being fed by people he was not used to.*
>
> *'As the situation stood in September 2003, Thomas had an established diagnosis of longstanding oesophageal reflux, which had been well controlled on standard medication. He had in the past had exacerbations but these had usually settled quickly on conservative treatment.'*

165 The GP said that at the time he was not aware that Mr and Mrs Wakefield were unhappy with the treatment decisions regarding Tom's gastrointestinal problems. He described how he prescribed different drugs to control Tom's symptoms and episodes of indigestion and this treatment was in accordance with assessments and recommendations from the Hospice. He also noted that Tom's parents had remained concerned about the management of their son's pain after the assessment and therefore he had arranged for further spinal X-rays which showed that there had been no specific deterioration since the previous X-ray.

166 With regard to Tom's weight, the GP said that there had been a weight chart in the nursing records at Penhurst School and that it was standard nursing procedure to regularly record the weights of all children at the school. He was confident that had there been any significant ongoing weight concerns, these would have been drawn to his attention. He also said Tom's oral intake had been variable and often had a major behavioural component to it. Although there were periods when his intake had been poor, in general he had a good appetite and was able to take things orally most of the time.

167 The GP said that he had never discounted the possibility that at some stage Tom would need a PEG feeding tube, but this was an option to be considered when oral intake definitely became insufficient. Given Tom's very significant behavioural problems, he felt that had a PEG feeding tube been fitted it was very likely that he would have pulled it out and this would have had significant adverse consequences. He did not recall a prolonged period when Tom's oral intake or weight loss would have merited the insertion of a PEG feeding tube. Therefore, he had not referred him to a specialist.

168 With regard to communication, the GP recalled that he had communicated a great deal with Tom's parents in the weeks between 26 September and 20 November 2003 about issues including pain relief.

169 The GP said that the report from the speech and language therapist would have arrived on the day before Tom was transferred to the Windrush Unit. Therefore, he would not have been in a position to take action in response to its findings.

## The Hospice's Medical Director's response to the Health Service Ombudsman's enquiries

170 My investigator contacted the Hospice's Medical Director – the medical consultant who was the Medical Director of the Hospice at the time of the events complained about. He said he remembered Tom and his family and he had a clear memory of Mr and Mrs Wakefield as loving and dedicated parents. However, given five years have passed since he saw Tom, he said he only had a '*very sketchy*' memory about details of discussions with Tom's GP and his parents about his care and treatment, and prognosis.

171 The Hospice's Medical Director said it was '*quite possible*' that he had suggested the GP prescribe morphine but he did not recall what he had discussed with the GP on this point. He also said he may have discussed whether Tom should have had an endoscopy with the GP, but he was clear that he would not have made an explicit recommendation to this effect. He said if he had suggested an endoscopy it would have been as a way of having some certainty about the diagnosis of oesophagitis. However, he also said Tom would have been a high risk for surgery and whatever might have been found during the examination may not have changed the treatment Tom was receiving. He said he doubted whether Tom would have suffered because he had not undergone an endoscopy.

172 My investigator told the Hospice's Medical Director that Mr and Mrs Wakefield had said he had repeatedly told them Tom was not dying. The Hospice's Medical Director said he doubted whether he would have said this as he was seeing Tom at the Hospice which was a facility which focused specifically on caring for people with life-limiting illnesses. He said he remembered that treating Tom was a matter of achieving a balance to give him the best quality of life. He also said it was inevitable that Tom would die.

## The advice of the Health Service Ombudsman's Professional Advisers

*Pain control*

173 My GP Adviser said that the GP seemed very concerned about Tom's complex problems and had liaised well with the team working at Penhurst School. He said Tom had been admitted to hospital with severe abdominal pain due to constipation on more than one occasion and the GP's concerns about the constipating effects of opioids were reasonable. He noted that it must have been very difficult to establish whether Tom's pain was from his scoliosis, his gut spasms or his oesophagitis. My GP Adviser said that the GP had tried to look at the problem of pain in a holistic way rather than simply increasing the strength of medication to control pain. He also noted that the GP had tried to get psychological advice to help him understand Tom's behaviour and its relationship to pain. My GP Adviser noted that Hospice records for May 2003 stated that the GP '*seems very clued up ... and is very actively involved*'.

174 My Pharmacy Adviser said records showed the GP had taken a reasonable approach to controlling a range of symptoms and this may have reduced Tom's pain. He said:

> '*Clinically, a decision to prescribe opioid analgesia such as MST* [morphine sulphate – a drug to treat severe pain] *for Tom would need to have been taken with great care. Most analgesics ... can have a tendency to cause or to exacerbate constipation. Opioids are particularly renowned for this and Tom was said to have been "sensitive" to the constipating effects of analgesics.*'

175 My Pharmacy Adviser added that it appeared that Mr and Mrs Wakefield were keen for a prescription for an opioid analgesic for Tom and that the GP appeared reluctant to prescribe this because he was concerned about unwanted side-effects which are commonly associated with treatment by opioids. He also noted that when the Hospice had written suggesting opioid analgesia they had cautioned that constipation could be a problem. My Pharmacy Adviser also said there is some evidence that there were difficulties in keeping opioids at Penhurst School. He said this may have been related to a lack of suitable secure storage or of suitable staff to guarantee that doses could be given on time by those legally and appropriately qualified to do so. However, my Pharmacy Adviser noted that by 27 October 2003, a scheme had been devised in which a rota was put in place for doses of MST to be given to Tom by his parents, by a Penhurst School nurse, or by the Surgery.

176 My Pharmacy Adviser said that records show that in April 2003 Tom was tried with an oral opioid but that this was not successful in managing his pain over ensuing months and that clinicians were concerned about exacerbating Tom's constipation. He said that Tom started receiving MST sometime in October 2003, before he was transferred to the Windrush Unit. My Pharmacy Adviser said further adjustments were made to Tom's medication and records from the Hospice suggested his background pain was better controlled at this time.

177 In summary, my Pharmacy Adviser said:

> *'... the GP can be said to have shown reluctance and may have been somewhat slow to respond to suggestions about prescribing opioid analgesics for Tom. However, the evidence, such as it is, points to the fact that he did respond to such suggestions in his own time. Opioid analgesics, when tried, did not always prove to be the panacea that the Wakefields had hoped for and they may have overlooked the comments from the hospice that oral morphine had not been successful when prescribed in the first half of 2003. However, during the period from the end of October to December 2003, MST was being used to good effect.'*

*Tom's weight*

178 With regard to Tom's weight and nutrition, my GP Adviser said people with Tom's type of problems should be weighed at least every two months. He said that he had not found any information in the records to show that Tom had been regularly weighed. He noted that Tom had lost 3.7kg between November 2003 and February 2004 and that photographs showed morphological evidence of weight loss over an 18-month period.

179 My GP Adviser explained that Tom would have been at risk of weight loss, but typically his weight problems would fluctuate. He also explained that monitoring Tom's weight loss was not necessarily the GP's responsibility and it was likely this would have been part of the basic care provided by Penhurst School. My GP Adviser noted that no mention of weight loss had been made at a multidisciplinary case conference held on 13 August 2003, which the GP attended.

180 My First Gastroenterology Adviser noted that a speech and language therapy report dated 19 November 2003, which the GP had not seen, recorded that Tom's eating and drinking skills had deteriorated and had been affected by his worsening general health and posture. He said this indicated that, by this time, Tom's nutritional status had already started to decline.

*Endoscopy*

181 My First Gastroenterology Adviser said Tom had gastric surgery as a young child, and explained that these complex procedures may have resulted in long-term reflux problems, a consequence recognised by the prescription of acid suppressants throughout Tom's life. He explained that oesophagitis and oesophageal ulceration may be intractable due to the difficulty of maintaining an upright posture after meals.

182 My First Gastroenterology Adviser said that, although Tom's general health had been declining during 2003, earlier intervention and diagnosis of his severe oesophageal ulceration may have improved Tom's chances of survival and would have allowed steps to be taken to reduce his upper abdominal pain.

183 My GP Adviser said that a decision on whether or not Tom should be referred for endoscopy was not straightforward. He said the GP had been very conscious of Tom's history and appeared to have felt that endoscopy would not provide any new information. My GP Adviser considered that the GP's explanation about not referring Tom for endoscopy was not unreasonable. He said other clinicians might well have come to a similar view because the risks of carrying out an endoscopy under a general anaesthetic, especially given Tom's spinal problems, potentially outweighed any health gain.

184 However, my GP Adviser said that had he received the letter from the Hospice asking him to consider a referral for endoscopy, although his instinct as GP might have been first to try a slightly more powerful acid suppressing drug, he would have discussed such a decision with his local gastroenterology specialist, before deciding whether to refer or not.

185 My GP Adviser said he could not establish whether the GP had discussed his decision not to refer Tom for endoscopy with Mr and Mrs Wakefield.

## The Health Service Ombudsman's findings

186 Mr and Mrs Wakefield are dissatisfied about the care and treatment provided for their son by the Surgery, particularly in terms of management of pain, monitoring his weight loss and the decision regarding an endoscopy.

*Management of pain*

187 My Professional Advisers have said that the GP's attempts to treat Tom's pain were reasonable. In particular, they drew attention to the GP's holistic approach to managing Tom's pain. This is illustrated by his attempt to get advice from a psychologist to help him understand Tom's distress, his unwillingness to simply increase doses of painkillers and his appropriate concern about side-effects of pain control. My Professional Advisers also noted that the GP referred Tom to the Hospice for assessment of his pain and the Hospice records show that the GP seemed aware of the relevant issues and was actively involved in his care. I also note that the Hospice's Medical Director said he may have suggested the GP prescribe morphine, but that this would have been a suggestion and not an explicit recommendation. I recognise the difficulties faced by the GP and acknowledge the efforts he made to accommodate the views of Mr and Mrs Wakefield and of other doctors, bearing in mind Tom's complex needs and the risks associated with different courses of action.

188 Having studied the available evidence and taken account of the advice provided by my Professional Advisers I am satisfied that the GP's clinical judgments about the management of Tom's pain did not fall below a reasonable standard in the circumstances. Therefore, I find there was **no service failure** in this regard.

*Monitoring Tom's weight*

189 The GP said he was not aware that there were any worries regarding Tom's nutrition and weight and that if the other professionals had concerns they would have brought these to his or Penhurst School's attention. The GP did not think Tom had a prolonged period of weight loss and he had not, therefore, thought it necessary to refer him for a PEG feeding tube.

190 My GP Adviser explained that although patients such as Tom should have their weight monitored regularly because they are at risk of fluctuations in their weight, it was not necessarily the GP's responsibility to ensure weights were recorded. It would have been his responsibility to investigate weight loss had it been brought to his attention. However, I have found no evidence that this was the case. In particular, weight loss was not mentioned at a multidisciplinary meeting about Tom which was attended by the GP. Also, it is unlikely that the GP had seen the speech and language therapy report which raises concerns about Tom's eating and drinking skills because the report is dated on the day before he was transferred to the Windrush Unit.

191 That said, it seems to me it would have been apparent that Tom was losing weight before he left Penhurst School. A photograph of Tom taken when he was 17 years old does not show someone who looked noticeably thin. However, in August 2003 the manager of Tom's respite placement noted he had lost considerable weight over the nine months since October 2002. Also, when Tom was admitted to the Windrush Unit he was described as being '*very slim*'.

192 It is only with the benefit of hindsight that a clear distinction between a fluctuation and a continual downward trend in weight can be identified. Given the risk that Tom would lose weight I can see that the GP could have been more proactive in matters relating to Tom's weight and nutritional status as part of his assessment of his health. However, monitoring Tom's weight was not necessarily the GP's responsibility and there is no record that concerns about weight or nutrition were brought to his attention.

193 On balance, having studied available evidence and taken account of the advice provided by my Professional Advisers, I find there is no evidence that the GP's clinical judgments about the management of Tom's weight and nutrition fell below a reasonable standard in the circumstances. Therefore, I find there was **no service failure** in this regard.

*The decision not to refer Tom for an endoscopy*

194 I have seen no record of any explicit recommendation from the Hospice that Tom should undergo an endoscopy. The Hospice's Medical Director could not recall the precise details of discussions with the GP, but he was clear that it would not have been his practice to make an explicit recommendation that Tom should undergo this procedure. Indeed, he said the purpose of any such investigation would only have been to confirm a diagnosis and that the risks and benefits to Tom would have had to be weighed carefully.

195 The GP has said that he did not refer Tom for an endoscopy because, in his view, the letter from the Hospice had not recommended immediate referral, but had suggested that medication changes should be tried first. The GP informed me that if Tom's indigestion problems had persisted or worsened, he would have discussed the merits of a non-urgent referral for endoscopy with a gastroenterologist. I have no reason to doubt this statement.

196 My GP and Gastroenterology Advisers said, as the Hospice staff had mentioned a referral for an endoscopy, it would have been better if the GP had discussed the matter with a specialist before reaching a decision. My GP Adviser said this is what he himself would have done. However, my GP Adviser also said the GP's reasoning about the risk that endoscopy would pose for Tom was reasonable.

197 Having considered the evidence I cannot see a compelling argument that the GP should have referred Tom for an endoscopy before his move from Penhurst School. There is evidence that the GP considered the options and made an assessment of the risks of the procedure. It seems likely to me that this would have been the approach which, after their discussion and correspondence between clinicians involved in Tom's care, the Hospice's Medical Director expected him to take. Furthermore, I note that the Hospice's Medical Director has said that he did not think Tom would have been disadvantaged because he had not undergone an endoscopy.

198 I am satisfied that the GP's decision not to refer Tom for an endoscopy did not fall below a reasonable standard in the circumstances. Therefore, I find **no service failure** in this regard.

## Complaint (b): complaint handling by the Surgery

199 Mr and Mrs Wakefield remain dissatisfied with the way the Surgery handled their complaint.

### Key events

200 On 27 July 2004 Mr and Mrs Wakefield complained to Oxfordshire PCT that the GP had failed to:

- react appropriately to the signs of Tom's medical condition;
- act on the advice of the Hospice consultant; and
- make urgent referrals for further investigation which meant the causes of Tom's problems were not identified.

201 They said that had these issues been dealt with properly Tom would not have been in pain and the sequence of events would have been different.

202 Oxfordshire PCT passed the complaint to the GP for local resolution and the GP twice (in August and October 2004) offered to meet with Mr and Mrs Wakefield in a conciliation meeting. However, they declined these offers because they said they had not been listened to on previous occasions.

203 On 6 January 2005 the GP responded to the complaint. He gave background information relating to Tom's challenging behaviour, his scoliosis and his gastrointestinal and feeding problems. He also explained the reasons why he was reluctant to prescribe opioid painkillers or refer Tom for an endoscopy. He described how he had taken action in response to Mr and Mrs Wakefield's concerns about Tom's pain, for example organising a spinal X-ray, and how he had responded to the assessments and recommendations from the Hospice, for example by adjusting Tom's medication. He also described how he had responded to Mr and Mrs Wakefield's concerns about provision of adult facilities for Tom by raising the issue in a detailed report to the Adult Learning Disabilities Team in August 2003.

## The Health Service Ombudsman's findings

204 In Section 2 I have described the standards governing the way in which NHS bodies should have handled complaints at the time of Mr and Mrs Wakefield's complaint. I have compared the Surgery's actions with those Regulations.

205 I find the Surgery acted appropriately in offering to try and resolve the complaint at a conciliation meeting. Mr and Mrs Wakefield had known the GP for some years and a face-to-face meeting would have been an appropriate way to try and resolve their concerns.

206 I find the GP's response addressed all the key issues in the complaint and provided an appropriate level of detail and explanation.

207 It seems the GP received the complaint via Oxfordshire PCT some time in August 2004 but did not respond in writing until 6 January 2005. Generally, I would consider this delay was unreasonable. However, I note that in this case the GP had twice offered to meet with Mr and Mrs Wakefield to discuss and resolve their concerns. When they declined these offers he responded in writing.

## Complaint handling by the Surgery: the Health Service Ombudsman's conclusion

208 In terms of complaint handling, I find the Surgery acted in line with the Regulations and demonstrated reasonable practice as set out in my *Principles of Good Administration*. Despite the delayed response I conclude, on balance, any shortcomings in the way in which the Surgery responded to Mr and Mrs Wakefield's complaint **do not amount to maladministration**.

## The complaint against the Surgery: the Health Service Ombudsman's conclusions

209 I find 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 below a reasonable standard in the circumstances. I find **no evidence of service failure** by the Surgery. I have considered the way in which the Surgery responded to Mr and Mrs Wakefield's complaint and I find **no evidence of maladministration**.

210 Therefore, I **do not uphold** Mr and Mrs Wakefield's complaint against the Surgery.

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

### Complaint (c): the actions of the Council

211 Mr and Mrs Wakefield complain that the Council failed to plan for, or commission, new provision for Tom, or to deal appropriately with his transition into adult accommodation. They said Tom's social worker had failed to pass on information regarding the offer (in October 2003) of a suitable permanent placement for Tom. They also complain about the way the Council responded to their complaints about Tom's transition to adult care. Although their complaint was investigated at Stage 2 of the Council's complaints procedure, Mr and Mrs Wakefield consider that they still lack an adequate response and remain uncertain of the actions taken by the Council in the light of its investigation.

#### Mrs Wakefield's recollections and views

212 Mrs Wakefield said it had been her understanding that a referral to Adult Social Services could not be made until Tom reached 17½ years old. Tom's previous social worker had done a lot. However, the new social worker who took over in February 2003 had not met with Tom until he had been in charge of his case for some considerable time. Mrs Wakefield said she could not see how he could possibly assess Tom's needs, or work effectively on his case, without meeting Tom. She said she had had great difficulty getting hold of the social worker as he never appeared to be on the end of a telephone.

213 Mrs Wakefield said she and Mr Wakefield had set out 'a hierarchy' of what they considered Tom's needs to be. They knew that it was unlikely that they would find somewhere that would meet all his needs; they had therefore indicated that they were prepared to be flexible. Despite this, they felt the social worker had made assumptions about the kind of accommodation they would accept.

214 Mrs Wakefield said it was untrue for Social Services to say that the family had turned down suitable placements for Tom. One placement had been offered in a Huntington's Chorea unit (an inherited disorder that leads to loss of control of movement and changes in personality). They felt there was a risk that Tom might be physically harmed by one of the patients there, all of whom were considerably older than Tom. The second place was too far away.

215 Mr and Mrs Wakefield were very angry that Social Services had not informed them about a suitable placement which had become available in October 2003. Mrs Wakefield had only learnt about the offer when the organisation concerned had written to her in January 2004. They also told her that Social Services had been notified of an offer in October 2003. She was certain that if Tom had been taken out of the environment he was in at this time, the course of events would have been different.

216 She thought it odd that Tom was judged to need a medical assessment 21 days into the notice period that the school had given. She said that if a medical assessment was genuinely required, this should surely have been identified earlier.

217 Mrs Wakefield said that, in her opinion, it was well known that Social Services in Gloucestershire were operating on a crisis management basis. It had been in Social Services' interests for Tom to remain at the school as long as possible because this delayed the need to find a placement for him.

218 Mrs Wakefield was unhappy that the Social Services Stage 2 investigation had not upheld the complaint that Tom had been 'placed' at the Windrush Unit. She considered that the matter had been glossed over on a technicality. She did not consider that the recommendations went far enough to prevent a recurrence.

219 Mrs Wakefield did not think that the other recommendations made in the Social Services' report had been implemented. The Council was still purchasing places and not actively trying to resource vacancies. Only two part-time transition workers had been appointed despite the commitments set out in the report. Mrs Wakefield wanted the people concerned to acknowledge and apologise for their failures, and the part they had played in contributing to the course of events.

## Evidence from the Council's records

220 In April 2002, when Tom became 18, his case was transferred from the Council's Children and Families Service to its Adult Learning Disabilities Team. Tom was allocated a specialist social worker but he left the service in December 2002. In his transfer summary he recorded that he had been working on two objectives: to identify appropriate respite placements for when the school was closed and to identify appropriate accommodation for Tom when he was due to leave the school. Other than this it seems that no specific plan of care had been drawn up.

221 A new social worker was appointed for Tom in February 2003.

222 It is unclear when exactly the search for appropriate accommodation for Tom started. Mr and Mrs Wakefield informed the investigator who conducted the Stage 2 investigation that Tom's social worker was looking for permanent accommodation some time before March 2002. Information made available by the Council to the Stage 2 investigation clarifies that during 2002 suitable establishments as opposed to actual placements were being sought. The records indicate that there was no specific activity between 21 December 2002 and the new social worker's visit to Mr and Mrs Wakefield on 27 February 2003, when their hierarchy of needs regarding a suitable placement for Tom was discussed.

223 Tom's social worker noted a discussion with Mrs Wakefield on 8 August 2003 in which she said she had been very impressed with an independent provider that might be able to offer accommodation to Tom in October, and that she would consider the placement should it arise.

224 On 3 October 2003 Penhurst School informed the Community Learning Disability Team that it was giving six weeks' notice to terminate Tom's placement, because Tom was not tolerating school.

225 On 23 October 2003 Tom's social worker was contacted about the offer of a residential place to Tom, by Voyage, an organisation that Mrs Wakefield had said she would consider. Mrs Wakefield did not become aware of this until January 2004, when the organisation concerned wrote to her, following her enquiries about vacancies. Voyage said:

*'I spoke to* [Tom's social worker] *on 23 October 2003 to apprise him of the situation at our small home in* [Somerset] *making* [him] *aware that we had a vacancy at this property which had the potential to provide for your son with relative immediacy.* [The social worker] *informed me during this conversation that Tom's needs had deteriorated and that he would need nursing care, that he was using morphine and* [a placement in Warwickshire] *was being considered.'*

226 In July 2003 it was noted that all of Tom's needs could be met by carers with the exception of pain relief and gut function, which needed to be carried out or monitored by a Registered Nurse. By the time of the assessment carried out in October 2003, there was a much higher need for nursing input into Tom's care. The difference of opinion between Penhurst School and Mrs Wakefield about the cause of Tom's self-harming behaviour was noted.

227 In summary, the social worker's records noted that from October 2002 Tom's scoliosis was worsening and pain medication was being administered. The community nurse from the Community Learning Disability Team had carried out an assessment of care needs in July 2003, and had noted that '*Tom's major need is for pain relief which is constantly being reassessed ... This is due to scoliosis*'.

228 On 13 November 2003 an urgent email was sent from the Community Learning Disability Team's manager to the Consultant in Charge at the Windrush Unit. It noted that a meeting had been held with the Consultant in Charge on 10 November 2003, to discuss the possibility of Tom '*coming in to Windrush on a short term basis for further assessment with a view to moving on to a longer term home*'. The email acknowledged that this would not be easy for the Windrush Unit given that their current brief was to vacate beds. The Windrush Unit would need reassurance that Tom would not become a 'bed blocker'. The email reiterated that the Windrush Unit appeared to be the only short-term option left. It said that Social Services would fund supplementary staff to cater for Tom's social care needs and that:

*'Strenuous efforts would be made to find placements to relocate some of your other Windrush patients and it would be very helpful if you can identify one or two that we could realistically focus on as a start – ones who would be easiest to move on, so we can practically make a start ASAP.'*

It was also noted that the Council had been trying hard to find long-term solutions for Tom and would continue to do so. It was proposed that a meeting be set up (to include Mr and Mrs Wakefield) to clarify how Social Services commissioning staff would work with health staff.

229 The email concluded:

*'We will continue to be jointly committed to looking at the long term solution for Tom and will be active in this, bearing in mind that it is understood that a Windrush admission would be temporary and for assessment and treatment only.'*

230 Tom was admitted to the Windrush Unit on 20 November 2003.

231 On 23 December 2003 the Social Services Joint Commissioning Manager (the Joint Commissioning Manager) responded to Mr and Mrs Wakefield's concerns about the failure to provide suitable permanent accommodation

for Tom. He noted Tom was in an appropriate placement and it had been agreed at the meeting held on 18 November 2003 that his stay at the Windrush Unit would allow for an assessment of his pain which, it had been agreed, was a top priority.

232 He said that in planning for people with disabilities, Social Services duties and obligations were discharged in a number of ways depending on individual circumstances, and that there was little direct provision of residential services:

> *'We purchase the services that we need, at the time that we need them, from the private, voluntary and independent sector. Our long term planning tends to be for sections of population rather than on an individual basis.'*

233 He noted that Mr and Mrs Wakefield's letter had alluded to the creation of a project team to create a facility for people with profound and multiple learning disabilities. The Joint Commissioning Manager said Social Services had a number of successful projects providing housing and services to people with profound and multiple learning disabilities, including working with housing and health authorities in the creation of such places. However, he said such projects took a long time to set up and that the last one had taken five years to complete.

234 He went on to note that Social Services now needed to create a new strategy for people with learning disabilities, taking into account the direction outlined in Valuing People. The approval of the Joint Commissioning Strategy Group would be needed before any new projects could be set up.

## The Council's investigation

235 In January 2004 Mrs Wakefield complained about the Council's planning of Tom's transition to adult care. The complaint was initially investigated by a customer relations officer. Subsequently, the complaint was investigated by an independent investigator (the Independent Investigator) at Stage 2 of the Social Services complaints procedure. The Independent Investigator met with Mr and Mrs Wakefield in March 2004 and then again in July and September 2004.

236 In July 2004 Mr and Mrs Wakefield informed the Independent Investigator that they wanted the investigation to consider the following:

- A failure to plan or commission provision.
- A failure to deal with transition.
- Significant Social Services failings in the handling of Tom's case.
- An inappropriate placement (the Windrush Unit).
- A failure to investigate Tom's physical problems.
- A failure to provide a specialised NHS assessment for profound and multiple learning disabilities.

They said they considered the authority had acted in a way that was contrary and damaging to the best interests, rights and life chances of a person with profound and multiple learning disabilities and his family.

237 The Independent Investigator interviewed Social Services staff, independent providers, another service user, and Mr and Mrs Wakefield. He examined the Social Services files for Tom, correspondence from Mr and Mrs Wakefield and the national guidance and standards, including Valuing People, Social Services Inspectorate inspection criteria, the Government's (2003) *Care Homes for Adults (18-65)*, the 2004 report of the Learning Disability Taskforce, which was set up after the publication of Valuing People, and the Council's Transitions Protocol (June 2002) for the transfer of young people with disabilities from children and families to adult care.

238 The report was issued in October 2004.

239 The Independent Investigator noted the standards set out by the Social Services Inspectorate in 1998 in *Moving into the Mainstream*. These said that Social Services departments should:

- regularly collect and distribute aggregate information about the numbers and needs of people with learning disabilities as well as information on resources, budgets and expenditure on services for people with learning disabilities;
- collaborate with other Council departments and organisations in preparing plans for services for people with learning disabilities;
- plan to address the needs of people in transition; and
- adopt a proactive approach to managing the market in relation to local services for young people with learning disabilities.

240 The Independent Investigator noted the Social Services Inspectorate standards that prevailed at that time also specified that:

- an effective commissioning strategy should be in operation which was responsive to changing and diverse population needs;
- the range of services available should be sufficiently broad and varied to meet service user and carer needs, take account of their preferences and achieve a balance of quality and coverage;
- arrangements for referral, assessment, care planning and monitoring and review should be convenient, timely and responsive to individual needs, preferences and ethnic diversity; and
- councils should work with partners to commission and deliver services that were responsive to individuals, safe and reliable, and offer a good range of choices.

241 The Independent Investigator said that he had been informed by the Council's interim Joint Commissioning Manager that:

- the Council did not have a commissioning strategy but was developing one;
- there were particular gaps for people with profound and multiple learning disabilities and challenging behaviour. The market was currently being mapped to assess the need for specialist services. Among the actions under consideration was to seek first refusal on placements arising in the county; and
- transition arrangements had been poor with information not being shared.

242 The Independent Investigator noted that in June 2002 the Council had adopted a new Transitions Protocol. However, Tom had already reached 18 and the new protocol could not be applied retrospectively. The Stage 2 report set out information about assessments of Tom's needs during 2002-03. The Independent Investigator noted that he could not investigate the medical treatment or the actions of health professionals as this lay outside the jurisdiction of the Social Services complaints procedure; he had therefore focused on whether Social Services had identified Tom's needs appropriately.

243 The Independent Investigator noted that Tom's worsening health had been reflected in four joint assessments of care needs completed by health staff between November 2002 and November 2003. The files also contained a series of reports on Tom's other care needs completed by school staff and others, which indicated an increasing need for medical input into Tom's care.

244 The Independent Investigator noted Tom's social worker had started looking for suitable establishments for Tom some time before March 2002. He left and a new social worker was allocated to Tom in February 2003. The new social worker informed the Independent Investigator that the Council did not have a list of providers that might be able to meet Tom's complex needs and that initially he had restricted his search to homes which offered nursing care. In June 2003 Mrs Wakefield had expressed her unhappiness with this approach, so he widened his search to include establishments that only provided residential care. The social worker had said it was good practice to anticipate future needs and in his opinion Tom's needs would be likely to require nursing care in the near future.

245 The social worker informed the Independent Investigator that he had looked at trade magazines, the internet and the National Care Standards Commission's website for a list of establishments able to offer care for people with learning and physical disabilities. He had also contacted two home-finding agencies and an association of care home providers as well as speaking to colleagues. He estimated that he had made approximately 95 telephone calls to try to find a placement for Tom.

246 The social worker had identified two potential placements, both of which Mr and Mrs Wakefield considered unsuitable because of their distance from the family home. Additionally, Mr and Mrs Wakefield said the vacant accommodation in the first placement was on the second floor, which meant it would have been difficult and time consuming for staff to take Tom out. Regarding the second placement Tom would have been the youngest resident by 25 years.

247 Mr and Mrs Wakefield had themselves identified two potential placements. The first declined to offer a place to Tom because of his self-harming behaviour. Mr and Mrs Wakefield were impressed by the second establishment and, on being informed that another vacancy might arise in the autumn of 2003, they informed Tom's social worker that they were happy in principle for Tom to move in should the place become available for him.

*The Council's Stage 2 investigation findings*

248 The Independent Investigator did not comment on the heads of complaint that involved clinical issues as these fell outside his remit.

249 The Independent Investigator found that no plans had been made for Tom's future accommodation other than to purchase such accommodation as it became available. Consequently, it had taken nearly two years to find Tom accommodation. He upheld the complaints that there had been a failure to plan for or commission new provision, and failure to deal with Tom's transition.

250 He did not uphold the complaint that there had been a failure to fully assess Tom's needs, as there were a number of thorough assessments, including joint assessments, on file.

251 The complaint that there had been significant Social Services failings in the handling of Tom's individual case was upheld. The Independent Investigator found that the Council's search for accommodation had been ineffective because there was no specific commissioning plan for Tom that took account of the way the market worked. The Independent Investigator found that neither the social worker nor the manager of the Community Learning Disability Team had notified the assistant team manager who was actively involved with Tom's case, or Mr and Mrs Wakefield, about the vacancy that became available in October 2003.

252 The Independent Investigator said that although it was clear that the Windrush Unit had been regarded as somewhere to 'place' Tom, it was in fact an NHS assessment unit and Tom had finally been admitted for medical assessment. He could not make any findings about this as he could not consider medical issues. Also, he noted that the Council had not technically made a placement as it had not funded care for Tom. However, the Independent Investigator recognised that the correspondence between the Council's staff and Mr and Mrs Wakefield did not acknowledge that there had been two reasons for Tom's admission: assessment and the fact that he was facing homelessness. In his view, therefore, the correspondence could be interpreted as being '*a less than accurate statement of the circumstances*'. The Independent Investigator said it was hard to criticise Social Services for Tom's admission to the Windrush Unit, given that there was no other place for Tom to go, and that extra effort had been made to try and meet Tom's needs while he was there.

253 The Independent Investigator said the PCT and Social Services had failed to plan for Tom's transition and had not been able to meet his needs in a reasonable time. However, he did not think that the Council had acted in a way that was contrary to the best interests, rights and life chances of a person with profound and multiple learning disabilities and his family. The Independent Investigator considered the lack of accommodation for Tom and uncertainty about his future added to the distress caused by his worsening condition.

254 The Independent Investigator went on to note that '*the Council appears to be planning in earnest to improve the situation*' and that he understood that '*transitions workers are to be appointed to work specifically with young people with disabilities*'.

255 He made the following specific recommendations:

> '...
>
> *i. While the authority's efforts remain focussed on purchasing for young people like Tom it should ensure that it receives vacancy bulletins from those local providers who produce them.*

*ii. To correct any misunderstanding resulting from the Joint Commissioning Manager's correspondence, the authority should acknowledge that Tom's admission to Windrush was a way to accommodate him, not simply as a period of assessment.*

*iii. The authority should acknowledge that it had been unable to meet the needs and reasonable expectations of Tom and his family in the provision of accommodation.*

*iv. The authority should apologise for the failure to pass on details of the Voyage placement.'*

256 The Independent Investigator concluded:

*'I have attempted to fairly decide these complaints assessing each on its own merits and I have not upheld all of them. The danger of this approach is that it may detract from my overall view on this complaint. I believe that Tom Wakefield and his family were entitled to expect that accommodation would be available within a reasonable time to meet Tom's needs and reasonable aspirations and without prolonged uncertainty. I believe that the authority failed to deliver this.'*

and

*'Clearly, the family have been through a harrowing time. I have been taken aback by the descriptions of Tom's condition when he was admitted to Windrush and his condition at the end. As a Social Work professional Mr B told me he was shocked by Tom's appearance and injuries when he saw him at Windrush. I can only imagine the distress caused to the family.'*

*The Council's response to the Stage 2 investigation report*

257 The Head of Adult Care Services wrote to Mr and Mrs Wakefield on 29 October 2004, enclosing a copy of the Stage 2 investigation report. She said it was clear that Mr and Mrs Wakefield had been through a very distressing time and that '*our failure in our ability to support you in, both finding a suitable placement for Tom, and in managing his transition from the Children and Families Service into Adult Services, has clearly contributed to your distress. I would like to extend my deepest apology for this*'.

258 She also said she agreed with the conclusion that both Tom and his family were entitled to expect that accommodation would be provided in a reasonable time and the Council had failed to deliver this. She went on to reassure Mr and Mrs Wakefield that the Council was committed to developing a commissioning strategy for people with learning disabilities, and that it was currently completing a mapping exercise to determine the need for specialised services.

259 She concluded by confirming that she was happy to accept all of the recommendations and apologised for the failure to pass on details of the placement that became available in October 2003.

260 Mr and Mrs Wakefield were exhausted and therefore decided not to pursue their complaint to Stage 3 of the Social Services complaints procedure. Following a second complaint to Social Services, which is not part of this investigation, Social Services staff met with Mr and Mrs Wakefield and asked if they wished to be involved in the development of the Joint Commissioning Strategy and to attend the Learning Disability Partnership Board. They declined.

261 The Council informed the Local Government Ombudsman that the following action has been taken as a consequence of Mr and Mrs Wakefield's complaint:

- A Learning Disability Joint Commissioning Strategy has been completed and signed off. A copy has been made available to the Local Government Ombudsman.
- The transitions policy is currently being revised, in the light of an initial pilot which had shown that the link to education services was not robust enough; a copy of the project plan has been forwarded to the Local Government Ombudsman and the Council confirmed that all milestones have been met.
- A transitions worker post had been established in the Children with Disabilities Team.
- Updates from providers with vacancies are faxed through to the team on a regular basis.
- A joint commissioner/provider group has been established and meets regularly.
- The block contract for the provision of residential care has been re-let to a new provider who was working with the Council to develop a wider range of provision for adults with learning disabilities.
- Independent sector providers are now standing members of the Learning Disability Partnership Board.
- The Council has increased the contracted service provision for people with profound and multiple learning disabilities.
- Commissioners are working with other regional commissioners to build more robust relationships with residential colleges and the Learning and Skills Council to improve transitional arrangements.
- Clear guidance has been given to all staff about the right of individuals and their nominated representatives to have access to information held about them.

262 The Local Government Ombudsman was also informed that the Children and Young Persons Department has a new field team structure with two teams, managed separately. One team is responsible for core assessments and section 17 (children in need) activity. The second team is responsible for transitions, looked-after children and short-term breaks. There is a part-time deputy manager for the transitions function, supported by two full-time transitions social workers and one family support assessor.

263 The Council said that to date it had secured 20 additional residential beds for people with profound and multiple learning disabilities, with more coming on line in 2008.

## The Local Government Ombudsman's findings

264 There is extensive legislation and guidance setting out the responsibilities of councils for assessing and arranging appropriate care for those who require community care.

265 Government policy guidance emphasises the importance of collaboration between agencies and the need for care plans to be person-centred. Valuing People emphasises the need for an anticipatory and person-centred approach to care planning in the provision of services for learning-disabled people. Valuing People also requires councils to establish Learning

Disability Partnership Boards and to take the lead role within these boards for ensuring that appropriate plans are drawn up and provision made for people with learning disabilities to whom councils had a duty of care.

266 I consider the Independent Investigator conducted a thorough Stage 2 investigation and quite properly did not consider matters about healthcare which lay outside the Council's remit.

267 In the course of the Stage 2 investigation the Council acknowledged that there was no commissioning strategy in place, there were gaps in its plans for people with profound and multiple learning disabilities and challenging behaviour and that transition arrangements had been poor, with information not being shared. It is clear that the Council had not met the relevant Social Services Inspectorate criteria. That was **maladministration**.

268 The offer of a place for Tom, in a home that Mrs Wakefield had indicated she would probably accept, came at around the time when Tom was given notice to leave by the school. Like the Stage 2 Independent Investigator I do not understand how such an opportunity was missed to pursue the suitability and availability of such an offer, given Social Services were well aware that there was an urgent need to find appropriate accommodation for Tom, and that Mr and Mrs Wakefield would be happy with the placement. I note that no record exists of this offer in Social Services' files. I conclude that there was a serious failure on the part of Social Services to manage Tom's transition in this respect, and that was **maladministration**. I conclude that to some extent the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons, in that transition planning to meet his needs was inadequate.

269 Mrs Wakefield informed the Local Government Ombudsman that Social Services were operating on a crisis management basis and that the school's agreement that Tom could stay until he was 20 meant finding provision for him ceased to be an immediate priority. It is clear that the school's decision to ask Tom to leave caught Social Services unprepared, as indicated in the email of 13 November 2003. This finding is supported by the fact that the apparent need for medical assessment arose only just before he was due to have to leave the school. The email went on to note that Social Services understood Tom's admission would pose difficulties for the Windrush Unit and reassurance would be wanted that Tom would not become a 'bed blocker'. I consider this email clearly indicates that the Partnership Trust did not regard the Windrush Unit as a provider of accommodation for clients such as Tom. Therefore, the Windrush Unit had not been considered for either a placement or assessment prior to the school giving notice. I consider the email also indicates that people's placements, including Tom's, were determined by what was available, and not on a person-centred basis. That was **maladministration**.

270 I therefore consider the Stage 2 Independent Investigator's decision to uphold the complaints that there had been a failure by Social Services to plan for or commission new provision to deal with Tom's transition and that there had been significant failings in the handling of Tom's individual case was reasonable.

271 In light of the fact that several joint assessments by Social Services had been carried out during the period from November 2002 to November 2004, I agree with the Stage 2 Independent Investigator's decision not to uphold the complaint about lack of appropriate assessments.

272 Because of his imminent homelessness and because admission to the Windrush Unit would allow for a comprehensive assessment of his health and social care needs, the Stage 2 Independent Investigator did not uphold the complaint that it was inappropriate to have placed Tom at the Windrush Unit. However, he concluded that the admission to the Windrush Unit had served a dual purpose and that this had not been fully acknowledged in the correspondence with Mr and Mrs Wakefield. The email of 13 November 2003 supports this view. It is clear that the Windrush Unit was being considered when Tom's notice to leave was about to expire. Due to Social Services' failure to properly deal with the offer of a suitable place made in October 2003, Tom had no other place to go. I am concerned to note therefore that the Council's letter of apology following the Stage 2 investigation report did not specifically acknowledge the Independent Investigator's view on this matter.

273 The Stage 2 Independent Investigator did not uphold the complaint that the PCT and Social Services had acted in a way that was contrary and damaging to the best interests, rights and life chances of an individual with profound and multiple learning disabilities and his family because this aspect of the complaint was about the consequences of a deficiency in planning for Tom. His view was that Social Services had not acted contrary to Tom's best interests but had not been able to meet his needs in a reasonable time because of a failure to plan properly for his future. I have been unable to find any evidence that there was any intention on the part of Social Services to act in a way that was contrary to Tom's and his family's interests. Assessments were carried out and some efforts were made to find accommodation for him, albeit in an unplanned and unstructured way with poor liaison and communication with other relevant organisations. Therefore, I consider the Stage 2 Independent Investigator's decision on this matter to be reasonable as far as it went.

## Injustice

274 I am pleased to see that Social Services agreed to implement the Independent Investigator's recommendations. The action that the Council has taken has been carefully examined and has been found to be robust. In view of this, there is nothing further I can suggest that would add any more value to the action already taken.

275 I am also pleased to see that the Council subsequently offered Mr and Mrs Wakefield the opportunity to be part of the development of the Joint Commissioning Strategy and to attend the Learning Disability Partnership Board. I regard this as appropriate.

276 However, I find that further consideration needed to be given to the consequences for Tom of Social Services' failure to plan effectively and make provision for his transition to Adult Services, including their failure to act on the offer of a suitable placement which was made in October 2003. It is not possible to establish what might have happened to Tom had he moved to this placement. I cannot know whether staff there would have taken different action to identify and manage the cause of his pain and declining health. Tom's family will never know if his prospects and his life would have been improved if Social Services had planned efficiently for his transition to Adult Services, had made proper provision for him and had pursued the placement offer made in October 2003. I consider this unanswerable question will remain a source of distress for Mr and Mrs Wakefield and I **uphold** this complaint to this extent and recognise that there is **unremedied injustice** for Mr and Mrs Wakefield.

277 We say more about injustice in Section 4 of this report.

### The Local Government Ombudsman's recommendations

278 I **recommend** that the Chief Executive of the Council apologise to Mr and Mrs Wakefield for the failings I have set out in this report.

279 I also **recommend** that the Council offer compensation of £5,000 to Mr and Mrs Wakefield in recognition of the injustice they have suffered in consequence of the maladministration I have identified.

### The Council's response

280 The Chief Executive of the Council acknowledged the failings identified in this report and unconditionally expressed his sincere apologies to Tom's family. I have outlined above some of the actions taken by the Council in respect of its failings in this case. In particular, I note the commitment to implement the recommendations made by the Council's Independent Investigator and the offer to involve Mr and Mrs Wakefield in commissioning and planning activity. I have already commented that I find these actions are appropriate and I am reassured that lessons have been learnt from this case. The Chief Executive told me about further recent actions by the Council. He also accepted my recommendation regarding a compensation payment.

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

## Complaint (d): the actions of the PCT

281 Mr and Mrs Wakefield complain that the PCT failed to liaise appropriately with the Council in planning for Tom's transition into adult accommodation.

282 National legislation, policy and guidance make clear that the PCT had its own responsibilities both as a commissioner and as a provider of health services, including for people with learning disabilities.

### The PCT's position

283 In correspondence the PCT acknowledged that at the time of the events described in this complaint:

- it did not have a joint commissioning strategy for services for people with learning disabilities;
- there were weaknesses in clinical governance arrangements;
- it did not have arrangements in place in line with all the relevant guidance;
- there were weaknesses in staff training; and
- health facilitators were not in place.

### The actions of the PCT: the Health Service Ombudsman's findings and conclusion

284 The lead responsibility for planning and making provision for Tom's transition to appropriate adult care lay with the Council. However, the extensive legislation and national guidance show that the PCT had its own responsibilities both as a commissioner and as a provider of health services. In particular, the PCT had a duty to commission health services that met nationally expected standards for all its population, including people with learning disabilities.

285 The PCT has confirmed that at the time of the events complained about, there were shortcomings in its planning for the needs of people with learning disabilities and it did not have arrangements in line with all the relevant guidance and responsibilities at the time. Although there was some input from the Community Learning Disability Team, health facilitators were not available.

286 Had the PCT fulfilled its own responsibilities in accordance with its legal obligations and in line with national policy and administrative guidance, there can be no guarantee that appropriate adult accommodation for Tom would have been found which addressed his complex health needs at the time he needed it. Nevertheless, the PCT's failure to fulfil its responsibilities in relation to people with profound and multiple learning disabilities meant the chances of Tom making an effective transition to adult accommodation were significantly diminished. Without the systems and structure in place, any attempt by the PCT to liaise appropriately with the Council in planning Tom's transition into adult accommodation was virtually bound to fail. Tom had complex needs related to his learning disability and the PCT failed to provide a service which met those needs. Therefore, I conclude there was **service failure** by the PCT and that this failure was for disability related reasons.

## Complaint (e): complaint handling by the PCT

287 Mr and Mrs Wakefield remain dissatisfied with the way the PCT handled their complaint.

### Key events

288 On 21 January 2004 Mr and Mrs Wakefield complained to the PCT that it had failed to liaise appropriately with Social Services regarding the need to properly plan for and provide an adult placement for Tom.

289 On 29 January 2004 the PCT acknowledged Mr and Mrs Wakefield's complaint but it did not formally respond to the complaint until prompted to do so by the Healthcare Commission. The PCT has explained that it knew the Partnership Trust and Social Services would be responding to similar complaints from Mr and Mrs Wakefield and, therefore, it felt it could add little to the responses produced by them.

290 On 12 June 2006, in response to the Healthcare Commission's recommendation, the PCT wrote to Mr and Mrs Wakefield and apologised for its failings. It said that as a result of events complained about lessons had been learnt and protocols had been amended.

### Complaint handling by the PCT: the Health Service Ombudsman's findings and conclusion

291 In Section 2 I have summarised the Regulations relating to the way in which NHS bodies should handle complaints. I have compared the PCT's actions with those Regulations.

292 Although I can understand why the PCT considered it could add little to responses which it knew were to be provided by the Partnership Trust and Social Services, this did not absolve it of the responsibility to respond to the complaint itself. It was not acceptable that Mr and Mrs Wakefield had to wait over two years for a response from the PCT. This was **maladministration**.

### Complaint against the PCT: the Health Service Ombudsman's conclusion

293 On the basis of evidence available to me and in the light of additional information provided by the PCT, I conclude that for disability related reasons the PCT's actions in relation to arranging an adult placement for Tom amounted to **service failure**. Furthermore, there was **maladministration** in the way it handled Mr and Mrs Wakefield's complaint.

### Recent action by the PCT

294 The PCT informed me of action it has taken to address the service failings in this case. It said it had taken action:

- to give patients and their carers a 'stronger voice' by, for example, improving advocacy services and involving users in the Learning Disability Partnership Board;
- to develop a joint commissioning strategy and change action plan which included review of services and wide consultation with locality groups and the Learning Disability Partnership Board; and
- to improve operational and management processes by, for example, agreeing a multi-agency transition pathway and setting up an exceptional needs panel focusing on joint decision making for funding and placements.

### Injustice

295 I have taken into account these recent actions by the PCT to improve services. However, the fact remains that at the time Tom needed help from the PCT he did not receive a reasonable standard of service. Although the Council had lead responsibility for planning for transition to adult care, we cannot know what difference it would have made to Tom and his family in terms of securing appropriate accommodation if the PCT at the time had fulfilled its responsibilities to people with profound and multiple learning disabilities. This unanswered question remains a cause of distress for Mr and Mrs Wakefield which has yet to be acknowledged and is, therefore, an **unremedied injustice**.

296 Therefore, I **uphold** Mr and Mrs Wakefield's complaint against the PCT.

297 We say more about injustice in Section 4 of this report.

### The Health Service Ombudsman's recommendations

298 I **recommend** that the Chief Executive of the PCT apologise to Mr and Mrs Wakefield for the failings I have set out in this report.

299 I also **recommend** that the PCT offer compensation of £5,000 to Mr and Mrs Wakefield in recognition of the injustice they have suffered in consequence of service failure and maladministration I have identified.

### The PCT's response

300 The Chief Executive of the PCT has asked me to place on record his sincere regret and unqualified apology to Mr and Mrs Wakefield for their suffering and distress. He told me the PCT unreservedly recognises its failures in this case and is committed to treating my report as a learning opportunity. I have outlined above some of the actions already taken by the PCT to address its service failings. The Chief Executive also accepted my recommendation regarding a compensation payment.

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

## Complaint (f): care and treatment at the Windrush Unit

301 Mr and Mrs Wakefield complain that Tom's admission to the Windrush Unit was inappropriate and that while there he received inadequate care and treatment. They complain specifically that the Partnership Trust did not investigate an injury to Tom's ear, that he was generally at risk and he was in a poor physical environment. They also complain that Tom's discharge from the Windrush Unit was badly managed.

### Key events

302 The Windrush Unit was a ward-based facility providing physical and mental assessment for adults with learning disabilities. People would usually be admitted for about 12 weeks. During that time an assessment would be made of all the factors thought to be affecting an individual's mental or physical state. By the point of discharge a patient should have had an established plan to inform their continued care and treatment.

303 On 20 November 2003, following a short assessment to determine his suitability, Tom was admitted to the Windrush Unit.

304 On admission the Consultant in Charge noted that Tom:

> *'... had shown a change in his presentation over the preceding 18 months ... thought to be related to increased pain, that set off a chain of deteriorating events with increasing self-injurious behaviour and increasing medication which may itself have been contributing to rather than improving the problems.'*

305 She set out a detailed plan for the assessment of Tom's needs, as follows:

> *'Physical assessment including full phlebotomy (blood testing).*
>
> *'Baseline monitoring to be carried out by nursing staff including:*
>
> - *weigh weekly;*
> - *twice daily pulse, temperature and blood pressure;*

- *chart sleep, bowels, bladder and diet.*

*'Referral to multi-disciplinary team including:*

- *Psychology team;*
- *SALT (Speech and Language Therapist), (for communication and swallowing);*
- *Dietician, diet and bowel function;*
- *OT (Occupational Therapy) for skills and activity;*
- *Physiotherapy ROM exercise recommendations, manual handling, postural management;*
- *Nursing risk assessments, care plans, baseline monitoring, pain assessment.*

*'Onward referrals to:*

- *Gastroenterology – regarding upper GI pain associated with eating and possibly relating to an ulcer or oesophagitis;*
- *Orthopaedics – review of scoliosis and right femoral head;*
- *Incontinence Nurse advice re: bowels;*
- *Pain clinic for assessment and advice re medication;*
- *Optician;*
- *Dentistry.'*

306 On 12 December 2003 Tom was reviewed by staff at the Hospice. A file note for this date said his background pain was better controlled since the introduction of MST (morphine sulphate) and noted his '*pain now? more clearly GI related*'.

307 On either 17 or 18 January 2004 Tom sustained an injury to his ear. The nursing records for 18 January 2004 note that his ear looked swollen, that the cause was to be queried and Tom was to see a doctor. The Consultant in Charge reviewed Tom's injury the next day. However, Tom developed a 'cauliflower ear' (when an ear becomes thickened or deformed due to physical contact) and was taken to A&E at the Acute Trust on 20 January 2004. The injury became infected and Tom required in-patient admission for wound drainage under general anaesthetic.

308 On 29 January 2004 a possible permanent placement was identified for Tom at Prospect Place, a permanent residential care home for adults with learning and physical disabilities.

309 On 13 February 2004 the Consultant in Charge at the Windrush Unit wrote to the manager of Prospect Place, to inform her that Tom did not intrinsically require nursing care, and that his healthcare needs could be met through the Community Learning Disability Team and generic services. She said a discharge summary would be sent with Tom on the day of his discharge, which would only contain information on his medication. She said a fuller summary would follow later.

310 On 23 February 2004 Tom moved into permanent accommodation, his new home at Prospect Place. His medical notes did not accompany him.

311 The discharge summary was sent nine days after Tom left the Windrush Unit. It noted details of his mental and physical condition and included information about treatment given, for example changes to his drug prescription. The summary noted that Tom had sustained an ear injury that could have resulted from sheering his upper ear whilst pulling his hand across the top of his head or could have resulted from contact with the head rest in his chair, or during transfer in the hoist. It was also noted that Tom had indicated, in a yes/no answer session some five days after the event, that the injury had occurred during hoisting and had been an accident. It had left him with some deformity in the cartilage of the ear.

312 In the discharge summary the Consultant in Charge said:

> *'As a forward placement was found in a community home for Tom ... agreement was made to move towards discharge rather earlier than I would ideally have anticipated as I still feel there are a lot of changes to be made to Tom's regime which will be difficult to do in the community in a stepwise controlled fashion.'*

and

> *'The ongoing use of morphine based pain killers is obviously problematic in a young man both in terms of the compromise to his respiratory system, the constipating side effects and the increased tolerance that he is likely to show if using this medication over the much longer term that we would anticipate his life continuing for.'*

313 The Consultant in Charge went on to note that Tom continued to have bowel difficulties and gastro-oesophageal reflux, which she said would warrant review by a gastroenterologist.

## Mrs Wakefield's recollections and views

314 Mrs Wakefield told my investigator she thought the Windrush Unit had been an inappropriate and unsafe place for Tom because it was a psychiatric unit and not, therefore, geared to assessing physiological needs. She felt his admission reflected the continuing assumption that Tom's behaviour did not have a physical cause.

315 Mrs Wakefield said she and her husband had at first been reluctant for Tom to transfer to the Windrush Unit. They felt that it was unlikely to be able to provide the social stimulation and therapeutic environment he required. However, they said that following discussion with a number of health and social care staff, they were persuaded that the Windrush Unit might offer the opportunity for all of Tom's needs – physical and behavioural – to be assessed, and were told that Social Services would provide additional support for Tom. Therefore, although Tom's referral to the Windrush Unit had come about as a result of a series of unfortunate events, rather than a coherent plan, Mr and Mrs Wakefield hoped it might actually turn out to be an opportunity to get to the bottom of Tom's pain and weight loss and result in a plan which would relieve their son's distress.

316 Mrs Wakefield said she and her husband thought the Windrush Unit was unsafe because they often found pills in Tom's bed, his bed clothes were often left unchanged, and he would sometimes be covered in blood. Often he would not be out of bed and would be left screaming in pain. She said there was nothing to stimulate patients. She felt that the Windrush Unit was '*a dumping ground*'. She said bathrooms were dirty and rubbish was left lying around and the environment was noisy and this disturbed Tom.

317 Mrs Wakefield said she was worried that Tom's weight was not regularly monitored while he was in the Windrush Unit and that no one had noticed how much weight he was losing. She said a PEG feeding tube had not been suggested. However, Tom had been referred for non-urgent endoscopy.

318 Mrs Wakefield said she had been told the ear injury was self-inflicted, but she did not think Tom could have done this. She said her son had later indicated that the injury had been caused accidentally. She was sure the injury had occurred in connection with the hoist system.

319 Mrs Wakefield understood that Social Services had agreed to fund social care staff to support Tom at the Windrush Unit and in this respect Tom had been '*a first*'. However, she said there had been no communication between Windrush Unit staff and the Social Services staff, who essentially had been left by Windrush Unit staff '*to get on with it*'. Consequently, Tom did not appear to have received basic nursing care or to have had the benefit of social care. Mrs Wakefield said that at times Tom had been left on his own for long periods. She said Tom never went out on trips, so she arranged transport for him.

320 Mrs Wakefield said when Tom was discharged into permanent accommodation at Prospect Place, she had arranged transport because she wanted to make sure he got there. She recalled that Prospect Place had not been given any information about him and the discharge process had been a shambles. Although staff at Prospect Place had been very good with Tom and were able to communicate with him, they had not been given relevant medical information and this had influenced the events that had followed.

## The Partnership Trust's position

321 The Partnership Trust's position is set out in the then Chief Executive's responses to Mr and Mrs Wakefield's complaints.

*Tom's admission to the Windrush Unit*

322 In his response of 23 February 2004 the Chief Executive explained Tom had been admitted for a medical assessment (envisaged as taking 12 weeks) which had coincided with the date for transfer from school. He said Tom had been admitted with the agreement of Social Services who had funded additional support as Mr and Mrs Wakefield considered Tom should have plenty of activity to occupy him. Social Services had continued to seek places for Tom and had identified two, one being short term and another being more permanent. He also said that it was his understanding (from Social Services) that Mr and Mrs Wakefield had turned down a number of placements because they felt they were unsuitable.

323 In his letter of 27 August 2004 the Chief Executive explained that the Windrush Unit was not a place of last resort but had a defined clinical role for two groups of clients. Some clients had been there for some time and alternative longer-term care placements were being explored while others were admitted for medical assessment and treatment. He acknowledged that this dual role was not ideal and could lead to a misunderstanding about the Unit's medical assessment and treatment role. He also acknowledged that the environment had been poorly managed at the time Tom was there.

324 The Chief Executive also said the Partnership Trust's records indicated that Tom's admission had been urgent and related to complex physical and behavioural needs. Tom's physical problems were detailed by the Consultant in Charge on admission and this seemed to indicate that Tom's admission was appropriate.

*The care and treatment provided to Tom*

325 In his response of 27 August 2004 the Chief Executive said liaison arrangements between Windrush Unit staff and the agency staff funded by Social Services had not been consistently effective. Consequently, the Partnership Trust's standards of health and social care had not been met.

326 In his letter of 14 September 2004 the Chief Executive said Tom had undergone a series of assessments and investigations including admission to the Hospice. The Hospice assessment report had supported the care plan drawn up at the Windrush Unit and had not suggested that any other referrals or additional investigations should be undertaken. He also commented that the Consultant in Charge had been aware that Tom had seen a number of consultants in Oxfordshire. She did not want to repeat previous assessments and had, instead, sought details from Oxfordshire.

*The injury to Tom's ear*

327 In his letter of 23 February 2004 the Chief Executive said he had been unable to establish how Tom had injured his ear because no incident form had been completed. He said the Consultant in Charge had concluded that the injury had arisen because of some sort of impact and had arranged for Tom to be seen in A&E at the Trust. In a subsequent letter of 14 September 2004 the Chief Executive said further investigation had not revealed the cause of the injury but it was possible that the injury was self-inflicted given Tom's history of self-harming.

*Discharge arrangements*

328 The Chief Executive addressed arrangements for Tom's discharge to Prospect Place in his letter of 14 September 2004. He explained that the Windrush Unit had only been informed by the Council on 5 February 2004 that Tom would move on 23 February 2004. He said the Consultant in Charge had provided Tom's new GP with a full discharge summary nine days after Tom's discharge which was in line with normal practice. He also said that after Tom's discharge the Consultant in Charge continued to have responsibility for some medical care for Tom, for example, she facilitated a clinical meeting about Tom which was held on 23 March 2004.

329 I also saw evidence of two reviews conducted by Partnership Trust staff about Tom's discharge. The report of the first review, which was undated, said:

- A review meeting had been set for 5 February 2004. Its purpose was changed to a discharge meeting at the start. Tom's named nurse had not been present nor had a representative from the Community Learning Disability Team. Information required for discharge had not been gathered prior to the meeting and no new GP had been identified. Tom's parents had been present and medical information was reviewed and discussed.

- No written referral had been made to the Community Learning Disability Team to alert them to Tom's discharge.

- A new GP for Tom had been identified on 12 February 2004 at a discharge meeting and the discharge summary had been dictated on 3 March 2004.

- The Clinical Nurse Manager at the Windrush Unit had not ensured that the discharge pack that normally accompanied people transferring for a new placement met the expected standard, nor had the Nurse Manager checked that transport was arranged.

330 The report of the first review said that it was unacceptable for the discharge process to be led by a relative or other non-professional and that the named nurse or designated deputy must be present to ensure that discharge took place in line with local policy. It stated that a checklist of documents that must be completed prior to discharge would be drawn up and adhered to in future.

331 The second review was held on 4 August 2004 and Community Learning Disability Team staff employed by the Partnership Trust attended. The report of the second review reiterated many of the points made in the earlier review and added the following:

- Tom had been transported to his new home in a taxi with an escort who staff at the home had said '*dumped and run*'. Tom had been left in a hallway and there was no handover discussion.

- No paperwork or notes accompanied Tom although some paperwork had been sent later in a carrier bag with incomplete/incorrect material. There was no discharge summary and the new GP received no information or contact details.

- Tom's notes were still at the Windrush Unit on 2 March 2004, so a member of the Community Learning Disability Team called to pick them up.

## The advice of the Health Service Ombudsman's Professional Advisers

*My Psychiatry Adviser*

332 My Psychiatry Adviser considered that Tom's admission to the Windrush Unit was appropriate and that Tom's clinical presentation matched the admission criteria for the Unit. He also felt that the Consultant in Charge had made a good initial plan for Tom. He was, however, concerned about the apparent failure to observe and react to Tom's weight loss during his stay at the Windrush Unit.

*My Nursing Adviser and my Learning Disability Nursing Adviser*

The nursing care provided to Tom at the Windrush Unit

333 My Nursing Adviser noted the instructions set out in the comprehensive management plan drawn up by the Consultant in Charge on Tom's admission. She said these would need to be carried out by nursing staff to help inform treatment plans for Tom. She said it was difficult to find any correlation between the Consultant in Charge's clinical requests and the reports in the available nursing notes. For example:

- Although the consultant had requested twice weekly weight measurement, weight was only charted 4 times in 96 days; 4 entries were made from 26 November 2003 to 12 February 2004 showing a decrease in weight from 34.2kg to 30.5kg. The adviser could find no plan of action addressing Tom's weight loss, or any indication that this information was passed to medical staff.

- There is no evidence in the records of input from a dietician or nutritionist, even though Tom continued to lose weight. Although the nursing notes for the Windrush Unit

frequently express comments such as '*refused all food*' and '*very little diet taken*', '*taking little diet*' there was no evidence in the nursing notes that staff were concerned with, or about, Tom's intake of food. There were few fluid and food recording charts.

- '*Recording of sleep pattern*' charts were available for six days in January 2004 and then for ten days before discharge in February 2004.
- Recording of bowel movements started in January 2004, and there were few entries regarding urine output.
- Medication charts had not been filled in.

334 My Nursing Adviser noted that no assessments had been made of pain and that pain assessment charts had been left blank. She said:

> *'... the few prescription charts available do not indicate that drugs have been given. Nursing records are not well written and do not give the reader confidence that the nursing staff were capable of caring for a patient with acute physical pain. Most entries made relate to subjective views from staff when Tom was screaming in pain or attempting to self-harm. Considering the amount of analgesia that was being administered over a prolonged period of time, and particularly when Tom was having increasingly higher dosages of opiates, it is surprising that monitoring of his respirations were not carried out more frequently. A lot of assumptions were made as to the cause of his pain possibly being abdominal, musculoskeletal, or both.'*

335 Five incident forms were started while Tom was in the Windrush Unit regarding:

- an injury to his nose
- bruising/swelling to his finger
- bruising to his arm
- further injury to his face
- pills found in bed.

336 My Nursing Adviser found that none of the incident forms had been fully completed, nor did they give any indication that action would be taken to prevent a recurrence. She could not establish from the nursing records if Tom's parents had been informed of all of these incidents. The Nursing Adviser was concerned that few risk assessments had been completed with regard to maintaining a safe environment for Tom.

337 In summary, my Nursing Adviser said Tom's weight fell quite dramatically during his stay at the Windrush Unit but was not monitored, his pain levels did not appear to have been well monitored or managed, and his nutritional needs were not assessed. She was critical of the nursing care delivered to Tom, including a failure to act sooner in delivering care for his physical needs. She considered the nurses in the Unit had not had the appropriate skills and knowledge to care for a patient such as Tom with his deteriorating physical condition. My Learning Disability Nursing Adviser concurred with my Nursing Adviser's views.

338 My Nursing Adviser said she had:

> *'... serious concerns relating to the nurses' professionalism in delivering patient care and their adherence to their professional body the Nursing and Midwifery Council's Code of Professional Conduct, which clearly set out the standards and guidelines to which all registered nurses must adhere.'*

#### The injury to Tom's ear

339 My Nursing Adviser noted that Tom had been asked questions by staff who often worked in the Unit as to how the injury had occurred. His parents were not present. His responses to the questions indicated that it had been an accident caused by the hoist. An incident form had not been completed at that time and the Nursing Adviser could find no evidence in the nursing notes that this was considered a serious injury to Tom, or that staff had been alerted to the severity of the incident to prevent it happening again. She concluded that it was too late now to establish how the injury had occurred.

#### Discharge arrangements

340 My Nursing Adviser said the discharge meeting had been poorly organised. There had been a lack of preparation for the meeting and this had resulted in no professional handover to the new placement. Tom had been transferred without key carers escorting him.

341 My Nursing Adviser noted that the discharge letter stated there had been assessments from speech and language therapy, occupational therapy and nursing therapy. However, the assessment reports that she had seen related to February 2003 from Penhurst School, and not to the care received in the Windrush Unit between November 2003 and February 2004. My Learning Disability Nursing Adviser also said no referral had been made to a dietician and that no psychology input had been obtained.

### Care and treatment at the Windrush Unit: the Health Service Ombudsman's findings

342 As there were distinct aspects to Mr and Mrs Wakefield's complaints against the Partnership Trust I will deal with each in turn.

#### *Tom's admission to the Windrush Unit*

343 Mr and Mrs Wakefield were concerned that Tom was inappropriately admitted to the Windrush Unit. I can see that in the context of Tom having received notice to leave Penhurst School Mr and Mrs Wakefield had concerns about the possibility of the Windrush Unit becoming a de facto placement for Tom by the Council, in the absence of the offer of adult accommodation. Nevertheless, in making a finding about the Partnership Trust I have to consider whether the decision to admit Tom to the Windrush Unit was reasonable. My Psychiatry Adviser said that, based on information from Tom's GP, Tom's behaviour had changed and his medication might need review, and taking account of an initial assessment by a nurse from the Unit, the Consultant in Charge had made an appropriate decision to accept Tom for assessment. Therefore, in terms of the Partnership Trust's actions in admitting Tom to the Windrush Unit, I find **no evidence of service failure**.

#### *Tom's care and treatment*

344 My Professional Adviser told me the Consultant in Charge at the Windrush Unit drew up a sound plan of action and social care staff were provided to ensure that Tom's social needs continued to be met while he was being assessed. However, the rest of Tom's stay at the Windrush Unit did not live up to this standard.

345 During the three months that Tom was a patient at the Windrush Unit, the Consultant in Charge did enact some of her plan. She completed the eradication of Tom's Helicobacter pylori (stomach bacteria) and treated his anaemia, but her plans for involving other professionals did not materialise. Despite her referrals, Tom was not seen by a gastroenterologist or by an orthopaedic surgeon. The arrangements for enabling the social care staff to work as part of Tom's team were not effective.

346 The failure to report the injury to Tom's ear and to report fully on other incidents meant Tom was placed at unnecessary risk of further injury or harm.

347 The Windrush Unit tried to serve two client groups with different needs. It was being closed down when Tom was a patient there and the physical environment was not well managed. I can understand that the Partnership Trust was in something of a dilemma because substantial investment to bring the Windrush Unit to modern standards would not have represented good use of public money. Nevertheless, it is not acceptable for patients to experience such a poor environment. These were matters that could have been addressed.

348 The General Medical Council's Good Medical Practice says that a consultant is responsible for ensuring the care provided for patients is co-ordinated and managed, and for ensuring that those to whom he or she delegates care are competent to provide the care involved. The Consultant in Charge said Tom had been discharged early and that she would have liked him to have stayed longer at the Windrush Unit. However, Tom spent over three months at the Windrush Unit – the normal length of stay for an assessment. Therefore, I find it hard to understand why there was not more progress during that time in implementing the Consultant's well designed plan.

349 I am also concerned that my Nursing Adviser considers nurses at the Windrush Unit lacked the skills necessary to care for Tom's considerable physical needs.

350 Turning specifically to the nursing care provided to Tom, my Nursing Advisers have found many examples of very poor nursing care. Tom's weight, food and liquid intake were not monitored. Bowel and bladder observations were few. Pain charts were left blank. Medication charts were not completed and Tom's respirations were not monitored while he was taking morphine. I note my Nursing Adviser has serious concerns about the nurses' professionalism and about their adherence to professional guidance. In view of the fact that the purpose of the Windrush Unit was to provide physical as well as psychiatric assessment for people with learning disabilities, I am particularly concerned that my Nursing Adviser considers nursing staff appeared to lack the skills to provide care to a patient such as Tom.

351 Tom was in the Windrush Unit for almost 14 weeks. At first there was a comprehensive plan for Tom and he did receive treatment and care. However, taken in the round and considering the evidence I have seen, including the advice of my Professional Advisers, I conclude that the overall care and treatment which Tom experienced while in the Windrush Unit fell significantly below a reasonable standard in the circumstances. I conclude that many of the failings in the Partnership Trust's care and treatment of Tom were for disability related reasons. This was **service failure**.

*The management of Tom's discharge to Prospect Place*

352 In Section 2 I refer to the Department of Health's good practice guidance Discharge from Hospital. The advice I have received and the evidence of reviews conducted by the Partnership Trust and the Community Learning Disability Team indicate that arrangements for Tom's discharge, and the discharge itself, fell well below the standards set out by the Department of Health. On discharge, he was put in a taxi and left at his new home. No proper handover of care and records took place. This was **service failure**.

### Care and treatment at the Windrush Unit: the Health Service Ombudsman's conclusion

353 Having considered the evidence about Tom's stay at the Windrush Unit, including the advice I have received and Mrs Wakefield's recollections and views, I conclude that there was **service failure** in the care and treatment provided for Tom and that this failure was in part for reasons related to his disability.

## Complaint (g): complaint handling by the Partnership Trust

354 Mr and Mrs Wakefield remain dissatisfied with the way the Partnership Trust handled their complaint.

### Key events

355 On 25 January 2004 Mr and Mrs Wakefield complained to the Partnership Trust about the injury to Tom's ear. Their main points of concern were:

- there was no contemporaneous incident report about the injury;
- there was no note of the incident in the communication book used by agency staff; and
- Windrush Unit staff had attributed the injury to Tom self-harming, but other medical opinion had indicated that he could not have inflicted such injury on himself.

They also said Tom was inappropriately placed at the Windrush Unit and had been placed there against their wishes because of a failure to plan and make provision for him.

356 On 23 February 2004 the Chief Executive responded with an explanation of the reason why Tom was placed at the Windrush Unit. He also described what Partnership Trust records showed staff had done on discovering Tom's ear injury. He said he had been unable to establish how the injury had occurred. He acknowledged that staff had been wrong to suggest Tom had injured himself and he apologised for this. However, later in the response he again said self-harm was a possible cause of the injury. The response also included a report of actions the Partnership Trust had taken to prevent recurrence of such an event, including improved incident reporting and record keeping.

357 Mr and Mrs Wakefield were not satisfied with this response and on 8 July 2004 they raised further concerns. Their main concerns were:

- the Windrush Unit had been an unsuitable placement for Tom, he had been placed there against their wishes (they had not refused other placements) and the environment was inadequate;

- the response about Tom's ear injury was inadequate, especially the investigation into how the injury had occurred and the suggestion that it had been self-inflicted;
- medical and social care were inadequate; and
- there had been no proper discharge arrangements for Tom's transfer to Prospect Place.

358 On 27 August 2004 the Chief Executive responded with further explanation about Tom's placement at the Windrush Unit and information about its function, facilities and arrangements for providing care. He acknowledged that the Windrush Unit did not provide the best environment for its two groups of clients and reported on the development of new facilities for clients with learning disabilities. He also acknowledged that the environment had been poorly managed and apologised for this. Furthermore, he acknowledged that liaison between Windrush Unit staff and agency staff had not been consistently effective which meant the aspirations for the standard of health and social care had not been met. He apologised for these shortcomings, but did not detail action taken to improve services. He also apologised for not being able to explain how Tom had injured his ear and enclosed copies of documents relating to the Partnership Trust's investigation of the cause of the injury.

359 On 14 September 2004 the Chief Executive responded to Mr and Mrs Wakefield's complaint about medical care. He explained about assessments which had taken place and plans which had been drawn up for Tom's care. He also said staff had been concerned that they did not repeat assessment unnecessarily.

360 With regard to the complaint about discharge arrangements, the Chief Executive said there had been some communication between professionals but the timescale had been short and there had been some uncertainty about ongoing responsibilities for Tom's care. He said a discharge summary had been sent nine days after Tom's discharge and this was in line with normal practice. He also described how meetings and discussions had taken place involving Windrush Unit staff after Tom had been discharged.

### Complaint handling by the Partnership Trust: the Health Service Ombudsman's findings and conclusions

361 In Section 2 I have summarised the Regulations relating to the way in which NHS bodies should handle complaints. I have compared the Partnership Trust's actions with those Regulations.

362 On the whole the Partnership Trust responded to Mr and Mrs Wakefield's complaint within a reasonable timescale, although the Chief Executive's third letter was sent more than two months after the second complaint was received. I accept that it was not unreasonable to split the response to the second complaint into two letters, although an integrated approach would have been better.

363 Each of the three responses from the Chief Executive addressed the key issues complained about, gave details about Tom's care and treatment and explored some of the rationale behind treatment decisions. However, it is clear from the Chief Executive's responses that investigation of some matters, especially discharge arrangements, was inadequate. On this matter the Chief Executive was defensive and provided excuses

rather than explanations. I was not convinced that the Partnership Trust had recognised and acknowledged its failings on this important issue. In contrast, my investigation has revealed significant failings in discharge arrangements.

364 That said, the Chief Executive did acknowledge and apologise for some failings, such as poor incident reporting, and did inform Mr and Mrs Wakefield about some changes which had taken place to address those failings. But there was no information about improvements in discharge planning.

365 I find that repeatedly suggesting that Tom had injured his own ear was inappropriate and insensitive, especially given the circumstances of the events complained about.

366 I conclude that the failings in the way the Partnership Trust handled Mr and Mrs Wakefield's complaint amount to **maladministration**.

## Complaints against the Partnership Trust: the Health Service Ombudsman's conclusions

367 Having studied the evidence available in the light of the advice of my Professional Advisers and considered Mrs Wakefield's recollections and views, I conclude that there was **service failure** in the Partnership Trust's management of arrangements for Tom's care and treatment, specifically:

i. failure to implement the plan of care drawn up on admission;

ii. failure to properly report the injury to Tom's ear;

iii. failure to provide a suitable physical environment;

iv. failure to provide a reasonable standard of nursing care; and

v. failure to make appropriate arrangements for Tom's transfer to Prospect Place.

368 I also conclude there was **maladministration** in the way the Partnership Trust handled Mr and Mrs Wakefield's complaint.

## Further information provided by the Partnership Trust

369 In response to the draft report the Partnership Trust provided me with a wide range of information to demonstrate action taken to address shortcomings identified in my investigation. These measures were detailed in an action plan and included:

- measures to improve care environments;
- additional skills training for professional staff, including incident reporting and emergency response training;
- introduction of new care pathways, benchmarking and other care quality improvement measures;
- improved liaison between professionals, for example using a Care Programme Approach for multidisciplinary discharge planning and documentation;
- improved multi-agency working, for example link posts with the Acute Trust; and

- improved risk management procedures and heightened focus on protection of vulnerable adults.

## Injustice

370 I have taken into account these recent actions by the Partnership Trust to improve services for people with learning disabilities. However, the fact remains that at the time Tom needed help from the Partnership Trust he did not receive a reasonable standard of service. Mr and Mrs Wakefield consider that Tom suffered unnecessarily while at the Windrush Unit. We cannot know whether the outcome for Tom would have been different had the Consultant's plan been pursued more effectively by the Windrush Unit's staff and if Tom had been provided with better treatment and care. However, it is clear that while Tom was in the Windrush Unit care and treatment were inadequate and, in particular, his weight continued to decline. Furthermore, he lacked social support. Failures to appropriately pursue referrals may have disadvantaged Tom.

371 Although there was no service failure by the Partnership Trust in Tom's admission to the Windrush Unit, there was service failure while he was there and, notably, in the management of his discharge. 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, Mr and Mrs Wakefield have had to wait four years to learn the truth about Tom's care and treatment in the Windrush Unit. This will undoubtedly have contributed to their distress which remains an **unremedied injustice**.

372 Therefore, I **uphold** Mr and Mrs Wakefield's complaint against the Partnership Trust.

373 We say more about injustice in Section 4 of this report.

## The Health Service Ombudsman's recommendations

374 I **recommend** that the Chief Executive of the Partnership Trust apologise to Mr and Mrs Wakefield for the failings I have set out in this report.

375 I also **recommend** that the Partnership Trust offer compensation of £10,000 to Mr and Mrs Wakefield in recognition of the injustice they have suffered in consequence of the service failure and maladministration I have identified.

## The Partnership Trust's response

376 The Chief Executive of the Partnership Trust has asked me to place on record his apology to Mr and Mrs Wakefield. He also offered to meet Mr and Mrs Wakefield to offer them his personal apologies. He told me the Partnership Trust is committed to learning from my report and outlined key learning points and actions the Partnership Trust has taken to address its service failings. The Chief Executive told me that in response to this case the Partnership Trust has produced an action plan which has been shared with Monitor (the government body which regulates NHS foundation trusts). That plan has also been reported to the Practice Standards Committee and progress is being monitored by the Partnership Trust Board. Furthermore, in 2009 the Chief Executive intends to commission an independent review of progress against the action plan and he will make this available to Mr and Mrs Wakefield and the wider public. He confirmed that the Partnership Trust is willing to work openly and collaboratively

with local and central bodies regarding the matters raised in this case. The Chief Executive also accepted my recommendation regarding a compensation payment.

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

### Complaint (h): care and treatment at the Acute Trust

377 Mr and Mrs Wakefield complain about the care and treatment provided for Tom by the Acute Trust, particularly with regard to pain management, hydration and nutrition from his admission on 6 April 2004 until his death on 25 May 2004.

#### Key events

378 Tom experienced considerable distress almost as soon as he moved to Prospect Place and was admitted to an acute hospital (not the subject of a complaint) on 2 March 2004, where he was found to be suffering from severe constipation. He was discharged back to his residential home on 5 March 2004.

379 On 6 April 2004 Tom was admitted to the Acute Trust. Events at the Trust between his admission and death on 25 May 2004 are summarised at Annex B.

#### Mrs Wakefield's recollections and views

380 Mrs Wakefield said that although she and her husband had concerns about some of the care provided by the Acute Trust, they had not complained at the time because they had already made several complaints about the care and treatment provided to Tom by other organisations and felt that they could not cope with any more. Mrs Wakefield said when Tom had been admitted to hospital she and her husband had been concerned by a consultant's attitude. She recalled that the consultant had said: '*there is not much that we can do here*'. The consultant concerned had not spoken to Tom. Afterwards they had placed a note by Tom's bedside informing staff that he could understand what was said and had the same feelings and sensitivities as everyone else.

381 Mrs Wakefield had been under the impression that Tom would be provided with palliative care when he had been admitted because she had been informed that the palliative care team at the Hospice would be contacted. However, she had subsequently found out that the palliative care team were not involved until 24 hours before his death.

382 Mrs Wakefield said she had asked about Tom's nutrition and had been told that he would be alright for a few days because he was being given fluids. She said that, however, Tom had been nil by mouth for a week before a PEG feeding tube was inserted. She said that everyone apart from her appeared to be aware that Tom's condition had deteriorated too much for him to survive. No one had told her what his chances of survival were.

#### The Acute Trust's position

383 In response to my enquiries the Acute Trust said Mr and Mrs Wakefield had not complained directly to the Acute Trust so it had not been able to respond to their concerns. When my investigative staff met staff from the Acute Trust they said they were very surprised that

Mr and Mrs Wakefield had complained about the care and treatment Tom had received because they believed they had developed a close and caring relationship with the family. Staff said they felt they had made reasonable adjustments to meet Tom's needs, for example, additional involvement of consultants and the former Deputy Director of Nursing. They said the adjustments they had made, including sensitive support for the family, were not always recorded.

384 Nonetheless, the Acute Trust said it intended to conduct an internal inquiry after the Ombudsmen had reported.

385 The Acute Trust provided details of policies and procedures, for example, about assessment, planning and delivery of care and administration of medicines. It also provided details about the Gloucestershire Patient Profile which is used for recording care and confirmed it provided training to all nursing staff on the use, completion and interpretation of this documentation. When my investigative staff visited the Acute Trust they were given a more detailed explanation about this method of documenting nursing care.

386 The Acute Trust said it had implemented the Essence of Care benchmarking standards of care, including benchmarking for nutrition. It also provided details about its Acute Pain Service.

387 The Trust said policies for reporting and recording of incidents had first been introduced in 2002 and had been revised subsequently. Learning from incidents was fed back to staff and used in training sessions to demonstrate the importance of reporting to improve practice and the safety of patients and staff. The Acute Trust acknowledged that learning from incidents and complaints needed to improve and had been identified as a key measure in relation to the Patient Safety Objective adopted by the Trust in 2007.

388 The Acute Trust said it recognised the needs of people with learning disabilities, and in line with the guidance set out in Valuing People it had collaborated with the Partnership Trust in developing a resource and training pack for staff which was available on all wards. Link nurses had been identified in areas where patients with learning disabilities were most likely to be admitted. A carers' group had been set up and a self-assessment proforma had been introduced.

## The advice of the Health Service Ombudsman's Professional Advisers

*My Gastroenterology Advisers*

389 My First Gastroenterology Adviser said by the time Tom was admitted to the Acute Trust his health had deteriorated too far for there to be a realistic prospect of recovery.

390 My Second Gastroenterology Adviser said:

> *'Tom suffered life-threatening episodes of respiratory failure that appear to be due to chaotic prescriptions of a mixture of interacting sedatives, analgesics and other medications. This was unacceptable. In the case of some opioids the prescriptions did not conform to legal requirements for controlled drugs. The ultimate responsibility for this lies with the prescribing doctor, but it is equally surprising that the prescriptions were not queried by pharmacy or nursing staff. It would appear that the situation may have been influenced by the perception of a pressing need to alleviate Tom's obvious distress and by the involvement*

*of a surprising number of junior doctors in the prescribing process. It seems clear from the record that some of the junior doctors involved "out of hours" in Tom's care were new to his clinical problems. This raises questions about the continuity of care, which hinges on the quality of the handover between doctors on consecutive periods of duty, assuming that such formal handover occurred (none are recorded in the clinical notes). I note that on one occasion (2 May 2004) both the house officer and the registrar on call were temporary locum appointments. There also appeared to be instances of inconsistencies or misunderstandings within the clinical team: for example, with regard to the purpose of PEG placement, the need to refrain from oral fluids or medications following PEG placement, and the required calorie content of gastric feeds. Such inconsistencies are suggestive of incomplete communications within the clinical team.*

*'...*

*'Having said this, there can be no doubt that Tom's medical problem was extraordinarily difficult to manage. As indicated by the acute pain consultant it is crucial to diagnose the cause of Tom's pain in order to treat effectively. However, despite reasonable efforts the cause of Tom's distress was never diagnosed – indeed, it could not be ascertained with certainty whether his behaviour indicated pain since pain, discomfort, displeasure and distress appeared to be indicated by the same behavioural mannerism.*

*'...*

*'While Tom was in the Acute Trust, there is remarkably little comment in the medical notes concerning Tom's weight loss and an extreme paucity of objective measurements of his weight. It is not clear from the record whether the tardiness in replacing a proper PEG tube, ... , contributed to his poor nutritional state. However, despite receiving appropriately calculated calorie feed through the larger of the temporary tubes, Tom failed to gain weight.*

*'...*

*'Very sadly, I feel that Tom's mode of death was consistent with the natural history of such a degree of disability. With the exception of the prescription issues referred to above, I do not think that the standard of care fell to an unreasonable level.*

*'...*

*'On balance, I have to conclude that there were issues, outlined above, regarding the prescription of Tom's medications that were not acceptable. I also feel that the very difficult management of Tom's pain should have been supervised by a specialist in pain management and not (apparently) left largely in the hands of some very junior doctors.'*

391 In their response to our draft report Mr and Mrs Wakefield asked that my Second Gastroenterology Adviser provide more detailed explanations about the advice he gave me. This further advice is at Annex C.

392 Mr and Mrs Wakefield also asked for information about re-feeding syndrome. My First Gastroenterology Adviser provided this information which is at Annex D.

*My Nursing Adviser*

The management of Tom's pain

393 My Nursing Adviser said the acute pain nurse contributed to assessment of Tom's pain when he was admitted and proposed a useful treatment plan. Pain core care plans commenced on admission but appeared to stop on 13 May 2004. She said whilst the nursing staff used care plans to evaluate Tom's daily medication there were no regular assessments of his pain. She considered the plans did not give an indication of the effects of analgesia or why breakthrough pain drugs were administered. There was no separate monitoring of Tom's pain once a syringe driver was in place.

Monitoring of vital signs

394 My Nursing Adviser said Early Warning Scoring System charts were used to monitor temperature, pulse and respirations and had been reasonably well filled in at some points during admission. She said recording of respirations is vital when opioids such as morphine are being used fairly regularly, especially in patients who are taking a 'cocktail' of drugs. Although Tom was receiving opioids regularly there was no record of his respirations during the first few days of his admission. Between 24 and 29 April 2004 Tom was receiving his opioids through a syringe driver and observations should have been recorded on a half-hourly basis to ensure no deterioration in his condition, but there is no indication that this happened.

395 My Nursing Adviser could see from Tom's medical records that on 22 April 2004 Tom became unresponsive with a respiratory rate of 6/7 breaths per minute. Naloxone was administered with good effect and, appropriately, an Acute Life Threatening Events-Recognition and Treatment (ALERT) Care Plan was commenced on 23 April 2004. She said a similar incident occurred on 24 May 2004 and naloxone was administered. Minimal observations were carried out for a short period. Oxygen was administered to Tom but not written up as a proper prescription.

396 My Nursing Adviser said:

> '*… for a patient as compromised as Tom was with aspiration pneumonia and recurrent chest infections, there should be serious consideration given as to whether an opioid overdose may have been a cause or contributing factor in the two serious events.*'

She said there was no evidence that Tom's parents had been told about these two serious episodes.

397 My Nursing Adviser said there were patient profiles in the nursing notes but they had been only partially completed. She explained that if patient profiles were not fully completed they could not contribute to the management of risk in caring for a patient with such complex needs. My Nursing Adviser reviewed the evidence about nursing records in the light of the Trust's additional explanation about documentation, but she found no reason to change her advice.

Monitoring of nutrition and fluid intake and gastrostomy care plan

398 My Nursing Adviser said Tom's nutrition and fluid intake were not monitored well. No nutritional nursing care plan was commenced on admission. Fluid balance charts (including intravenous fluid charts) were poorly completed

often giving no indication for days whether Tom had passed any urine. My Nursing Adviser said there seemed to be no plan for managing Tom's hydration on the occasions when his feeding tube or drip 'fell out'.

399 However, my Nursing Adviser found evidence in speech and language therapy and dietician records that Tom was reviewed regularly. She said these records showed consideration had been given to appropriate timing and duration of feeding and there was evidence of discussion with nurses and carers, for example about the most appropriate position for Tom when he was receiving nutrition via his PEG feeding tube. She also said there was evidence of multidisciplinary discussions and engagement of carers regarding management of the feeding tube, for example regarding caring for the feeding tube insertion site and monitoring for infection. My Nursing Adviser said the therapy records showed a reasonable level of assessment and care planning for management of the PEG feeding system.

400 My Nursing Adviser found no record of Tom's weight until 10 May 2004. There are further records of his weight on 17 and 21 May 2004. My Nursing Adviser considered this to be an extremely serious omission on the part of nursing staff.

### Bowel management

401 Tom had a history of severe constipation over a long period of time and required laxatives, a good diet, and enemas to aid his bowel movements. My Nursing Adviser noted that Tom's parents frequently commented to the nursing staff that they were concerned about Tom's bowels. My Nursing Adviser said that in circumstances such as these she would have expected, as a minimum, a care plan outlining how Tom's bowels could be managed. However, there was no care plan; instead, notes were written sporadically in the communication sheets. These range from *'severely constipated'* to *'loose bowel movements'* and *'smelly green stools'*. She was concerned to see that nothing was recorded in the notes to suggest there might have been a problem with his bowels.

### Privacy and dignity

402 My Nursing Adviser said:

> *'The nursing records available do not give the impression that this young and severely disabled man was afforded the best possible care available. There is no evidence to indicate that on a daily basis his hygiene needs such as bathing, mouth care, bowel management and social needs were met.'*

403 My Nursing Adviser noted that carers from Prospect Place visited regularly and may have been involved in his care. However, she said Tom's care was the responsibility of the nursing staff at the Acute Trust and, as such, all of his needs should have been assessed, planned, evaluated and recorded as having been given by the nursing staff during his admission. The nursing records do not indicate this was the case.

### Communication with Tom and his family

404 My Nursing Adviser said she could find no clear evidence in the nursing records that communicating with Tom or assisting his understanding of what was happening to him was discussed with his family.

405 In summary, my Nursing Adviser considered there was evidence of:

- poor assessment and planning to meet Tom's individual physical needs;

- poor monitoring of Tom's respiratory rate;
- failure to observe the deterioration in Tom's condition;
- poor record keeping, for example, in risk assessment, about tissue viability and on fluid charts;
- poor incident recording and reporting; and
- lack of concern over two serious events relating to his drug therapy.

406 My Nursing Adviser said many aspects of care in the Acute Trust fell below a reasonable standard of nursing care, which should have been provided by registered nurses to any patient in their care. She therefore had serious concerns relating to the nurses' adherence to the standards set out in key documents including the Nursing and Midwifery Council's Code of Conduct.

*My Learning Disability Nursing Adviser*

407 My Learning Disability Nursing Adviser said Tom's care had been planned and communicated via standardised care plans which did not take into account his disabilities and communication deficits. She commented that no member of nursing staff appeared to acknowledge that these care plans were unsuitable for Tom. My Learning Disability Nursing Adviser could find no evidence that communicating with Tom and/or those communicating on his behalf had been fully addressed by the Acute Trust.

*My Pharmacy Adviser*

408 My Pharmacy Adviser said calculating an appropriate dose of medicines for a patient as frail as Tom was difficult and would have been complicated by his ongoing weight loss. He noted there may have been a significant risk of unwanted side-effects emerging from a number of the medicines he was receiving and that, although Tom was an adult, given his frailty, the advice of a pharmacist with paediatric experience, or a paediatrician, could have been helpful in tailoring doses more appropriately to his individual requirements. He could find no evidence to indicate that this had been done while Tom was in hospital.

409 My Pharmacy Adviser said there were frequent occasions where correct procedures for writing prescriptions had been overlooked. For example, very few of the medicines written up for 'as required' administration included any additional directions for nursing staff to follow in order to assist them in deciding whether or not an 'as required' dose should be given. He noted that some of the 'as required' prescriptions did not state, as they should have done, the circumstances when a dose might need to be given, a maximum number of doses per day, and the minimum interval between doses or the maximum dose in a 24-hour period. He said the 'as required' prescription for morphine on 15 April 2004 was especially poor, lacked detail and was, therefore, potentially dangerous. He was also concerned to see that the prescription which was written to supply Tom with diamorphine via a syringe driver was incorrectly dated and contained no indication, as it should have done, of the amount of diamorphine to be delivered through the syringe driver within a specified time.

410 My Pharmacy Adviser said there were many potential side-effects from the individual drugs and combination of drugs which Tom was taking. He noted that opioids suppress respiration and taking baclofen at the same time can enhance this problem. Furthermore, he said the sedative effects of drugs like diazepam are increased in a patient taking opioids.

411 My Pharmacy Adviser explained that it was by no means certain that Tom would have experienced all, or indeed any, unwanted side-effects. However, he agreed with my Nursing Adviser's concern that Tom should have been monitored more closely, particularly in the early stages of his admission.

412 My Pharmacy Adviser expressed concern about the regime set up for administration of diamorphine to Tom via a syringe driver. He said the regime did not conform to the recommended method for the control of chronic pain. He said that he could understand and sympathise with the reasons behind choosing to load the syringe driver with a lower dose of diamorphine than was going to be needed, then relying upon additional bolus injections to control Tom's breakthrough pain. However, he said each injection was likely to have caused distress and to have run the risk of Tom suffering unnecessary pain. He said that with this method of pain control more effort and rigour should have been applied to monitoring his clinical response and vital signs, with emphasis on his respiratory rate.

413 My Pharmacy Adviser said the fact that small doses of naloxone were used to good effect pointed to opioid toxicity as the cause of Tom's respiratory depression.

## Care and treatment at the Acute Trust: the Health Service Ombudsman's findings

414 Mr and Mrs Wakefield asked me to investigate the care and treatment which Tom received at the Acute Trust in the seven weeks leading up to his death.

415 It is clear to me that the combination of Tom's complex health needs, poor nutritional state and disabilities meant that reaching a diagnosis and finding appropriate clinical treatment presented a significant challenge. I do not think staff at the Acute Trust shied away from this challenge. I have not seen any evidence that the investigations carried out could be considered unreasonable and I have seen evidence of appropriate measures which were taken to address some of Tom's needs, such as inserting and managing a PEG feeding tube. However, there is also evidence of some failings in nursing care, particularly in assessment, planning and record keeping, relating to nutrition and hydration, and pain management.

416 Having considered all the evidence and taken account of prevailing standards and the advice of my Professional Advisers, I do not think that a list of all the specific failings in what was a complex and challenging situation would provide the most appropriate representation of Tom's experience in the last two months of his life or the nature of the failures of the Acute Trust. Rather, I have decided to consider his care and treatment in the round. From this perspective, I find there is compelling evidence that the Acute Trust failed to provide Tom with a reasonable standard of care and treatment in the circumstances.

417 I have identified aspects of the care and treatment provided by the Acute Trust where I consider the failings are particularly significant:

- The co-ordination and supervision of Tom's care fell well below prevailing standards. Junior doctors and locum staff appeared to lack support in caring for Tom. There was no clear evidence of the appropriate involvement of a pharmacist in the management of his medication. At times communication between the members of the clinical team appears to have been confused. The General Medical Council's booklet Good Medical Practice provides very clear guidance about consultant responsibility for ensuring care is co-ordinated across disciplines, for example, suitable arrangements should be in place when the consultant is not available and locum and junior staff should be properly supported. There is evidence that this did not happen in Tom's case.

- Record keeping was poor and there were gaps in Tom's health records. Both the General Medical Council and the Nursing and Midwifery Council regard good record keeping as an absolutely essential element of nursing and medical care.

- There is evidence of inadequate observations to maintain Tom's safety while he was receiving morphine.

- The arrangements for calculating and managing Tom's medication, particularly his morphine, were poor. Tom was frail, yet his weight seems not to have been factored into the calculation of the dosages of all his medicines. Tom was being given many drugs, yet there was no obvious plan for managing the potential for interaction between them. Instructions for the delivery of Tom's medication were inadequate and created the potential for adverse effects. During the time that Tom was receiving infusions of diamorphine his respiratory rate fell on at least two occasions to a level that required naloxone to be administered. The ALERT arrangements instituted after the first event were not properly followed through and a similar incident occurred soon after.

- The incidents referred to above were not properly recorded, nor was the incident when the nurse allowed some intravenous feed to run through at one time. Vulnerable patients such as Tom rely on staff to demonstrate the highest levels of integrity and accountability. The failure to properly report and record these highly significant incidents put Tom at greater risk of recurrence.

- My Nursing Adviser has pointed to failings in the nursing care provided to Tom. She considered these failings meant the nursing care provided was below the levels expected by the Nursing and Midwifery Council and guidance such as Essence of Care. I have seen nothing which persuades me to question that advice. Rather, it leads me to question whether staff knew how to make appropriate adjustments for a person with learning disabilities.

- My Nursing Adviser and my Learning Disability Nursing Adviser said that the core care plans drawn up on admission did not take into account Tom's disabilities and communication problems. Again, this leads me to question whether staff knew how to make appropriate adjustments for a person with learning disabilities.

- There is no evidence that Tom's parents were made aware of his prognosis and it seems to me that Mr and Mrs Wakefield were not properly involved in discussion about their son's imminent death.

### Care and treatment at the Acute Trust: the Health Service Ombudsman's conclusion

418 I am left in no doubt that the Acute Trust failed to provide Tom with a reasonable level of care and treatment in the circumstances. I consider that many of the failings in the Acute Trust's care and treatment of Tom were for disability related reasons. This was **service failure**.

### Injustice

419 I note my Professional Advisers' views that by the time Tom reached hospital his condition had deteriorated to a point where recovery was unlikely. Nevertheless, I have identified that there were significant failings in the standard of care provided to Tom. This service failure by the Acute Trust contributed to the injustice of unnecessary distress and suffering for Tom and his family and is an **unremedied injustice**.

420 Therefore I **uphold** Mr and Mrs Wakefield's complaint against the Acute Trust.

421 We say more about injustice in Section 4 of this report.

### The Health Service Ombudsman's recommendations

422 I **recommend** that the Chief Executive of the Acute Trust apologise to Mr and Mrs Wakefield for the failings I have set out in this report.

423 I also **recommend** that the Acute Trust offer compensation of £10,000 to Mr and Mrs Wakefield in recognition of the injustice they have suffered in consequence of the service failure I have identified.

### The Acute Trust's response

424 The Chief Executive of the Acute Trust asked to place on record his apology to Mr and Mrs Wakefield. He also offered to meet them to express his personal apologies. He said the Acute Trust is committed to learning from this case and is developing an action plan to address the issues highlighted by my investigation. He explained that this plan will be notified to Monitor and progress would be reported to the Acute Trust Board. Furthermore, the Chief Executive said he would be happy to share the action plan with Mr and Mrs Wakefield. He accepted my recommendation regarding a compensation payment.

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

## Complaint (i): the Healthcare Commission's review of Mr and Mrs Wakefield's complaints

425 Mr and Mrs Wakefield are dissatisfied with the way the Healthcare Commission (the Commission) handled their complaint. They say the Commission's review has not addressed all of their complaints, the Commission has not considered all the relevant information, and the Commission did not take appropriate advice.

## The basis for the Health Service Ombudsman's determination of the complaints

426 The regulations and standards which apply to the Commission's handling of complaints are set out in Section 2 of this report. When assessing the way in which the Commission handled Mr and Mrs Wakefield's complaints I have regard to those regulations and standards and to my own *Principles of Good Administration* and *Principles for Remedy*.

## The Health Service Ombudsman's jurisdiction and role

427 Section 1 above sets out the basis of my jurisdiction in relation to complaints made to me that a person (or body) has sustained injustice or hardship in consequence of maladministration by the Commission in the exercise of its complaint handling function.

428 When complaints have already been reviewed by the Commission, I do not normally carry out an investigation of the original complaint, but investigate the way in which the Commission has conducted its review. Specifically, I consider whether:

i. there were any flaws in the Commission's review process which make the decision unsafe;

ii. the Commission's decision at the end of the review process was reasonable; and

iii. the service the Commission provided was reasonable and in line with its own service standards.

429 When I uphold a complaint about the Commission's complaint handling, because I find that the review process was flawed, or the decision unreasonable, I normally refer the complaint back to the Commission for it to remedy the failure by conducting a further review.

## The Health Service Ombudsman's decision

430 For the reasons given below, I **uphold** Mr and Mrs Wakefield's complaint about the Commission's complaint handling. However, I did not consider it appropriate to recommend a further review by the Commission and I therefore decided to investigate the complaint myself.

## The Commission's reviews

*Key events*

431 Mr and Mrs Wakefield first complained to the Commission in February 2005. Their complaints were that:

- the GP failed to search for the causes of Tom's pain, or to act on the advice of the Hospice doctor;
- the Partnership Trust failed to investigate the impact injury to Tom's ear, failed to carry out appropriate medical investigations, and failed to discharge Tom properly;
- the environment at the Partnership Trust had been unsatisfactory; and
- the PCT had failed to plan properly for Tom's transition into permanent adult accommodation.

432 Mr and Mrs Wakefield said they considered that Tom's death was preventable and had occurred as a result of a combination of failures that had been raised on numerous occasions. Mr and

Mrs Wakefield also said that, although they had not previously complained about the Acute Trust, they wanted the Commission to consider the care and treatment Tom received while he was a patient there because it formed an integral part of his care and would better inform the Commission's overall understanding of their complaint.

433 The Commission's Case Manager wrote to the GP, the Partnership Trust and the PCT in May 2005 to ask for records and files. There was then a gap of five months until Mencap met with the Commission on 25 October 2005 to find out what was happening. They were told that a decision was expected by the end of November 2005.

434 The Commission wrote to Mr and Mrs Wakefield six months later in April 2006 to apologise for the further delay and to update them with the progress of its review. Mr and Mrs Wakefield were informed that, as three different health providers had been complained about, separate case numbers had been allocated to the respective complaints.

*The Commission's first decision*

435 The Commission issued its first decision on 28 April 2006. In its letter, the Commission only addressed Mr and Mrs Wakefield's complaint against the PCT. The Commission found that, although Mr and Mrs Wakefield's complaint had been acknowledged by the PCT, the PCT had held back from issuing a full response because of the proximity of the anniversary of Tom's death. When it learned that the Commission would be investigating the complaint, the PCT decided not to respond until the Commission had finished its investigation. The Commission decided to refer the complaint back to the PCT recommending that the PCT apologise and explain its reasons for not responding, and address Mr and Mrs Wakefield's complaint, albeit belatedly.

*The PCT's response*

436 The PCT wrote to Mr and Mrs Wakefield on 12 June 2006. The PCT said there was little it could add to the responses that Mr and Mrs Wakefield had received from the Partnership Trust and Social Services, except to say that as a service commissioner it would be looking at how the identified shortcomings had been addressed, particularly with regard to communication issues between different clinical teams and professionals, and in improving the quality and speed of communication. The PCT apologised for its failings and said that it had learnt from this complaint and had amended its protocols to reflect this.

*The Commission's second decision*

437 On 12 May 2006 the Commission issued its second decision about Mr and Mrs Wakefield's complaint. This addressed the complaint against the GP. The GP had informed the Commission that he no longer held Tom's clinical records; however, he sent the Commission a copy of the computerised GP patient summary notes and a prescribing history for Tom. There is no evidence to indicate that the Commission asked for medical records from any other source.

438 The Commission sought clinical advice from a GP (the Commission's First GP Adviser) who, on the basis of the information provided by the GP, concluded that he '*had acted entirely appropriately in looking after Tom*'. He said that the GP's explanations for his clinical decisions were accurate and appropriate and were supported by the clinical records.

439 In the light of the clinical advice which the Commission had obtained, the Commission decided not to take any further action on the complaint against the GP.

*The Commission's final decision*

440 On 10 May 2006, two days before the second decision was issued, Mencap contacted the Commission to raise their concerns about the Commission's first decision. They said Mr and Mrs Wakefield were dissatisfied that, after 15 months, the Commission had decided to refer their complaint about the PCT back to the PCT – and that their other complaints had not been addressed at all.

441 On 21 June 2006 the Commission informed Mr and Mrs Wakefield that, although decisions on the complaints against the PCT and the GP had already been issued on 28 April and 12 May 2006, in the light of Mencap's letter, these complaints would now be reconsidered together with the complaint against the Partnership Trust which appeared not to have been considered at all up to that point. No mention was made of Mr and Mrs Wakefield's complaint about the Acute Trust.

442 In October 2006 the Case Manager informed Mr and Mrs Wakefield that their case was being reallocated to another case manager. The new Case Manager spoke to Mrs Wakefield in November 2006 to clarify the heads of complaint; she wrote to her on 21 November 2006 to confirm that she would be reviewing the complaint in its entirety.

443 The Commission split Mr and Mrs Wakefield's complaint against their GP into six issues which included their concerns that the GP failed to search for the causes of Tom's pain, act on the advice of the Hospice doctor or manage Tom's nutritional needs adequately. As part of its review, the Commission obtained advice from a different GP (the Commission's Second GP Adviser). In her report the Commission's Second GP Adviser referred to the General Medical Council's 2006 version of Good Medical Practice, to information contained on an American website concerned with gastrointestinal endoscopy, and to National Institute for Clinical Excellence guidance on dyspepsia issued in August 2004. She concluded that:

- it was unclear whether Tom's parents were present when the decision not to refer Tom for endoscopy was discussed on 17 October 2003. However, the GP's grounds for not referring Tom for endoscopy were reasonable;
- it was unlikely that vomiting or feeding difficulties were major problems for Tom during the time in question;
- there was no evidence to suggest that a PEG feeding tube had been considered; however, the Adviser did not consider that the conditions for the insertion of a PEG feeding tube had been met up to November 2003;
- there was no evidence of a formal diagnosis of hip dislocation and she thought the GP's management of Tom's pain had been reasonable; and
- communication between the healthcare professionals and Tom's parents could have been improved. She recommended that a clear indication be given as to who is expected to make a referral for specialist advice. She recommended that the GP review his practice and protocols against the National Institute for Clinical Excellence guidance CG17 on dyspepsia.

444 The Commission divided Mr and Mrs Wakefield's complaint against the Partnership Trust into five issues which included their concerns that staff

failed to investigate the impact injury to Tom's ear, failed to carry out appropriate medical investigations and failed to discharge Tom properly. As part of its review, the Commission sought professional advice from a learning disability nurse (the Commission's Learning Disability Adviser) and a consultant psychiatrist (the Commission's Psychiatric Adviser).

445 The Commission's Learning Disability Adviser made some general comments about the way in which transition should have been handled. However, she focused on the injury that Tom sustained while a patient at the Partnership Trust. She was critical of the Partnership Trust's investigation into Tom's injury and did not consider that the Trust's response went far enough. The only record of this advice is a note of her discussion with the Commission's Case Manager. It is unclear whether this adviser reviewed Tom's nursing records.

446 The Commission's Psychiatric Adviser said:

- in view of Tom's deteriorating health, his admission to the Partnership Trust was not inappropriate. He noted that a carefully considered clinical plan had been drawn up and some progress had been made. He felt that urgent referral had not been required;

- the Partnership Trust had acknowledged that Tom's discharge had not been handled well, and that action had been taken to ensure that there would not be a reocurrence. Further, the Partnership Trust appeared to have been quite open about shortcomings and had initiated action to produce system changes and there was nothing more that he could add; and

- he had been struck by the meticulous efforts of the Consultant in Charge. Tom had received a relatively good standard of care at the Partnership Trust and much of the remaining unresolved complaint stemmed from differing views on the optimum approach to Tom's clinical management.

447 The Commission's Psychiatric Adviser did, however, make some recommendations. These included that the Partnership Trust:

- consider whether it required input from a dedicated GP to look after the patients' physical health needs and a specialist liaison nursing team to facilitate access to mainstream secondary medical care;

- consider more consultation with key stakeholders regarding care; and

- embrace the latest guidance on consent which, if it had been used fully, would have evidenced consultation with partners in Tom's care.

448 The Commission issued its final decision on 31 January 2007. In respect of Mr and Mrs Wakefield's complaint about the PCT, the Commission said that, in its response of 12 June 2006, the PCT had explained why it had not responded initially to Mr and Mrs Wakefield's complaints, offered an apology for that, and had subsequently reviewed the responses which Social Services and the Partnership Trust had provided. The Commission concluded that this was an appropriate response from the PCT as a service commissioner, and that no further action on the part of the PCT was warranted.

449 The Commission did not uphold any of Mr and Mrs Wakefield's complaints about the GP.

450 The Commission did not uphold Mr and Mrs Wakefield's complaints about the appropriateness of Tom's admission to the Partnership Trust or the failure of staff there to carry out medical tests. The Commission concluded that the Partnership Trust had been open about the failures in the discharge process and was satisfied that changes had been put in place to ensure that discharge arrangements were more effective in the future. The Commission did, however, uphold Mr and Mrs Wakefield's complaint about the Partnership Trust's investigation into the injury which Tom sustained while in its care. The Commission recommended that the lessons from the incident be shared with staff and the Partnership Trust offer Mr and Mrs Wakefield an unreserved apology for the way in which this incident was handled.

451 The Commission made no reference to Mr and Mrs Wakefield's complaint about the Acute Trust.

## The advice of the Health Service Ombudsman's Professional Advisers

452 I asked my Professional Advisers for their views about the Commission's clinical advice. They considered that the advice from the GP and consultant psychiatrist was appropriate. However, they were concerned that the Commission did not seek appropriate professional advice about Tom's general medical and nursing needs while he was at the Partnership Trust. Such advice has been critical to my investigation of the Partnership Trust's actions.

## The Health Service Ombudsman's findings

453 I have explained that I assess the way in which the Commission conducted its review by considering the review process, the decision and whether the service provided was reasonable.

454 I find that the Commission's process was flawed. It is clear that Mr and Mrs Wakefield wanted the Commission to bring all four aspects of their complaint together and investigate them in the round. The Commission did not do this, deciding instead to split Mr and Mrs Wakefield's complaint into discrete elements.

455 The Commission then failed to address significant aspects of Mr and Mrs Wakefield's complaint. Initially, the Commission only provided decisions about two of the four bodies that Mr and Mrs Wakefield had complained about (the PCT and the GP). Mr and Mrs Wakefield's complaint about the Partnership Trust and Acute Trust were not addressed. Following Mencap's intervention, the Commission decided to re-review their complaints. This was the Commission's opportunity to get its handling of Mr and Mrs Wakefield's complaint right. The Commission's final report, issued on completion of the reconsideration process, did address Mr and Mrs Wakefield's complaints about the GP, PCT and Partnership Trust as a whole. That said, I can understand their disappointment that the Commission's report contained no synthesis of its findings – and still no mention was made about their complaint against the Acute Trust.

456 I also have concerns about the Commission's clinical advice. First, the Commission did not obtain Tom's full health records to inform its assessment of the care provided by the GP. I am not persuaded that either of the Commission's

GP Advisers could reach a properly informed view about Tom's care and treatment without this information.

457 Secondly, my Professional Advisers have raised concerns that the Commission did not seek appropriate professional advice about Tom's general medical and nursing needs while he was a patient at the Partnership Trust. I would expect that when the Commission reviews complaints which involve clinical care, it would obtain appropriate advice from professional advisers with relevant experience and expertise. Clearly, in order to properly and comprehensively address Mr and Mrs Wakefield's complaint about the standard of care and treatment their son received at the Partnership Trust, the Commission should have obtained appropriate medical and nursing advice. Whilst the Commission appears to have taken advice from a specialist learning disability nurse, the only record of that advice is a note of a discussion between that adviser and the Commission's Case Manager, and it is unclear whether the Commission's Learning Disability Adviser had reviewed Tom's nursing records. My findings from my own investigation have raised serious concerns about the nursing care provided to Tom and underline the extent to which the absence of appropriate general nursing advice impacted on the quality of the Commission's response.

458 I find that the clinical advice which the Commission obtained was inappropriate and inadequate. This renders its decisions unreliable and unsafe.

459 Finally, I find that some of the Commission's decisions were not adequately explained. The Commission did not uphold Mr and Mrs Wakefield's complaint about the GP, but did not explain why its Clinical Adviser had reached the view that the GP had acted entirely appropriately in looking after Tom. I note also that, in respect of the Commission's final decision, the Commission's Psychiatric Adviser found that the care and treatment provided by the Partnership Trust had been reasonable, yet he made a number of significant recommendations for improvement. The Commission appears to have accepted this view and reflected it in its final decision letter without questioning the contradictory messages that such a response conveyed to Mr and Mrs Wakefield.

460 I also find that the Commission provided a poor service. It took the Commission 15 and 17 months to complete the reviews of Mr and Mrs Wakefield's complaints about the PCT and the GP respectively, and 8 months to complete the re-review. Its service standard at the time was that, in the majority of cases, the review process should take no longer than six months. Whilst I do not consider that the length of time it took the Commission to complete the reviews would necessarily, in itself, amount to a poor service, I was concerned to note that there were long gaps during its first and second reviews when the Commission did not keep in touch with Mr and Mrs Wakefield. In particular, there appear to have been two occasions where the Commission did not contact Mr and Mrs Wakefield for approximately five months. One of the six *Principles of Good Administration* (referred to in Section 2 of this report) is that public bodies should be customer focused, and specifically that they should tell people if things are going to take longer than they had said they would. Failing to do this, and failing to have made contact with the complainants for such lengthy periods of time does not, in my view, reflect good administrative practice or customer service.

461 I conclude that the failings I have identified in the Commission's handling of Mr and Mrs Wakefield's complaint amount to **maladministration**.

## Injustice

462 The injustice arising from the Commission's maladministration is that Mr and Mrs Wakefield did not get the joined-up, comprehensive review of their complaints to which they were entitled. The Commission's review fell far short of a reasonable standard and, in particular, did not provide them with the explanations they sought.

463 Therefore, I **uphold** Mr and Mrs Wakefield's complaint against the Commission.

## The Health Service Ombudsman's recommendation

464 I **recommend** that the Commission apologise to Mr and Mrs Wakefield for failing to carry out a proper review of their complaint.

## The Commission's response

465 The Chief Executive has accepted my recommendation and she will write to Mr and Mrs Wakefield to express her apologies once this report has been issued.

# Section 4: the Ombudsmen's final comments

## Introduction

466 Mr and Mrs Wakefield's overarching complaint is that Tom's death was avoidable, that he suffered unnecessarily and received less favourable treatment for reasons related to his learning disabilities. In this the final section of our report we address Mr and Mrs Wakefield's overarching complaint.

467 In assessing the actions of the Surgery, the PCT, the Partnership Trust, the Council and the Acute Trust we have taken account of relevant legislation and related policy and administrative guidance as described in Section 2 of this report. We have taken account of available evidence and considered the advice of our Professional Advisers.

## Was Tom treated less favourably for reasons related to his learning disabilities? The Ombudsmen's conclusions

468 Mr and Mrs Wakefield believe their son was treated less favourably for reasons related to his learning disabilities.

469 The Local Government Ombudsman concluded that some of the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons.

470 The Health Service Ombudsman found that there were shortcomings in the PCT's fulfilment of its responsibilities with regard to the planning for the health needs of people with profound and multiple learning disabilities and concluded that this service failure by the PCT was for disability related reasons.

471 The Health Service Ombudsman also found service failures by the Partnership Trust and concluded that some of these service failures, in terms of managing Tom's discharge and Tom's care and treatment, were for disability related reasons.

472 The Health Service Ombudsman also found service failure in relation to the nursing and medical care provided by the Acute Trust and concluded that some of these service failures were for disability related reasons.

473 In Section 2 we set out our approach to human rights. On that basis, we also conclude that the service failure and maladministration at the Council, the Partnership Trust, the PCT and the Acute Trust constituted a failure to live up to human rights principles, especially those of dignity and equality.

474 There is no evidence of any positive intention to humiliate or debase Tom. Nevertheless, the standard of service does raise the question whether the actions of the Council, the Partnership Trust, the PCT and the Acute Trust constitute a failure to respect Tom's dignity.

475 In these respects we conclude that the maladministration and service failures we have found showed inadequate respect for Tom Wakefield's status as a person.

## Did Tom suffer unnecessarily?

476 The Health Service Ombudsman concludes 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?

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

478 In considering whether to make a finding about avoidable death we assessed whether the injustice or hardship complained about (in this case Tom's death) arose in consequence of the service failure or maladministration we have identified.

479 We have concluded that there was public service failure by the Council, the PCT, the Partnership Trust and the Acute Trust and that those combined failings resulted in significant unremedied injustice for Tom and his parents. Mr and Mrs Wakefield will never know if, had appropriate arrangements been in place – as they should have been – for Tom'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.

480 However, on balance, we cannot say that Tom's death was in consequence of the service failure or maladministration we identified. Rather, we have seen that Tom's condition was declining for many years and that this decline began before the events complained about. Therefore, we cannot conclude that Tom's death was avoidable.

## Mr and Mrs Wakefield's response to the Ombudsmen's draft report

481 Mr and Mrs Wakefield were dissatisfied with the outcome of some aspects of our investigation. Their response to our report contained many detailed points which we have addressed separately in liaison with Mencap. However, Mr and Mrs Wakefield's dissatisfaction focused primarily on the Health Service Ombudsman's decision not to uphold their complaint against the Surgery. They continue to believe that the '*actions of the GP were pivotal*' to what happened to Tom. They also strongly disagree with the decision of both Ombudsmen where we did not conclude that Tom's death was avoidable. In particular, Mr and Mrs Wakefield do not accept that their son was '*in an inevitable decline*'. They asked for a more detailed explanation of the advice provided by the Second Gastroenterology Adviser. They also said that essential evidence in support of their position could be provided by the Hospice's Medical Director and they asked for him to be interviewed.

482 In response to Mr and Mrs Wakefield's concerns the Health Service Ombudsman asked for further, more detailed advice from the Second Gastroenterology Adviser (now included at Annex C of this report) and she arranged for the Hospice's Medical Director to be interviewed (now included in the section of this report relating to the Surgery).

483 The Health Service Ombudsman carefully considered the additional information provided by the Second Gastroenterology Adviser and the interview evidence of the Hospice's Medical Director. However, she found no evidence that would cast doubt on her findings and decisions about the Surgery. Furthermore, after careful deliberation, neither Ombudsman found any grounds in the new evidence which would cast doubt on their conclusion about whether Tom's death was avoidable.

## Our concluding remarks

484 In earlier sections of this, our joint report, we have set out our investigation and findings with regard to the care, treatment and service Tom Wakefield and his parents received from the Council, the NHS and the Healthcare Commission. We are acutely aware that our findings will undoubtedly cause further distress to Mr and Mrs Wakefield and that they do not agree with all our conclusions. However, we can assure them that their complaints have been thoroughly and impartially investigated and that our conclusions have been drawn from careful consideration of detailed evidence, including the opinion of independent professional advisers.

485 We hope our report will provide Tom's family with the explanations they seek and reassure them that lessons have been learnt and learning shared as a result of their complaint, so that others are now less likely to suffer the same experiences as they and their son did. We also hope that our report will draw what has been a long and complex complaints process to a close.

Ann Abraham
**Parliamentary and Health Service Ombudsman**

Jerry White
**Local Government Ombudsman**

March 2009

# ANNEX A

## Good Medical Practice, 2001: Relevant sections

### The duties of a doctor

*'Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:*

- *make the care of your patient your first concern;*
- *treat every patient politely and considerately;*
- *respect patients' dignity and privacy;*
- *listen to patients and respect their views;*
- *give patients information in a way they can understand;*
- *respect the rights of patients to be fully involved in decisions about their care;*
- *keep your professional knowledge and skills up to date;*
- *recognise the limits of your professional competence;*
- *be honest and trustworthy;*
- *respect and protect confidential information;*
- *make sure that your personal beliefs do not prejudice your patients' care;*
- *act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;*
- *avoid abusing your position as a doctor; and*
- *work with colleagues in the ways that best serve patients' interests.*

*In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.'*

### Providing a good standard of practice and care (sections 2 and 3)

*'Good clinical care must include:*

- *an adequate assessment of the patient's conditions, based on the history and symptoms and, if necessary, an appropriate examination;*
- *providing or arranging investigations or treatment where necessary;*
- *taking suitable and prompt action when necessary;*
- *referring the patient to another practitioner, when indicated.*

*'In providing care you must:*

- *recognise and work within the limits of your professional competence;*
- *be willing to consult colleagues;*

- *be competent when making diagnoses and when giving or arranging treatment;*
- *keep clear, accurate, legible and contemporaneous patient records which report the relevant clinical findings, the decisions made, the information given to patients and any drugs or other treatment prescribed;*
- *keep colleagues well informed when sharing the care of patients;*
- *provide the necessary care to alleviate pain and distress whether or not curative treatment is possible;*
- *prescribe drugs or treatment, including repeat prescriptions, only where you have adequate knowledge of the patient's health and medical needs. You must not give or recommend to patients any investigation or treatment which you know is not in their best interests, nor withhold appropriate treatments or referral;*
- *report adverse drug reactions as required under the relevant reporting scheme, and co-operate with requests for information from organisations monitoring the public health;*
- *make efficient use of the resources available to you.'*

## Working with colleagues (section 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. When working in a team, you must:*

- *respect the skills and contributions of your colleagues;*

*...*

- *communicate effectively with colleagues within and outside the team.'*

## Arranging cover (section 39)

*'You must be satisfied that, when you are off duty, suitable arrangements are made for your patients' medical care. These arrangements should include effective hand-over procedures and clear communication between doctors.'*

## Delegation and referral (section 46)

*'Delegation involves asking a nurse, doctor, medical student or other health care worker to provide treatment or care on your behalf. When you delegate care or treatment you must be sure that the person to whom you delegate is competent to carry out the procedure or provide the therapy involved. You must always pass on enough information about the patient and the treatment needed. You will still be responsible for the overall management of the patient.'*

# ANNEX B

## Summary of events at the Acute Trust

**6 April 2004**
Tom was admitted following a request from his GP for investigation and treatment of pain. He had opened his bowels that day and the abdominal X-ray performed on admission did not reveal anything diagnostic. Constipation was ruled out. The surgical team found it extremely difficult to assess Tom, but routine examinations and investigations for abdominal pain were performed. He was promptly transferred to the care of the gastroenterology clinical team. The consultant was on leave for the first week of Tom's admission. There was liaison with Tom's mother, his carers and the GP. Advice was sought from a consultant specialising in the management of acute pain who emphasised the importance of establishing an accurate diagnosis of the cause of the pain to enable a logical management plan.

The gastroenterology team discussed the various known causes of Tom's pain. Although it was clear that Tom had suffered with musculoskeletal pain for some time it was thought, on balance, that Tom also had abdominal pain – primarily because of his decreased appetite and '*spasms of the abdominal wall*'.

The initial management plan for Tom was to try to exclude a gastrointestinal cause for his symptoms by investigating Tom by endoscopy under sedation, by abdominal ultrasound and by treating him for constipation even though the X-ray taken on admission had not shown specific evidence of this.

**13 April 2004**
The Community Learning Disability Team notes indicate they offered support to ward staff at the Acute Trust in managing Tom. The Community Learning Disability Team Speech and Language Therapist requested a referral for a swallow assessment, and ward staff reported that a referral had been made. The Community Learning Disability Team Speech and Language Therapist noted that Tom was eating custard and breathing it into his upper respiratory passages before swallowing. Therefore, in her view, he was at risk of aspiration. She also noted that he appeared to have a chest infection and she suggested that Tom should be 'nil by mouth' (that is, he should be given no fluid or food orally).

**15 April 2004**
An endoscopy was performed. This revealed inflammation of the gullet with ulceration caused by gastric acid from the stomach through a wide opening between the stomach and the gullet. Tom was treated with strong doses of proton pump inhibitors – drugs to suppress acid production so that refluxed gastric products are less likely to damage the gullet and cause pain. This treatment did not seem to provide Tom with relief.

**16 April 2004**
The Acute Trust's Speech and Language Therapist assessed Tom and found his swallow to be unsafe, with risk of inhalation of swallowed food and liquid. She recommended that Tom should be nil by mouth and a PEG feeding tube should be fitted. Tom was hydrated intravenously.

**17 April 2004**
Tom's health records show his white blood cell count was raised, implying continued infection despite intravenous antibiotic treatment.

**20 April 2004**
An abdominal ultrasound was performed but revealed nothing abnormal.

**21 April 2004**
A CT scan showed no evidence of a source of pain in the biliary tract, pancreas or abdomen, but did reveal extensive pneumonia in the lower half of Tom's left lung. This was treated with intravenous antibiotics.

**22 April 2004**
Tom suffered an episode of severe respiratory failure which did not appear to be related to his pneumonia, but resulted from a loss of respiratory drive (a failure to breathe). His respirations fell to 7 per minute. He responded rapidly to an injection of naloxone, an antidote to drugs of the morphine group.

The Community Learning Disability Team nurse noted her concern about the standard of nursing care provided to Tom, and about the uncertainty regarding Tom's future. She noted there was a difference of view between health professionals, for example, with regard to insertion of a PEG feeding tube. She noted it had been agreed that there should be a meeting to discuss these concerns and agree a way forward.

**27 April 2004**
A PEG feeding tube was inserted and feeding was initially successful, but Tom's pain was still not well controlled.

**3 May 2004**
A further respiratory crisis occurred when Tom's pulse rate became markedly elevated and his blood oxygen saturation level fell well below normal. It was thought that this was caused by further inhalation of refluxed feed from the stomach. It was therefore decided that all PEG feeding should occur during the day while Tom was sitting up, rather than at night while he was lying down.

**5 May 2004**
PEG feeding was stopped when a carer accidentally pulled out the PEG feeding tube. Nutrition was provided intravenously.

A nurse allowed 300ml of intravenous feeding through in a short time.

**7 May 2004**
A substitute PEG feeding tube of paediatric size was inserted, to allow administration of drugs.

**11 May 2004**
The small tube was replaced by a larger one.

**12 May 2004**
The Community Learning Disability Team notes record that although the PEG feeding tube had been refitted little feed was going in. The Speech and Language Therapist expressed concern regarding Tom's weight, which she noted as being approximately 4 stone.

**19 May 2004**
The Community Learning Disability Team's Speech and Language Therapist noted that when she had visited Tom, although she had found him to be better, he was still very thin and was losing weight although the PEG feed was being increased.

**20 May 2004**
The PEG feeding tube fell out while Tom was being bathed and a new tube was inserted.

**23 May 2004**
During the night Tom suffered a further respiratory crisis with reduced respiratory rate associated with hypothermia. He was reviewed by an Intensive Therapy Unit consultant.

**24 May 2004**
Tom suffered another episode of severe respiratory failure which did not appear to be related to his pneumonia, but resulted from a loss of respiratory drive. Naloxone was administered.

**25 May 2004**
Tom died at 5.00pm.

# ANNEX C

## Further clinical advice provided by the Second Gastroenterology Adviser

The following detailed clinical advice was provided by Dr Ralph Barry in response to Mr and Mrs Wakefield's comments on the draft report.

## Avoidable death

On this issue Dr Barry said:

> *'Mr and Mrs Wakefield challenge the finding in the draft report that Tom's death was not avoidable. This finding is based in part on the statement in my initial advice that, "I feel that Tom's mode of death was consistent with the natural history of such a degree of disability". I remain of this opinion.*
>
> *'...*
>
> *'It is important to understand, however, that the statement refers to the manner of Tom's sad death, not the timing. The clinical evidence indicates that Tom's death occurred as a result of the progressive physical consequences of the brain injuries sustained at birth, of which his learning disabilities were but one manifestation.'*

Dr Barry described the neurological consequences of Tom's cerebral palsy (other than his learning disabilities) and the consequential vulnerability of his respiratory system. He said:

> *'The weakness, rigidity and inco-ordination of the muscles of the upper throat resulted in inhalation of swallowed liquids which causes collapse of the lung by blocking the airways. Infection of the collapsed lung will usually follow (pneumonia). In Tom, the risks of major inhalation were markedly increased by the free reflux of stomach contents backwards into the oesophagus. The marked kyphoscoliosis (abnormal curvatures that result from abnormal muscle stresses on the spine) seriously decreases lung volumes and also considerably reduces movements of the ribs. As a result, ventilation of the lungs is seriously impaired (restrictive lung disease) as also is the ability to cough effectively. This impairment of the protective cough reflex further increases the risks of developing pneumonia and the reduced lung volumes exacerbate the consequences of such infections. It is for these reasons that I consider lung problems as the Achilles heel of this particular neurological damage. There is clear, objective evidence in the clinical record that Tom had episodes of serious inhalation and an established pneumonia in the period prior to his death.*
>
> *'I believe Tom's death was entirely consistent with the pattern I have outlined above, but I am unable to say it was avoidable. Rather, it was a consequence of his difficulties in swallowing and gastro-oesophageal reflux. The impaired swallowing was a consequence of the neurological damage sustained at birth. The gastro-oesophageal reflux had also been a problem since infancy.'*

## The nature and time of Tom's decline

On this issue Dr Barry said:

> *'Much of the evidence for Tom's "decline" comes from the observations of his parents and various carers and antedates Tom's admission to the Acute Trust. On the basis of the documentation available to me, there seem to be three strands to Tom's deterioration in health namely progressive weight loss, pain and*

*(possibly) reflux oesophagitis (inflammation, ulceration or bleeding of the oesophagus caused by reflux of acid from the stomach).*

'***Progressive weight loss***

*'It would appear that visible weight loss became a concern to his carers some time in the autumn of 2003 as evidenced by: (i) documented 3.7kg weight loss between November 2003 and February 2004; (ii) Speech and Language Therapy assessment on 19 November 2003 recording a decline in nutritional status; (iii) photographic evidence of weight loss over a period of 18 months; and (iv) correspondence from the manager of the Respite Centre which refers to a considerable weight loss over nine months since October 2003. I also note that Tom was described as "very slim" on admission to the Windrush Unit. It is apparent that much of Tom's weight loss occurred before his admission to the Acute Trust. However, given the visible evidence of weight loss, it is surprising that there is such a paucity of objective measures of Tom's weight during his admission to the Acute Trust. By 17 and 21 May 2004, Tom's weight was recorded as 25 and 28.3kg respectively which is clearly abnormal for his age.*

'***Pain***

*'Pain was clearly a long-standing feature of Tom's condition. The date of onset is not clear. It was responsible for his admission to the Acute Trust in March and April 2004, but was also the apparent reason for his referral to the Hospice in March 2003. The correspondence from the Hospice indicates that the cause of pain was believed to be multifactorial, but that the dominant cause was probably musculoskeletal (meaning that it arose from his muscular spasticity and skeletal deformity). At that time, pain from his bowel was also believed to be a factor, but pain from reflux oesophagitis was not considered significant.*

*'The impression from the records is that the pain contributed to Tom's "decline" because of increasing severity or frequency and the difficulty in controlling it.*

'***Reflux oesophagitis***

*'It is difficult to be certain that reflux oesophagitis was a true factor in Tom's "declining health", but I understand that it is an important factor in his parents' eyes. However, the timing of the onset of symptoms of oesophagitis is clear, because Tom required surgery in infancy for bleeding oesophagitis caused by gastro-oesophageal reflux. The clinical correspondence from Tom's carers prior to his admission to the Acute Trust indicates that Tom was treated with antacid medications throughout his life because of perceived reflux symptoms.*

*'In respect of these three factors, I would offer the following observations.*

*'The most obvious and visible component of Tom's decline is his weight loss. His nutritional deterioration was not inevitable and his parlous nutritional state should undoubtedly have received earlier and more aggressive attention. On admission to the Acute Trust, the medical notes do not convey a sense of urgency in his nutritional management, although the recognition of impaired swallowing on 16 April 2004 required the discontinuation of oral feeding before the insertion of a PEG feeding tube. However, notwithstanding Tom's obvious weight loss, he died of infection*

*(pneumonia) and not of starvation. The cause of the pneumonia was inhalation pneumonitis in the context of impaired lung function and gastro-oesophageal reflux that had been present from infancy. The presence of oesophagitis is symptomatic of the gastro-oesophageal reflux but is not directly relevant to inhalation – the cause of his death.*

*'In their response ... Mr and Mrs Wakefield reasonably ask, "At what point do the clinical advisors think that it was reasonable to assume that Tom's life was at risk ...". My response would be, from the time at which it was recognised that Tom's swallow was unsafe (19 November 2003, confirmed again on 16 April 2004). However, the risk of inhalation dated from infancy.*

*'Tom's pain was a very distressing component of his "decline" and I am very critical of the management of his pain. However, I have not said that at no point was Tom's pain fully investigated. Tom underwent various blood tests and X-rays immediately on admission to the Acute Trust and was then appropriately referred to specialist gastroenterologists who investigated by further blood tests, upper gastrointestinal endoscopy, ultrasound scans, computed tomography (CT scans) and the further advice of a consultant specialist in pain was also obtained. Notwithstanding these investigations, the definitive cause of Tom's pain was not specifically identified – as witnessed by several references in the clinical record to this uncertainty.*

*'From Mr and Mrs Wakefield's response to the draft report, it seems they are of the view that his pain was caused by reflux oesophagitis and would have been relieved by early diagnosis at endoscopy. I am obliged to regard this (very understandable) belief as an unsafe assumption for the following reasons. In reflux oesophagitis, pain does not correlate well with the severity of the visible changes in the oesophagus. Severe, bleeding oesophagitis may be completely painless. Pain can also be quite severe in the total absence of any visible inflammation. Of direct relevance, however, is the observation that Tom's pain was not relieved or modified when his oesophagitis was treated with very powerful acid suppressants following endoscopy in the Acute Trust.'*

## Is there a point at which an opportunity to prevent or delay Tom's decline was missed?

On this point Dr Barry said:

*'I am unable to identify any evidence of a specific point at which an opportunity existed to change the course of Tom's decline. However, I remain of the view that after the Autumn of 2003, when Tom's weight loss appears to have been identified, appropriate nutritional support should have been instigated. Arguably, this may have arrested his weight loss or even improved his resistance to infection. However, Tom's death resulted from inhalation which was not specifically related to his declining weight.'*

## Conclusion

Dr Barry concluded by saying:

*'It is apparent that I had failed to make it explicitly clear in my initial advice that Tom's very sad death was related to the progressive physical consequences of his brain injury (not his learning disabilities) and the functional*

*abnormalities of his lower oesophagus that had been present from infancy. I have tried to clarify these issues above.*

*'I remain critical of the issues highlighted in my original advice. I fully appreciate the concerns that Tom's parents have eloquently expressed and I am conscious of the distress they have suffered. From the moment of birth, death cannot be avoided, only postponed, and only very rarely is it possible to say when. In Tom, the volume of his gastro-oesophageal reflux was an ever-present danger. Once his ability to swallow became impaired, presumably a consequence of the neurological damage sustained at birth, episodes of inhalation and consequential pneumonias seem inevitable.'*

# ANNEX D

## Re-feeding syndrome

Mrs Wakefield asked about 're-feeding syndrome'. She wondered whether Tom had suffered from this while he was at the Acute Trust and whether it was one of the factors leading to his deterioration and death.

The First Gastroenterology Adviser explained that 're-feeding syndrome' occurs when malnourished patients are fed too aggressively after a period of starvation. The body switches over to using glucose as an energy source with high levels of insulin released which drives essential minerals, such as phosphate, into cells and increases magnesium and potassium loss in the urine. These changes affect all body organs and are potentially very dangerous. The careful monitoring of the blood levels of these minerals is essential when feeding is restarted. He noted that because a post mortem was not carried out it was not possible to say whether Tom suffered from 're-feeding syndrome' in addition to his other conditions. We note that the Acute Trust has informed us that its retrospective review of records demonstrates that 're-feeding syndrome' did not occur in Tom's case.

We hope that this information is of some help to Mrs Wakefield.

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