

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

## Part six: the complaint made by Mrs Ryan

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## Second report

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## Section 1: introduction and summary

1 This is the final report of my investigation into Mrs Ryan's complaint against Kingston Hospital NHS Trust (the Trust). The report contains my findings, conclusions and recommendations with regard to Mrs Ryan's areas of concern.

### The complaint

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

3 On 26 November 2005 Mr Ryan suffered a stroke. Care Home staff called an ambulance and he was admitted to the Trust accompanied by one of his carers. He arrived at the Accident and Emergency Department (A&E) at around 5.15am and was admitted to the Clinical Decision Unit before being transferred to the Ward later that day. The Ward was a general medical ward with 16 beds allocated to endocrine consultants and 14 beds allocated to respiratory consultants. The Ward had no specific facilities for the care of stroke patients. There was no stroke unit at the Trust. While Mr Ryan was in the Ward carers from the Care Home stayed with him and took responsibility for some of his basic care. However, the relationship between the carers and Ward staff broke down during the course of Mr Ryan's hospital stay. His Community Learning Disability Team Nurse, whose role was to look after Mr Ryan's health needs as a person with a learning disability, also visited him on several occasions.

4 The stroke affected Mr Ryan's ability to swallow and as a result he could not eat or drink normally. Over the weeks which followed he was seen and assessed by various members of the multidisciplinary team, including speech and language therapists, a consultant respiratory physician (the Consultant), and junior doctors and nurses. He also underwent tests and investigations. The clinical team found it difficult to assess and treat Mr Ryan because he could not co-operate fully with them. They waited until 12 December 2005 before deciding that Mr Ryan's ability to swallow had not returned and alternative feeding would be needed. However, no attempt was made to feed Mr Ryan nasogastrically or intravenously.

5 On 13 December 2005 doctors decided to insert a percutaneous endoscopic gastrostomy (PEG) feeding tube, so that Mr Ryan could be given liquid feed via a tube passed through the wall of his abdomen into his stomach. However, this has to be inserted during a formal operation, and by the time an appropriate slot could be found in the operating theatre timetable Mr Ryan had developed pneumonia and was too ill to undergo surgery. Doctors decided that Mr Ryan was unlikely to survive and palliative care was introduced. With palliative care the focus is on alleviating the symptoms of the illness, rather than treating the illness itself. Mr Ryan died five days later, on 21 December 2005, twenty-six days after he was admitted. The primary causes of death, as recorded on his death certificate, were '*aspirational pneumonia*' (pneumonia which developed because he inhaled stomach contents causing an infection) and '*cerebrovascular accident*' (a stroke). '*Down's Syndrome*' was recorded as a secondary factor.

- 6 Mrs Ryan says she was not worried about her son when he was admitted to hospital because she thought Trust staff would protect and care for him and he would be safe *'in good hands'*. However, she believes Trust staff had no understanding of people with learning disabilities and they may have been afraid of him. She says this led them to ignore him so his needs were not met and he *'starved to death'*. Mr Ryan's sister says the Trust *'didn't bother feeding [him] because he had Down's Syndrome'*.
- 7 Mrs Ryan acknowledges that the Trust has worked hard to find out what happened to Mr Ryan and that the Trust has been open and transparent about failings it identified in his care and treatment. She also recognises that the Trust has acknowledged and apologised for those failings. However, she does not agree with all the Trust's explanations. In particular, she does not agree with the Trust's position that the acknowledged failings in Mr Ryan's case were not specifically related to his learning disabilities.
- 8 Mrs Ryan has given permission for Mencap to act as her representative. Mencap have assisted Mrs Ryan since she first complained to the Trust in February 2006.

### The overarching complaint

- 9 Mrs Ryan believes her son's death was avoidable and that he received less favourable treatment at the Trust for reasons related to his learning disability. I have called these aspects of her complaint 'the overarching complaint'.

### Complaint against the Trust

- 10 Mrs Ryan complains that:

**Complaint (a):** the Trust failed to meet Mr Ryan's basic needs because he was not fed for 26 days. She wants to know why her son's nutritional needs were not properly assessed, why he was not referred to a dietician and why no action was taken to feed him during this time.

**Complaint (b):** staff at the Trust failed to communicate effectively with each other and she wants to know why this occurred.

**Complaint (c):** Mr Ryan *'starved to death'* and his death was avoidable.

**Complaint (d):** the Trust failed to respond appropriately to her complaints about Mr Ryan's care and treatment. Mrs Ryan wants to know why it took the Trust so long to give her an explanation about how her son died and why it did not classify his death as a Serious Untoward Incident as soon as he died.

- 11 Mrs Ryan says she has not had full answers to all her questions about Mr Ryan's care and treatment and she hopes the Ombudsman's investigation will provide her with those answers. Mrs Ryan also wants to know if the actions taken by the Trust following its investigation of the circumstances of Mr Ryan's death are appropriate and whether they will prevent a recurrence of similar events.
- 12 She also hopes the outcome of her complaint will be that other people will not go through the same experience as Mr Ryan.

## The Ombudsman's remit, jurisdiction and powers

### General remit of the Health Service Ombudsman

- 13 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 my wide discretion I 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.
- 14 When considering complaints against an NHS body, I 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 trust to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the body.
- 15 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.
- 16 I may carry out an investigation in any manner which, to me, seems appropriate in the circumstances of the case and in particular may make such enquiries and obtain such information from such persons as I think fit.
- 17 If I find that service failure or maladministration has resulted in an injustice, I will uphold the complaint. If the resulting injustice is unremedied, in line with my *Principles for Remedy*, I may recommend redress to remedy any injustice I have found.

### Premature complaints

- 18 Section 4(5) of the *Health Service Commissioners Act 1993* states that the Health Service Ombudsman may not generally investigate any complaint until the NHS complaints procedure has been invoked and exhausted, and this is the approach I take in the majority of NHS complaints made to me.
- 19 However, section 4(5) makes it clear that if, in the particular circumstances of any case, the Ombudsman considers it is not reasonable to expect the complainant to have followed the NHS route, I 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 my discretion after proper consideration of the facts of each case.
- 20 In this instance, Mrs Ryan's complaint has not been considered by the Healthcare Commission. However, the complaint is one of a group of six cases submitted to me by Mencap about care and treatment of people with learning disabilities. Therefore, I decided it was in the public interest for the complaint to be considered as one of a group of those linked cases under the provisions of the Act which governs my work.

### The investigation

- 21 During the investigation my investigator met Mrs Ryan, her family and her representatives to ensure I had a full understanding of her complaint. I also examined all relevant documentation about the case including: Mr Ryan's health records from the Trust; complaint correspondence between Mrs Ryan,

Mencap and the Trust; papers related to the attempted resolution of the complaint; and papers about an internal inquiry conducted by the Trust which included details of actions taken by it to remedy failings which it identified. The Trust also provided additional information in response to my specific enquiries.

- 22 I obtained specialist advice from a number of professional advisers (my Professional Advisers): Dr A G Rudd, a consultant physician specialising in stroke care (my Medical Adviser); Ms E Onslow, a senior nurse with experience in acute nursing (my Acute Nursing Adviser); Ms M Bering and Ms L L Clark, senior learning disability nurses (my Learning Disability Nursing Advisers); and Ms H Crawford, a consultant speech and language therapist (my Speech and Language Therapy Adviser).
- 23 My Professional Advisers are specialists in their field and in their role as my advisers they are completely independent of any NHS body. Their role is to help me and my investigative staff understand the clinical aspects of the complaint.
- 24 In this report I have not referred to all the information examined in the course of my investigation, but I am satisfied that nothing significant to the complaint or my findings has been overlooked.

## My decision

- 25 Having considered all the available evidence related to Mrs Ryan's complaint, including her recollections and views and her comments on the draft report, and taken account of the clinical advice I have received, I have reached the following decisions.

## Complaint against the Trust

- 26 I have found **service failures** in the care and treatment provided by the Trust for Mr Ryan. These included failings in stroke care, clinical leadership, communication and multidisciplinary team working as well as failings in care and treatment; in particular, the failure to feed Mr Ryan.
- 27 Furthermore, there was **maladministration** by the Trust in its handling of Mrs Ryan's complaint. The Trust did not fully recognise or acknowledge its failures. As a consequence, Mrs Ryan was not given complete answers to her questions about her son's care and treatment. In addition, the response to her complaint was unreasonably delayed. However, I have not found that this maladministration was for disability related reasons.

## The overarching complaint

- 28 I have concluded that in many respects the service failures I identified occurred for disability related reasons and that the Trust's acts and omissions constituted a failure to live up to human rights principles of dignity, equality and autonomy.
- 29 I have also concluded that, had the service failures which I have identified not occurred, it is likely Mr Ryan's death could have been avoided.
- 30 As it is likely their son's death could have been avoided, Mr Ryan's parents have suffered an **injustice** which can never be remedied. I **uphold** Mrs Ryan's complaint.
- 31 In this report I explain the detailed reasons for my decision and comment on the areas where Mrs Ryan has expressed particular concern.

## Section 2: the basis for my determination of the complaint

### Introduction

- 32 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, I generally begin by comparing what actually happened with what should have happened.
- 33 So, in addition to establishing the facts that are relevant to the complaint, I 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. I call this establishing the overall standard.
- 34 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.
- 35 Having established the overall standard I then assess the facts in accordance with the standard. Specifically, I 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.
- 36 If so, I 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.

- 37 The overall standard which I have applied to this investigation is set out below.

### The general standard

#### Principles of good administration

- 38 Since it was established my Office has developed and applied principles of good administration in determining complaints of service failure and maladministration. In March 2007 I published these established principles in codified form in a document entitled *Principles of Good Administration*.
- 39 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.
- 40 I have taken all of these Principles into account in my consideration of Mrs Ryan's complaint and therefore set out below in greater detail what the *Principles of Good Administration* says under these headings:<sup>1</sup>

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

- 41 In October 2007 I published a document entitled *Principles for Remedy*.<sup>2</sup>
- 42 This document sets out the Principles that I consider should guide how public bodies provide remedies for injustice or hardship resulting from their service failure or maladministration. It sets out how I 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.
- 43 I have taken the *Principles for Remedy* into account in my consideration of Mrs Ryan’s complaint.

## The specific standards

### Disability discrimination

#### Legal framework

##### ***Disability Discrimination Act 1995***

- 44 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.
- 45 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.
- 46 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.
- 47 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

<sup>2</sup> *Principles for Remedy* is available at [www.ombudsman.org.uk](http://www.ombudsman.org.uk)

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

- 48 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

- 49 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.
- 50 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.
- 51 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.'*

- 52 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**

- 53 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.
- 54 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.

- 55 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.
- 56 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.'*

- 57 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)**

- 58 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.
- 59 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).
- 60 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'.
- 61 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'.

62 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*.

63 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)***

64 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)***

65 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.’*

**In practice**

66 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.

67 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.

68 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.

- 69 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.
- 70 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman 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 Ombudsman 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.
- 72 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*.
- 73 Of particular relevance to the delivery of health care 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.

## Human rights

### Legal framework

#### **Human Rights Act 1998**

- 71 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.

### Policy aims

- 74 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.

75 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.

76 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.’*

77 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.’*

78 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 HRA 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

79 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.

80 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.

81 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).

- 82 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman 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 Ombudsman 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.

## Professional standards

### The General Medical Council

- 83 The General Medical Council (the body responsible for professional regulation of doctors) publishes a booklet, *Good Medical Practice* (Good Medical Practice), which contains general guidance on how doctors should approach their work. This booklet represents the 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 work. Key sections of the booklet current at the time of this complaint are set out at Annex A.

- 84 Paragraph 5 of Good Medical Practice, 2001, says:

*'The investigation or 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 patients' 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

- 85 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: standards for conduct, performance and ethics* (the Code of Conduct), 2004, 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.

- 86 Section 2 of the Code of Conduct current in 2005 says:

*'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.'*

- 87 Amongst other issues, the Code of Conduct sets out nurses' duty to minimise risk to patients and to maintain clear and accurate records. It also stresses the importance of teamwork. Section 4 says:

*'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.'*

- 88 In *Making a Difference: strengthening the nursing, midwifery and health visiting contribution to health and healthcare* (Making a Difference), issued in 1999, 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 the events complained about benchmarking tools were available for eight areas, including food and nutrition, and the safety of clients with mental health needs in acute mental health and general hospital settings. NHS Trusts were expected to develop and implement local policies that ensured compliance with the benchmark standards.

## Standards for the management of stroke patients

- 89 At the time Mr Ryan was admitted to hospital specific national and professional standards were in place which described benchmarks for the care and treatment of people who had suffered strokes. The *National Clinical Guidelines for Stroke* was issued by the Royal College of Physicians in 2000 and 2004. Key extracts from the 2004 guidelines are set out at Annex B. The *National Service Framework for Older People* issued in 2001 also included standards for stroke services. These documents set out, for example, standards for the development of specialist stroke units, guidelines for testing and investigating patients and requirements for multidisciplinary working.

- 90 In summary, the chronology of the Department of Health's expectations with regard to stroke care services were:

- April 2002 – every general hospital caring for people with stroke should have plans to introduce a specialised stroke service.
  - April 2003 – every hospital caring for older people with stroke should have established clinical audit systems to ensure delivery of the *National Clinical Guidelines for Stroke*.
  - April 2004 – primary care groups/trusts should have ensured that 100% of all general hospitals caring for people with stroke would have a specialised stroke service as described in the stroke service model.
- 91 The national and professional guidelines describe arrangements which should be in place for the care of stroke patients. Even where a stroke unit is not available, the guidelines are clear that patients should receive focused care

and treatment to meet their needs as a person who has suffered a stroke. Mrs Ryan's complaint particularly concerns nutrition. On this aspect of care, whether a patient is in a specialist unit or a general ward, the guidelines (when considered together with prevailing standards of practice described by the Professional Advisers) suggest the care pathway should be the same. A standard swallowing test should be performed by a suitably qualified person as soon as possible after admission. If this shows swallowing is impaired nothing should be given by mouth until swallowing returns. At this stage only intravenous fluids should be given for hydration.

- 92 The Medical Adviser said that until National Institute for Clinical Excellence (NICE) guidelines were introduced in 2006, there was no set time which should be allowed to elapse before alternative methods of feeding should be considered. However, he suggested that the body of medical opinion would agree that if there is no sign of improvement in swallowing after about a week, medical staff should put a plan in place for alternative feeding. He said usually this involves short-term nasogastric feeding (providing liquid food via a tube – a nasogastric tube – passed through the nose into the stomach), although intravenous feeding (providing sterile liquid containing nutrients through drips into the blood stream) can be considered, with a longer-term plan for percutaneous endoscopic gastrostomy (PEG) feeding. He also said feeding via a PEG feeding tube can be expedited if there are problems with nasogastric or intravenous feeding.

## Local policy at the Trust

- 93 The Trust had not established a stroke unit at the time Mr Ryan was admitted, although it was negotiating with the local primary care trust (the PCT) on this issue. However, a draft stroke pathway had been drawn up and agreed with the PCT. This was based on services which were available at the Trust and existing arrangements for transferring stroke patients who needed rehabilitation to local hospitals with specialist facilities. The draft pathway includes some elements from the *National Clinical Guidelines for Stroke*, such as the timeframes for brain scanning and prescription of aspirin. It mentions '*multidisciplinary rehabilitation and assessment*', but gives no detail on areas such as swallowing assessments or feeding and there are no specific links to policies such as the Trust's Eating and Drinking Policy.
- 94 The Trust's detailed Eating and Drinking Policy was drawn up by a working party involving speech and language therapists from the Trust and the PCT and was in place at the time Mr Ryan was admitted to the Ward. The policy focuses on the role of speech and language therapists and includes guidelines on assessment and management of eating and drinking problems, procedures and quality standards, legal and ethical issues, including consent, as well as training and professional competences. Proformas for various speech and language therapy activities are also included.
- 95 The policy stresses the importance of multidisciplinary team working (including doctors, dieticians, other therapists and community staff) and the role of speech and language therapists within that team. The first core standard is:

*'Speech and Language Therapists will not work in isolation in the management of Eating and Drinking Difficulties, but will work as part of a multi-disciplinary team (MDT) and liaise closely with other professionals and relatives involved in the care of the client/patient.'*

- 96 The policy also states that where there is unresolved disagreement amongst the team about the management of eating and drinking and where there is risk to the individual patient, the speech and language therapist should escalate the issue to the line manager.

## Complaint handling

### NHS complaint handling

- 97 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).
- 98 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 the 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.
- 99 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.

- 100 *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.

### Serious Untoward Incidents

- 101 A Serious Untoward Incident can arise from clinical or non-clinical circumstances. In clinical practice such an event usually relates to a situation where a failure in clinical care, such as poor standards of care and treatment or a clinical error, had resulted in serious harm to a patient, or had put them at risk of harm.

## Section 3: the investigation

### Background

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

### Mr Ryan's stroke

103 Information about the nature, cause and likely outcome of Mr Ryan's stroke is central to an understanding of his disabilities and is relevant to my consideration of all aspects of Mrs Ryan's complaint. Therefore, I now set out some clinical information about strokes in general, followed by the Medical Adviser's assessment of available information about Mr Ryan's stroke.

### Clinical information about strokes

104 Every year around 150,000 people in the UK suffer a stroke. Most people are over 65, but anyone can have a stroke, including children and even babies. A stroke is the third most common cause of death in the UK and the single most common cause of disability (*What is a stroke?*, The Stroke Association, May 2007).

105 A stroke happens when the blood supply to part of the brain is cut off and this means that brain cells can be damaged or destroyed. Because the brain controls everything the body does, damage to the brain will affect body functions such as movement, swallowing and speech. A stroke can also affect mental processes, such as thinking, learning and communication.

106 A stroke can cause brain tissue to die. This is called cerebral infarction and an infarct can be tiny or affect a larger part of the brain.

107 There are two main causes of stroke. The most common type of stroke is a blockage (an ischaemic stroke) which happens when a clot blocks an artery that carries blood to the brain. The second type of stroke is a bleed when a blood vessel bursts causing bleeding into the brain (haemorrhagic stroke).

### The nature, cause and likely outcome of Mr Ryan's stroke

108 My Medical Adviser studied Mr Ryan's health record. He said:

*'The stroke that Mr Ryan sustained was due to a blocked artery in the right side of the brain. Assessment of the severity of a stroke is made by a detailed clinical assessment of the deficits the patient has as well as seeing the amount of brain tissue affected on the brain scan. Unfortunately, there is little detail in the medical notes as to precisely what the impairments were that Mr Ryan had. It is reported that he had a paralysis of his left side and he had difficulties swallowing but it is not indicated whether he had some of the other features associated with right sided brain lesions [abnormalities] such as loss of vision on the left, loss of sensation (one brief mention in the notes suggesting that this may have been a problem) or problems with perception. Clinical examination was clearly difficult because of the learning disabilities but examination by a neurologist or stroke physician may have been helpful in determining the nature of the stroke more precisely.'*

*'I have seen the report of the scan but not the scan itself. On the basis of the report the amount of damage to the brain was significant but not very extensive. It sounds like the sort of stroke that one would normally expect the patient to survive, although often with long-term residual neurological deficits [problems with physical and mental functions]. Up to 50% of stroke patients have swallowing difficulties on admission to hospital. The majority of these do recover within the first few weeks. Some people take several months to recover and others are left with long-term difficulties. There is no literature that I am aware of that describes the natural history of stroke in people with Down's syndrome. I would not expect Down's syndrome to have a major impact on survival rates, however, as in this case the ability of the patient to participate in rehabilitation may well have a negative effect on recovery of function.*

*'No explanation was found to explain why Mr Ryan had his stroke at such a young age.'*

## Complaint against the Trust

### Complaints (a) and (b): failure to feed Mr Ryan and communication between staff

#### Key events

109 The basic facts about Mr Ryan's stay at the Trust are set out above. A more detailed chronology of key events extracted from Mr Ryan's health records is provided at Annex C.

110 Mrs Ryan complains to me about two specific aspects of Mr Ryan's clinical care – the Trust's failure to feed him and the failures in communication between different members of Trust staff. The facts about why Mr Ryan was not fed and why there were communication failures are inseparable from information about his overall care as a person disabled by a stroke. Therefore, I have considered these aspects of the complaint together because the key issues and available evidence are fundamentally linked.

111 Mrs Ryan complains that the Trust failed to meet Mr Ryan's basic needs because they did not feed him for 26 days after he suffered a stroke. She wants to know why her son's nutritional needs were not properly assessed, why he was not referred to a dietician and why no action was taken to feed him during this time. Mrs Ryan is also concerned that staff at the Trust failed to communicate effectively with each other about Mr Ryan's care and treatment.

#### Information from records of the actions of key individuals and groups of staff

112 Mr Ryan was admitted to the Trust on 26 November 2005. Later that day it was noticed that he may have aspirated and from that point onward he was given no food or fluid by mouth.

113 A junior doctor saw Mr Ryan during the evening of 26 November 2005. He recorded the probable aspiration and ordered that Mr Ryan should be given nothing by mouth. Over the following ten days Mr Ryan was seen on various occasions by junior doctors who noted that he was still not eating or drinking. During this time he was also reviewed by the Consultant on three occasions. However, there is no record that the Consultant made any assessment or decisions about feeding Mr Ryan as part of these reviews. On 7 December 2005 a junior doctor recorded

his view that alternative feeding methods should be considered and on the following day a junior doctor wrote that feeding should be discussed with the Specialist Registrar (the Specialist Registrar). However, there is no record of any such conversation and it was not until 12 December 2005 that the Specialist Registrar wrote in the notes that feeding would be discussed with the Consultant the following day.

114 On 13 December 2005 (the 18th day of Mr Ryan's admission) the Consultant decided that a gastroenterologist (a consultant specialising in disorders of the stomach and intestine) should be asked to insert a PEG feeding tube. It seems that a medical student was asked to liaise with the gastroenterologist because on 15 December 2005 a medical student recorded that there would be no space in the operating theatre for five days. He also recorded that he had discussed the possibility of inserting a nasogastric tube with the speech and language therapist. The medical student wrote that in his view a nasogastric tube should be inserted. Later that evening Mr Ryan deteriorated and the following day (the 21st day of his admission) the Consultant reviewed Mr Ryan's condition and decided that palliative care should be introduced.

115 The nursing records do not contain any assessment of Mr Ryan's nutritional needs, apart from an incomplete Malnutrition Universal Scoring Tool (an assessment process used to measure whether a person is at risk of malnutrition) completed on the day he was admitted. Nor was there any plan to ensure that he received hydration or nutrition. There is no evaluation of his nutritional status during his stay; for example, it appears he was never weighed. The only nursing records about hydration and nutrition are frequent remarks that drips were running and that Mr Ryan was to be given nothing orally. There is no note in the

nursing record of any concern about Mr Ryan's hydration or nutrition. There is no written record which shows that any nurse expressed concerns about the fact that Mr Ryan was receiving no nutrition whatsoever.

116 Mr Ryan was referred to the speech and language therapist (the Speech and Language Therapist) on 29 November 2005 and she first assessed him the following day. She found there was a high risk that he would aspirate and said he should be given nothing by mouth. Subsequently, the Speech and Language Therapist reviewed Mr Ryan on eight occasions. When Mr Ryan was able to co-operate with her assessment, she recorded that he was at risk of aspiration and that he should be given nothing by mouth. On 7 December 2005 she clearly wrote a request in the notes for the team to consider alternative feeding methods because by that time Mr Ryan had received no nutrition for 12 days. Five days later she attended a meeting with ward staff, carers and staff from the Community Learning Disability Team. She again noted her concerns that Mr Ryan had been given no nutrition. Her final review was on 16 December 2005, the day on which the decision was made to offer Mr Ryan palliative care only.

117 Mr Ryan was never formally referred to a dietician. By chance, a dietician noticed him when she was carrying out an audit on the Ward. On 12 December 2005 she discussed the situation with the Speech and Language Therapist, noting that Mr Ryan had been without food for 16 days. On the following day, the day on which the Consultant decided a PEG feeding tube should be inserted, the dietician reviewed him again and recorded that she would provide a feeding regime once the PEG feeding tube had been inserted. Mr Ryan was not seen again by a dietician.

- 118 On 28 November 2005 the Community Learning and Disability Nurse visited Mr Ryan. She wrote in the medical notes asking to be involved in decisions about his care and treatment. She visited again on 30 November 2005 and wrote in the notes asking doctors to review Mr Ryan's hydration and nutrition. She asked if intravenous feeding could be considered. She also participated in the meeting about Mr Ryan on 12 December 2005, when concerns about nutrition were discussed with the Speech and Language Therapist and ward staff, and in the meeting with the Consultant on 16 December 2005 when palliative care arrangements were discussed.
- 119 I have seen no evidence which shows what actions were taken by Mr Ryan's carers who were with him most of the time he was in hospital. However, Mr Ryan's family have said the carers raised their concerns about hydration and nutrition with ward staff.

### Information from staff interviews conducted for the Trust's internal inquiry

- 120 The Trust provided summaries of interviews with staff which were held as part of the internal inquiry into the circumstances of Mr Ryan's stay at the Trust. I say more about the internal inquiry later in this report. The interviews were conducted by the full inquiry panel on 6 and 8 December 2006 (almost a year after Mr Ryan died). The summaries are not direct transcripts, but appear to be typed records of notes made during the interviews. I have not reproduced the interview records in full, but have selected extracts where information sheds additional light on what happened to Mr Ryan, particularly in terms of stroke care, nutrition and communication.
- The Consultant*
- 121 The Consultant told the internal inquiry that ideally Mr Ryan would have been admitted to a stroke unit where the multidisciplinary team would have been able to meet his needs. He suggested that such multidisciplinary arrangements were not in place on the Ward which was a busy, general ward. With hindsight, he recognised that there should have been a multidisciplinary team approach to Mr Ryan's care.
- 122 The Consultant was asked why no one became concerned about Mr Ryan's nutrition. He said he relied on the Speech and Language Therapist to tell the doctors when a stroke patient could be fed. He said the Speech and Language Therapist did not speak to anyone, she only wrote in the notes and junior doctors may not have picked up on this. He also said he thought Mr Ryan would not tolerate a nasogastric tube because he was pulling out his drips and was not tolerating suction to clear his upper respiratory tract. However, he thought that the nurses had attempted to pass a nasogastric tube. He would normally expect nurses to realise that doctors expected them to attempt to pass a nasogastric tube from reading the medical notes. The Consultant explained that it was usual to wait for five to seven days for a PEG feeding tube to be fitted, but the situation was more complicated for Mr Ryan because he could not give consent.
- The Specialist Registrar*
- 123 The Specialist Registrar explained to the internal inquiry that he had only become involved in Mr Ryan's care when he returned from leave on 12 December 2005. He said when he saw Mr Ryan on that day he recognised he was very ill and nutritionally depleted and it was on the following day that the Consultant decided

that a PEG feeding tube should be inserted. He recognised that multidisciplinary team working had been poor and that relations with Mr Ryan's carers had been strained. He did not think the way he had communicated with Mrs Ryan about the decision to initiate palliative care had been poor.

#### *The Matron*

124 The Matron told the internal inquiry that she covered several wards. She said she supported ward staff but her role focused on bed management and discharge. She said she had not been made aware of any concerns about Mr Ryan until there was a dispute with his carers. She explained that the wards were starting nutrition benchmarking and she would have expected concerns about the Malnutrition Universal Scoring Tool assessment to be raised through this route.

125 The Matron also confirmed that in her experience junior doctors often conducted ward rounds without senior doctors, and patients were not seen by doctors at weekends.

#### *The Ward Sister*

126 The Ward Sister told the internal inquiry that she thought Mr Ryan was not fed because there was a breakdown in communication. She said all staff were very concerned but they thought the Speech and Language Therapist was talking to the doctors. She said she remembered talking to doctors, but they said they would be reviewing the situation. She also confirmed that doctors had not asked for a nasogastric tube to be passed and no attempt was made by nurses to pass a nasogastric tube.

127 The Ward Sister said that Mr Ryan's carers helped with his hygiene needs. She felt that the ward staff had a good relationship with Mr Ryan's Community Learning Disability Team Nurse, but that the carers did not communicate very proactively with the ward team. She would have expected carers to raise any concerns with her, but she did not remember them approaching her with concerns about Mr Ryan. With hindsight, she wished she had communicated better with the Community Learning Disability Team.

#### *The Speech and Language Therapist*

128 The Speech and Language Therapist who was interviewed was not the person who had provided care for Mr Ryan. However, she said her colleague who had provided that care had liaised with doctors who told her they were escalating the issue of feeding. She confirmed that her colleague had taken no further action to escalate her concerns although she realised that nothing was happening about feeding Mr Ryan.

#### *The Community Learning Disability Team staff*

129 Two members of the Community Learning Disability Team were interviewed together by the internal inquiry panel. One of these was Mr Ryan's Community Learning Disability Team Nurse who had visited Mr Ryan several times at the Trust. They explained that the Team did not use a care facilitator model because the facilitative role was shared amongst team members. They also explained that they had not taken on the role of Mr Ryan's care manager because he had been placed at the Care Home by Haringey Social Services (not the local social services agency) who retained responsibility for care management. Also, the carers did not report to them. They said the role of the Community Learning Disability Team was to look after Mr Ryan's health needs.

130 They also explained that the carers told them Mr Ryan was in hospital about two days after he was admitted. They said when a learning disability client is in hospital the Community Learning Disability Team try to help doctors and nurses, particularly by communicating about the client's needs. They said that at that time they would not have challenged the hospital's decisions, but subsequently they had developed an escalation protocol. They also said the hospital may have misinterpreted the role of the carers, who would not necessarily have had clinical experience.

131 The Community Learning Disability Team Nurse said she knew Mr Ryan would be phobic in a hospital environment and that he would try to resist attempts to insert tubes and would pull them out. She noted his behaviour was less challenging than usual because he had suffered a stroke. However, she said that, in her judgment, he would have pulled out a nasogastric tube.

132 The Community Learning Disability Team Nurse said it had been more difficult to liaise with doctors than with the nurses. She had left messages in the notes for doctors and tried to bleep them, but she found it very difficult to get in touch with them. They did not attend the multidisciplinary meeting which was set up at her request and did not respond to her request to contact her after that meeting.

133 The Community Learning Disability Team Nurse said carers did not make her aware of their concerns about Mr Ryan's care until some time around 14 December 2005 and she was surprised to learn how relationships with ward staff had deteriorated.

### The Trust's explanation about what happened to Mr Ryan

134 The Trust's initial explanations about what happened to Mr Ryan were given in response to Mrs Ryan's complaint and follow-up correspondence between the Trust and Mencap. I consider the way in which the Trust responded to the complaint later in this report. In this part of the report I am concerned with the Trust's subsequent position on the care and treatment provided for Mr Ryan, that is, the explanations it has given Mrs Ryan following the internal inquiry which reported in January 2007.

135 On 8 September 2006 the Trust set up an internal inquiry. The purpose of the inquiry was:

*'To examine all the relevant circumstances surrounding the care and treatment of Martin Ryan following his admission to [the Trust] on 26 November 2005 up to his death on 21 December 2005. To assess the adequacy of the care provided and to report findings and recommendations. To understand and consider the failure to escalate the complaint within the organisation.'*

136 The members of the inquiry panel were: the Medical Director at the Trust; a Non-Executive Director at the Trust; the Head of Governance at the Trust; the Director of Nursing at St George's NHS Trust; and a Consultant in Learning Difficulties at South London and the Maudsley NHS Trust. The panel reviewed documents, conducted interviews with staff and noted developments since Mr Ryan's death.

137 The inquiry panel's final report set out their opinion about what had happened to Mr Ryan. The findings of the internal inquiry are set out in detail at Annex D. The key findings about Mr Ryan's clinical care were: care was inadequate because Mr Ryan's nutritional needs were not met; there was a lack of continuity of care; medication was not given on time; communication with Mr Ryan's family and between members of the multidisciplinary team was poor; there was friction between staff on the Ward and the carers; expert help offered by the Community Learning Disability Team was rejected; no one acted as Mr Ryan's advocate; medical care was fragmented; there was no clinical leadership from the Consultant or the Ward Sister; the Speech and Language Therapist had a limited view of her role; and there was no co-ordinated multidisciplinary approach to care and clinical decision making. Furthermore, there was no stroke unit and no body of staff trained to care for stroke patients.

138 The report concluded that:

*'The care afforded to [Mr Ryan] fell well short of that which should have been expected, ...'*

139 The inquiry panel made nine recommendations about clinical care. Subsequently the Trust Board added six more recommendations. The recommendations are set out at Annex E and I consider them in more detail later in the report when I discuss the actions taken by the Trust in response to the internal inquiry.

140 In February 2007 copies of the report were sent to Mr Ryan's parents and Mencap. The Trust also met with them to discuss the report and actions which had been taken as a result of the inquiry recommendations.

### Additional information from the Consultant

141 In response to the draft report the Consultant has drawn my attention to the fact that he was on leave from 6 to 12 December 2005.

### The advice of my Professional Advisers

142 My Professional Advisers reviewed Mr Ryan's health records. They also studied all available information about: the complaint to the Trust (including complaint correspondence and papers related to the investigation into the complaint, such as statements from clinical staff); and the Trust's inquiry (including background information, interview notes, notes of meetings – including Trust Board meetings – the report itself and information about follow-up action).

#### *The advice of my Medical Adviser*

143 My Medical Adviser compared the care and treatment Mr Ryan received with national standards for stroke care in place at the time. He said that in addition to the guidance on care for stroke patients set out in the *National Clinical Guidelines for Stroke* and the *National Service Framework for Older People*, there were other international guidelines available, for example those produced for the European Union. However, he noted that *'few recommendations were followed in this case'* and *'many aspects of the care that Mr Ryan received were below acceptable standards'*.

144 My Medical Adviser said:

*'I do not think that the care Mr Ryan received met acceptable standards for a patient with stroke. There were many aspects that did not accord with national guidelines as available in November 2005.'*

*'Mr Ryan was not admitted to a stroke unit at any stage of his illness nor was there involvement, as far as I can tell from the notes, by any physician with expertise in stroke during the admission. Stroke unit care has been shown in multiple randomised controlled trials to reduce mortality and disability compared to general medical care. This evidence formed the basis of the recommendation that all patients with stroke should be managed on a stroke unit in the National Clinical Guidelines (2000 and 2004) and led to the National Service Framework for Older People setting a milestone that by April 2004 all hospitals in England should have a specialist stroke service.*

*'There is no evidence through his stay of any effective multidisciplinary working, objective or goal setting. These processes are central to stroke rehabilitation and the failure to undertake these basic clinical practices was I believe central to the subsequent failures in management.*

*'There was a delay in brain imaging after admission of 3 days (the 2004 National Clinical Guidelines recommend a maximum of 24 hours unless there is indication for more urgent scanning). In retrospect, however, I do not think that this resulted in any harm to the patient.*

*'No secondary prevention [treatment to try and prevent a further stroke] was given to Mr Ryan throughout his stay. He should have received aspirin within 48 hours of admission (once the scan had confirmed that the stroke was due to ischaemia [reduced blood flow] rather than haemorrhage). In fact although the drug was prescribed it was never given because it was*

*written to be given orally and Mr Ryan was "nil by mouth". There is no reason why the drug could not have been given rectally.*

*'The failure to carry out a swallowing assessment on admission (as recommended in many guidelines and statements of good practice) led to Mr Ryan being allowed access or [sic] food and fluid over the first 24 hours, which probably contributed to his first chest infection within 24 hours of admission.*

*'There was unacceptable delay in considering Mr Ryan's nutritional needs. It was clear from shortly after admission that he was unable to swallow safely. At the time of his admission there were no definitive NICE nutritional guidelines or stroke guidelines defining precisely how long it was reasonable to delay the provision of alternative sources of nutrition in dysphagic patients [patients who are unable to swallow safely]. However, my view, and I suspect the view of the majority of stroke clinicians, would have been that if after a week there was no sign of recovery of a safe swallow then alternative means of feeding should have been introduced. The medical team did not appear to even consider the issue of nutrition until day 12 when the Pre-Registration House Officer [a junior doctor] wrote a comment in the notes that he would discuss it with the registrar. Four days later it was written that the registrar would discuss feeding with the consultant the following day and only then was a referral made for a gastrostomy tube to be inserted.*

*'...*

*'The only circumstance where withholding food is acceptable is where a decision has been made that palliative care is the appropriate course; this was not the situation in Mr Ryan's case. I accept that nasogastric feeding may have been difficult or impossible and [the Community Learning Disability Team Nurse] who knew him well stated in her evidence to the internal inquiry that she thought he probably would not have tolerated the tube but I do not think that failure should have been assumed and therefore used as a reason not to attempt tube insertion. The alternative of using intravenous feeding would have been a possibility but was not apparently considered. Use of restraints to allow nasogastric feeding is controversial but is used in some units for restless and confused patients. Early referral for gastrostomy insertion would I believe have been justified. It is not a major procedure and the tube is easy to remove once swallowing returns. The primary responsibility for deciding on feeding policy for a patient lies with the medical team; however, effective multidisciplinary teamworking would have led to the issue being addressed much earlier than it was in this case, even where the medical team was failing to deal with the problem. The medical records do indicate that [the Community Learning Disability Team Nurse] and the speech and language therapist wanted the issue of nutrition addressed. From the evidence given by [the Consultant] it would appear that he did not read the notes and was dependent upon his junior staff to be kept informed of developments. This is not a satisfactory situation where there are no multidisciplinary team meetings.'*

<sup>145</sup> In terms of the way in which professionals communicated with each other and with Mr Ryan's family, my Medical Adviser said:

*'Involving families and other carers in the management of stroke patients is essential for effective care. This is especially important where the stroke patient is unable to speak for himself. There were clearly problems in this case with communication, especially between the physicians and the family and this undoubtedly contributed to the dissatisfaction that has been expressed following Mr Ryan's death. I saw no evidence in the notes that the consultant met or even [tele]phoned the family until 16 December at which stage the decision to switch to palliative care had already been made. The Speech Therapist and Physiotherapist did meet with the carers earlier in the course of the admission however it is not clear that they were able to provide the family with a comprehensive picture of management.'*

*'...*

*'Interprofessional communication does not appear to have been effective. Although there was good quality [medical] note keeping there was little evidence that the team acted upon recommendations made by the individual clinicians. In my view by far the most effective way that this can be avoided in the future is to have at least weekly multidisciplinary meetings attended by senior clinicians (including the consultant physician).'*

### *The advice of my Acute Nursing Adviser*

146 My Acute Nursing Adviser agreed with the Medical Adviser that, in all the circumstances, the Trust did not provide Mr Ryan with a reasonable standard of care. Having reviewed the nursing records she identified shortcomings in assessment, care planning, record keeping, communication, leadership, lack of proactive nursing and a failure to meet Mr Ryan's nutritional needs. She said:

*'The admission assessment was superficial and there is no evidence in the clinical records to indicate that attempts were made to complete the nursing assessment at any time during Mr Ryan's hospital stay. There are two core care plans indicating risk of convulsions and impaired respiratory function. Neither of these reflects the individual and specific needs of Mr Ryan which were complex.*

*'...*

*'As Mr Ryan was unable to communicate his own needs it would have been good practice to have discussed his usual activities of daily living with his family and carers. It is clear to me that ... if assessment had been more thorough then a more robust and person-centred plan of care could have been developed.'*

147 My Acute Nursing Adviser noted that the Malnutrition Universal Scoring Tool assessment was poorly completed (it was not signed or dated). She also said that because Mr Ryan's height and weight were estimated and no attempt was made to use alternative methods to assess his nutritional state accurately, it was an unreliable measurement. However, she did note that the tool appeared to show

that Mr Ryan was at high risk of malnutrition and should have been referred to a dietician and reassessed in two days. My Acute Nursing Adviser said there is no evidence that anyone carried out either of these actions. She noted the *'almost daily entries in the nursing records'* that Mr Ryan was *'NBM'* (to have nothing to eat or drink by mouth) but there was no evidence that nurses raised concerns about this or took any proactive action about this aspect of Mr Ryan's care. She said:

*'I would have expected any ward manager to have taken ownership of the situation and instigated appropriate initiatives to ensure that Mr Ryan had a clear management plan that reflected his needs. It would have been reasonable (and good practice) to have sought advice and direction from senior nursing and legal advisers in relation to the legal and ethical dilemmas surround[ing] this case but I cannot see that to have taken place.'*

148 With regard to the failure to feed Mr Ryan my Acute Nursing Adviser said:

*'It appears that a decision had been made to try NG [nasogastric] feeding although there was no management plan with regard to this in the medical notes. From the documentation of nursing care it appears nursing staff were not aware of this decision. They also considered that attempting to pass an NG tube would be impossible. This appears to be related to the fact that previous attempts at passing a nasopharyngeal airway [a plastic tube to allow secretions to be suctioned from the respiratory tract] by the physiotherapist had proved to be difficult, that Mr Ryan had removed his intravenous cannula on a number of occasions and the*

*Learning Disabilities Team had apparently advised that he would not tolerate an NG or PEG feeding tube. There appears to be no evidence of any discussion regarding alternative methods of fluid administration, for example, the use of subcutaneous route.*

*'In my opinion, the lack of any attempt to pass an NG tube was wholly unacceptable. The communication between all members of the multidisciplinary team was also extremely poor and contributed significantly to the fact that Mr Ryan was not fed for 26 days. The decision to insert a feeding tube was not discussed until the consultant ward round on 13 December and it is my opinion that this discussion should have taken place earlier in view of Mr Ryan's lack of dietary intake.'*

149 She also noted that standards for record keeping set out by the Nursing and Midwifery Council were not met because *'documentation in relation to the nursing care of Mr Ryan [was] poor'* and nurses failed to meet requirements in the Code of Conduct. She specifically said the nurses did not behave as required by the Code of Conduct because they did not take action to minimise the risk to Mr Ryan associated with poor nutrition.

150 My Acute Nursing Adviser agreed with my Medical Adviser that there is evidence of poor multidisciplinary communication. She said this was particularly significant in terms of the misunderstanding between doctors and nurses about passing a nasogastric tube. She found no evidence that nurses attended medical ward rounds (which she regards as essential to ensuring continuity of care through multidisciplinary interaction) and no evidence that they knew how to escalate clinical concerns.

She noted that the Code of Conduct requires nurses to raise concerns when they believe a patient's care is being compromised, but the ward nurses did not do this in Mr Ryan's case.

151 My investigator specifically asked my Acute Nursing Adviser for her view on professional liaison between Trust staff and Mr Ryan's carers. She said it appeared that the carers provided basic, personal care while he was on the Ward. However, she noted that following the stroke Mr Ryan's needs would have changed and it would have been good practice for the Trust nurses to have established the level of care which the carers were able to provide as soon as possible following his admission. She also said the carers' nursing interventions should have been incorporated into an individualised care plan, shared care should have been encouraged and Trust nurses should have been proactive in supporting the carers. In her view this would have allowed difficult issues, such as the use of restraint and the rationale for carers taking notes, to be discussed openly. She concluded that Trust nurses and carers did not engage effectively with each other and this led to failings in the nursing care Mr Ryan received.

#### *The advice of my Speech and Language Therapy Adviser*

152 My Speech and Language Therapy Adviser had no criticisms of the standard of care provided by the Trust's Speech and Language Therapist. She said: the response to the referral was *'timely and appropriate'*; the assessment appeared to be *'as detailed as possible and appropriate to Mr Ryan's presentation'*; the review schedule was regular; and the same speech and language therapist saw Mr Ryan on eight out of nine of his contacts with a speech and language therapist which is *'good practice and ensures continuity of care'*. She also said:

*'The recordings in the case notes were clear, decisive and unambiguous. Throughout the management of Mr Ryan the SLT [Speech and Language Therapist] states clearly, repeatedly and unequivocally, that the recommendations for non-oral feeding should be considered.'*

153 My Speech and Language Therapy Adviser also noted that the Speech and Language Therapist took part in the first multidisciplinary meeting when Mr Ryan was in hospital. She said it was regrettable that there was no doctor present and that there appeared to have been no forum for discussion with members of the multidisciplinary team and no pathway or protocol for actioning recommendations for alternative feeding. My Speech and Language Therapy Adviser did say there was no documented evidence that the Trust's Speech and Language Therapist had contacted her community colleague. However, she noted that from evidence presented to the Trust's inquiry, it appears contact did take place.

154 My Speech and Language Therapy Adviser agreed with my other Professional Advisers in their opinion that, in all the circumstances, Mr Ryan did not receive a reasonable standard of care. She said:

*'The care and treatment did not appear to be multidisciplinary in a "joined up" way, holistically focused, or person centred way. The individuals treating Mr Ryan worked in an isolated, individual way. They did not appear to work as a functional multidisciplinary team.'*

155 She also said 'no-one was competently and holistically taking responsibility for decision making and for co-ordinating care and treatment for Mr Ryan' and that Trust staff did not utilise the expertise offered by the Community Learning and Disability Team staff.

#### *The advice of my Learning Disability Nursing Advisers*

156 My First Learning Disability Nursing Adviser said it was not in question that Mr Ryan did not receive a reasonable standard of care. She confirmed that communication between Trust staff and staff from the Care Home was poor and had apparently broken down to such an extent that there was animosity between the two groups. She also noted that the learning disability nurses would probably not have had experience in nursing stroke patients, especially in a general hospital setting.

157 My First Learning Disability Nursing Adviser identified key failings in Mr Ryan's care. In her view, these were that he was not admitted to a stroke unit and there had been a breakdown in communication between members of the multidisciplinary team.

158 My Second Learning Disability Nursing Adviser said the primary causes of the substandard service which Mr Ryan received at the Trust were failures in basic care and treatment, including communication and nutrition. She particularly pointed to poor communication with learning disability specialists in the community team.

#### **My findings**

159 As I have previously said, the fact that Mr Ryan received inadequate care is not disputed by the Trust. Their internal inquiry uncovered major clinical failings which I have set out at

Annex D. These have been openly accepted and acknowledged by the Trust. Mrs Ryan and Mencap have seen a full copy of the report of the internal inquiry and have discussed the findings with the Chief Executive. However, Mrs Ryan still has some specific outstanding questions about Mr Ryan's care and treatment. She wants to know more about why staff on the Ward failed to feed her son and why communication between staff was so poor.

160 In Section 2 I have set out the legal and policy framework which is relevant to this complaint; also, and at Annex B, I have described the care and treatment that national and professional guidelines say should have been provided for Mr Ryan. I have also outlined above aspects of the multidisciplinary nutritional care the Trust's own Eating and Drinking Policy says should have been provided for him.

161 It is clear from the evidence I have seen that what policy, guidelines and professional standards say should have happened to Mr Ryan after he suffered a stroke, particularly in terms of his nutritional care, did not happen. I now consider how failure to comply with those national, professional and local standards resulted in key failings in Mr Ryan's care and treatment and led to the failure to feed him.

#### *Failings in stroke care*

162 My Professional Advisers all said the standard of care and treatment which Mr Ryan received as a stroke patient constituted a failure of service. My Medical Adviser also said a major failing in Mr Ryan's case was the fact that the Trust had not responded to national and international recommendations on stroke care, especially those set out in the *National Clinical Guidelines for Stroke*. Possibly the key recommendation of these guidelines is:

*'Stroke services should be organised so that patients are admitted under the care of a specialist team for their acute care and rehabilitation.'*

163 My Medical Adviser said the advantages of stroke units had been mentioned in the 2000 clinical guidelines and a milestone had been set in the *National Service Framework for Older People* that all English hospitals should have a stroke unit by April 2004. It is indisputable that because there was no stroke unit at the Trust until early 2006, the Trust failed to meet the requirements of the *National Clinical Guidelines for Stroke* and the *National Service Framework for Older People* on this key point.

164 At the time when Mr Ryan was admitted in November 2005, services for stroke patients at the Trust were fragmented. As a consequence, Mr Ryan was admitted to a busy general medical ward where the focus was mainly on respiratory and endocrine disorders. He was placed under the care of a consultant who specialised in respiratory medicine and who had no special expertise in stroke care.

165 The Trust had agreed a draft stroke pathway with the PCT. This did show that the Trust was trying to cope with deficits in its stroke services by setting up links with other local healthcare organisations. However, the draft pathway included only some aspects of essential stroke care set out in the *National Clinical Guidelines for Stroke* and did not include information, or directions about where to find additional information, about meeting stroke patients' basic needs, such as nutritional care. Therefore, the draft stroke pathway fell short of professional and national expectations in terms of planning for a stroke unit.

166 My Medical Adviser told me Mr Ryan did not receive effective stroke care because the Trust failed to organise services to provide effective care and treatment for stroke patients. As my Medical Adviser has said, Mr Ryan was not assessed or treated according to existing guidelines. For example, he was never assessed by a senior clinician with an interest in stroke, such as a neurologist, and, although he should have had a brain scan within 24 hours of admission, he was not scanned until day 4 of his stay. Also, the guidelines said Mr Ryan should have received aspirin to try and prevent a second stroke. However, as my Medical Adviser noted, aspirin was prescribed, but never given because Mr Ryan was not able to take anything by mouth. Apparently, there was no attempt to administer aspirin rectally which my Medical Adviser said would have been a suitable alternative route. Furthermore, there was no team of experts skilled in the management of the needs of stroke patients, for example speech and language therapists, dieticians and nurses, who could identify and meet Mr Ryan's basic needs, including his nutritional needs. This was **service failure**.

167 My Professional Advisers agree that in addition to the failings directly associated with stroke care, major problems in Mr Ryan's case were those identified by the Trust's internal inquiry – lack of clinical leadership, inadequate communication and poor multidisciplinary team working. They suggest that these were at the heart of the shortcomings in Mr Ryan's care and led directly to the failure to feed him. In their advice, my Professional Advisers cite many instances of these three key failings. I now set out some of these detailed examples to explore Mrs Ryan's questions about why her son was not fed.

### *Failings in clinical leadership*

168 My Medical Adviser and my Acute Nursing Adviser said neither the Consultant nor the Ward Sister provided effective clinical leadership either for their professional group, or the ward team as a whole. For example, the health records and evidence to the internal inquiry show that neither of the lead professionals had set up effective systems of organising care and treatment. Crucially, the internal inquiry identified that the nursing shift patterns did not encourage continuity of care and medical cover was fragmented with no effective arrangements at weekends. Most worrying is the clear fact that neither of the lead professionals recognised that the basic standard of care which doctors and nurses in their charge were providing for a very ill man was inadequate.

169 In terms of the Consultant's leadership role in ensuring Mr Ryan was adequately nourished, I note my Medical Adviser said:

*'The primary responsibility for deciding on feeding policy for a patient lies with the medical team.'*

170 However, it is clear to me that the Consultant did not fulfil his role as the person with overall responsibility for Mr Ryan's care and I agree with the Medical Adviser that there is evidence that his clinical leadership was poor in this regard.

171 On the day of admission a junior doctor recorded that Mr Ryan could not swallow and correctly said he should be given nothing by mouth. I note that no formal swallowing assessment was performed on the day of admission as required by the *National Clinical Guidelines for Stroke*. However, I note that my Speech and Language Therapy Adviser said that, subsequently, the Speech and Language

Therapist performed appropriate assessments of swallowing, discussed her findings with nurses, junior doctors and Mr Ryan's carers, and repeatedly wrote her findings and advice in the health record.

- 172 Despite the Speech and Language Therapist's assessment that Mr Ryan would need alternative feeding because his swallow was not returning, the medical team, led by the Consultant, did not make a decision about alternative feeding until Mr Ryan had been in hospital for 18 days. Soon after this, Mr Ryan became too ill to undergo the operation to insert the PEG feeding tube.
- 173 In my criticism of the Consultant's clinical leadership, I also draw attention to his evidence to the internal inquiry. It seems he focused on the roles of other professionals regarding failings in Mr Ryan's nutritional care, rather than accept his own shortcomings. For example, in relation to the failure to feed Mr Ryan, he suggested the Speech and Language Therapist should have told him Mr Ryan's swallow was not returning and that nurses should have attempted to pass a nasogastric tube. However, it is clear that the Consultant did not fulfil his lead responsibility to assess Mr Ryan's nutritional state, to respond to the Speech and Language Therapist's specialist advice and devise a plan about Mr Ryan's nutrition which other professionals could follow. This was a fundamental failing in care and treatment and a major reason why Mr Ryan was not fed.
- 174 As I have said in paragraph 141 and in Annex C of this report, the Consultant was on leave for part of the time during Mr Ryan's stay at the Trust. I accept that this means the Consultant could not have been personally involved in Mr Ryan's care and treatment during this period of leave. However, as I have set out in Annex A,
- 'Good Medical Practice' requires a doctor who is responsible for a patient's care to ensure that *'arrangements are in place to provide cover at all times'*. It is clear to me that such suitable arrangements were not in place as regards Mr Ryan's medical care.
- 175 The shortcomings in the clinical leadership by the Consultant were **service failure**.
- 176 In terms of nursing leadership, I note the Matron's evidence to the internal inquiry suggests she was able to give little support to the Ward Sister because her role was mainly as a bed manager for several wards. The only evidence of the Matron's direct involvement in Mr Ryan's case is a record of the dispute which arose between ward staff and carers two days before Mr Ryan died. There is no evidence that she fulfilled her senior clinical role to guide the Ward Sister or advise on care and treatment or facilitate developments in nursing. For example, in her evidence to the internal inquiry she said that benchmarking on nutrition was just being introduced. However, as I have said above, the Essence of Care guidance had been in place since 2001.
- 177 Having remarked on the inadequate support provided by the Matron to the Ward Sister, I note the advice of my Acute Nursing Adviser that there is also no evidence that the Ward Sister herself provided even basic clinical leadership in this case. There is no indication that she took the lead, as she should have done, in monitoring and managing Mr Ryan's care and condition. There is no evidence that she supervised the actions of nurses in her team, or that she had put in place arrangements to guide or support team members. Moreover, it appears she was not aware of the nursing failings which the Acute Nursing Adviser identified in this

case, including the poor assessments (such as the incomplete Malnutrition Universal Scoring Tool assessment), inadequate care plans and substandard delivery and evaluation of nursing care. In particular, I note the advice of my Acute Nursing Adviser that there is no evidence of any nursing action specifically aimed at meeting Mr Ryan's nutritional needs. In her evidence to the internal inquiry the Ward Sister said nurses were concerned about Mr Ryan's nutrition. I have seen no evidence that she took a lead in managing those concerns, such as taking independent action within her professional boundaries or escalating the situation to senior clinical or management staff. The shortcomings in the clinical leadership by the Matron and the Ward Sister were **service failure**.

#### *Failings in communication and multidisciplinary team working*

- 178 The multidisciplinary team comprises all professionals involved in the care of an individual patient or a group of patients. Membership will vary depending on the nature of a person's illness and their specific needs. For a stroke patient the multidisciplinary team would usually include doctors, nurses, speech and language therapists, dieticians and other specialist therapists, such as physiotherapists. The wider multidisciplinary team would include community professionals, such as community nurses, and carers.
- 179 National, professional and local policy and guidelines stress the importance of multidisciplinary team working in stroke care. However, the evidence I have seen shows how poor communication and team working between professionals meant that the approach to Mr Ryan's care, including his nutrition, was fragmented, unplanned and ineffective. I will describe some examples to show how different

members of the multidisciplinary team failed to communicate effectively and how this impacted on Mr Ryan's nutritional care.

- 180 The Consultant held no formal multidisciplinary meetings on the Ward and it seems he and his team regarded the Consultant ward round as the only clinical discussion and decision forum, despite the fact that other professionals involved in Mr Ryan's care could not always attend the ward round. Some examples, including the Consultant's own actions and omissions, show how ineffective the notes and ward rounds were in this regard.
- 181 The health records suggest the Consultant only saw Mr Ryan six times during his 26-day stay on the Ward (although I note he was on leave for about a week during that time). Therefore, I was particularly concerned that all clinical decision making seemed to hinge on the Consultant's ward round. It appears that everyone, even the Specialist Registrar, waited until the Consultant arrived on the Ward before making key treatment decisions. The Medical Adviser has pointed out that even when the Consultant did review Mr Ryan it seems he did not use the information he received to inform his decision making. If he had, he would have seen the concerns expressed by the Community Learning Disability Team, the Speech and Language Therapist and the junior doctors. In fact, the Medical Adviser has suggested the Consultant relied on his junior doctors to tell him what was happening and then expected them to write in the notes on his behalf. The Consultant only wrote personally in the notes following the meeting on 16 December 2005 about palliative care.

- 182 During his interview with the internal inquiry panel the Consultant said he expected the nurses to read the notes to find out about his plan for Mr Ryan's nutritional care. He suggested that had they done so they would have seen that a nasogastric tube should have been passed. In contrast, he said he expected the Speech and Language Therapist to talk to him rather than rely on writing in the notes. In fact, as I have said, the notes do not contain any plan to manage Mr Ryan's nutrition, such as an instruction to attempt nasogastric feeding, until 13 December 2005 when Mr Ryan had already been in hospital for 18 days. On that day a junior doctor recorded the Consultant's decision about the PEG feeding tube. This evidence shows that poor communication led to confusion about what actions nurses and others had taken, or should have taken, with regard to feeding Mr Ryan.
- 183 On the basis of information from the Trust's internal inquiry my Medical Adviser questioned whether the Consultant was in the habit of reading the medical notes to see what colleagues had written there. The Consultant disputes this. However, the key point is not whether the Consultant did or did not read the medical notes. Rather, it is whether those notes were used effectively as a tool for communication and multidisciplinary teamwork. It is clear that, in terms of Mr Ryan's nutrition, relevant information in the medical notes was not acted upon until it was too late to instigate effective artificial feeding for him.
- 184 I find that multidisciplinary communication methods were not in place or failed to work effectively. This was **service failure**.
- 185 In her interview with the internal inquiry the Ward Sister said nurses were very concerned about Mr Ryan's nutrition and talked to doctors about their concerns. There is no record of this. Also, I have seen no evidence that nurses contributed to discussion at the Consultant's ward round, or that they used any other means to communicate their concerns either to each other (for example, via care plans), or to senior clinicians or managers. This was **service failure**.
- 186 As I have said, the Speech and Language Therapist was a key member of the team responsible for Mr Ryan's care. Essentially her role was to assess whether Mr Ryan could swallow safely and to advise on deterioration or improvement in his swallowing.
- 187 In the findings of the Trust's internal inquiry the Speech and Language Therapist is criticised for not escalating her concerns about Mr Ryan's nutrition. I agree that she did not act in line with the Trust's own Eating and Drinking Policy which said that if there was difficulty or disagreement with feeding decisions a speech and language therapist should involve senior staff. That said, she was the first professional who recognised and recorded that alternative feeding should be considered and she did this within a week of admission. Also, she did attend a meeting with the Community Learning Disability Team Nurse and ward nurses where nutrition was discussed. Regrettably, no doctor attended that meeting and, in fact, no action about nutrition was taken as a result of the discussion.
- 188 Normally a dietician would contribute expertise to the team caring for a stroke patient. The dietician's role is mainly to ensure individual patients, or groups of patients, receive the correct diet to meet their nutritional needs. Mrs Ryan has asked specifically why a dietician

was not involved in discussions and decisions about her son's nutrition. The simple answer is that no one informed the dieticians about Mr Ryan's feeding problems. The Malnutrition Universal Scoring Tool assessment which should have led to a request for dietetic advice was poorly completed and not actioned. That said, there is probably little the dietician could have offered because other team members had not established a way of feeding Mr Ryan. There would have been no point in the dietician advising on the nature and content of his diet when there was no way of feeding it to him.

189 As I have said, community staff are also part of the multidisciplinary team. In Mr Ryan's case, his carers appropriately alerted Community Learning Disability Team staff that he was in hospital two days after he was admitted. Community Learning Disability Team staff had a responsibility to help Trust staff understand and meet his health needs while he was in hospital and Trust staff had a responsibility to seek out and respect that input. As my Acute Nursing Adviser has suggested, it seems there was an over-reliance on Mr Ryan's carers to fulfil this role, when it is likely they had very little experience of acute healthcare. The Community Learning Disability Team Nurse did visit Mr Ryan on several occasions and there is evidence that she tried to influence decisions about his nutrition by writing in the notes, asking for a multidisciplinary meeting and attempting to contact doctors. Trust staff did not respond to her or actively seek her advice and in so doing failed in their professional duty as set out in the Nursing and Midwifery Council's Code of Conduct and the General Medical Council's Good Medical Practice to work effectively with colleagues to plan and deliver optimum care for Mr Ryan. This was **service failure**.

#### *Failure to feed Mr Ryan and communication between staff: my conclusion*

- 190 I conclude that the key reasons for the significant shortcomings in Mr Ryan's care and treatment, and in particular his nutritional care, were failings in provision of stroke services as well as failings in clinical leadership, communication and multidisciplinary team working.
- 191 The Trust's failure to comply with national directives on the development of a stroke unit or to organise existing services to provide effective stroke care, is at the heart of this case. Had such co-ordinated services existed there would have been more chance that Mr Ryan would have received care and treatment organised and provided by a group of clinical staff who, although experts in their own field, would come together to deliver effective care focused on the needs of a stroke patient.
- 192 In the absence of a specialist stroke facility, the Trust's professional healthcare and management staff should have worked together and with community colleagues and organised available resources to ensure they delivered a reasonable standard of care for Mr Ryan. Sadly, this did not happen. Instead, the staff who cared for Mr Ryan appeared to work in isolation from each other and no one took the lead in managing his care. In particular, the medical team, led by the Consultant, failed to comply with the standards set out in Good Medical Practice and the nursing team, led by the Ward Sister, failed to comply with their professional Code of Conduct.
- 193 As a result of the Trust's organisational failings and the flawed actions and omissions of Trust staff, Mr Ryan was not fed for 26 days. This was **service failure** which was at least in part for disability related reasons.

## Complaint (c): malnutrition and starvation

- <sup>194</sup> One of the conclusions of the Trust's internal inquiry was that Mr Ryan's death could not be attributed to the poor care and treatment he received. Subsequently, the Trust has put forward a view, based on its analysis of academic papers carried out after the event, that there was a high chance that Mr Ryan would have died as a result of the stroke.
- <sup>195</sup> Mrs Ryan does not accept the Trust's explanation about the reasons why Mr Ryan died. She believes that he '*starved to death*' and she wants to know whether he would have survived if he had received adequate nutrition.
- <sup>196</sup> I can fully understand why Mrs Ryan believes her son '*starved to death*'. He was not fed for 26 days and it is an indisputable fact that people need food to live and that without sufficient food people weaken and eventually die. However, the questions which I have to address are whether there is sufficient evidence to support Mrs Ryan's view of the reason why Mr Ryan died and whether his death could have been avoided. To assess these questions I turn to the expert advice of my Medical Adviser. In the light of his advice, I look at information about the severity of Mr Ryan's stroke and consider the impact of the lack of specialist stroke care and malnutrition on his chances of survival.

### The advice of my Medical Adviser

- <sup>197</sup> In terms of the severity of Mr Ryan's stroke, my Medical Adviser said information about the nature of Mr Ryan's stroke and the physical and mental consequences for Mr Ryan were not fully documented. For example, it was clear that Mr Ryan could not move his left side and could not swallow, but there was no firm evidence

about any other possible effects of the stroke, such as loss of sensation or vision. However, from the limited documentary evidence that he had seen (including the report of the brain scan), he thought damage to Mr Ryan's brain was '*significant but not very extensive*'. My Medical Adviser cautiously said it seemed Mr Ryan had suffered the sort of stroke which he would normally expect a patient to survive. However, he also said that patients who do survive such strokes usually have long-term mental and physical problems.

- <sup>198</sup> In terms of the medical facilities provided for Mr Ryan, my Medical Adviser pointed to the recommendations in the *National Clinical Guidelines for Stroke*. These guidelines were drawn up on the basis of carefully conducted and validated research and, as I have previously said, the overarching recommendation about organisation of stroke services was that they should be grouped into a stroke unit. My Medical Adviser said there is evidence that the mortality rate and level of disability amongst stroke patients who are admitted to specialist stroke units is lower than amongst those who are admitted to general medical wards.
- <sup>199</sup> My Medical Adviser said there is sufficient evidence to show that Mr Ryan became malnourished during his time in hospital. In terms of the impact of malnutrition on likely survival the Medical Adviser said:

*'Prolonged starvation would in my view have made it less likely that [Mr Ryan] would have made a neurological recovery, made him more susceptible to infection and less able to combat infection when it occurred. I think therefore that there is a real possibility that delay in feeding contributed to his death.'*

and

*'I think it is likely that malnutrition contributed to Mr Ryan's death although this is impossible to prove.'*

- 200 My Medical Adviser considered all the representations made in response to my draft report and he found nothing which persuaded him to change his original advice.

### My findings

- 201 I have taken account of my Medical Adviser's opinion. Based on this advice it seems reasonable to assume that, even though he suffered a severe stroke, Mr Ryan would have had a better chance of survival if he had been admitted to a hospital where stroke services were organised in the way described in the *National Clinical Guidelines for Stroke*.
- 202 Also, it is clear from my Medical Adviser's advice that Mr Ryan would have been less likely to develop infections if he had been fed. However, my Medical Adviser said that it is impossible to prove that malnutrition either contributed to or caused Mr Ryan's death.

### Malnutrition and starvation: my conclusion

- 203 Given the magnitude of the failings in Mr Ryan's care and treatment I, like Mrs Ryan, find it difficult to accept the Trust's position that those failings did not contribute to his death. My Medical Adviser told me that the evidence suggests Mr Ryan had a '*significant*' stroke and, as I have said in paragraph 104, according to the Stroke Association, stroke is the third most common cause of death in the UK. Therefore, I do not doubt that Mr Ryan was at risk of dying as a result of impairments caused by the stroke.

One of those impairments was his inability to swallow safely. It cannot be disputed that this led directly to the need to ensure he received adequate nutrition by artificially feeding him. To my mind, especially given the limited information we have about the nature of the stroke itself, it is not possible to separate the direct impact of Mr Ryan's stroke from the life-threatening consequences of that stroke, such as the inability to eat normally.

- 204 In the light of the opinion of my Medical Adviser, I conclude that it is impossible to say for certain whether Mr Ryan would have survived if he had been fed. However, what I can say is that because of the failings of Trust staff, Mr Ryan was not fed for 26 days and this undoubtedly placed him at considerable risk of harm. I conclude that although it is impossible to prove that malnutrition and starvation contributed to or caused Mr Ryan's death, it is likely that the failure to feed him for a prolonged period was one of a number of failings which led to his death. This was **service failure** which was at least in part for disability related reasons.

### Complaint (d): complaint handling by the Trust

- 205 Mrs Ryan is dissatisfied with the way in which the Trust handled her complaint about her son's care and treatment. She says the Trust failed to respond appropriately to her complaints and she wants to know why it took the Trust so long to give her an explanation about how her son died. She also wants to know why the Trust did not classify his death as a Serious Untoward Incident as soon as he died. She believes this may have been for reasons related to his learning disabilities. Mrs Ryan also wants to know

whether the changes which the Trust has put in place following Mr Ryan's death will make a difference to the care and treatment of other patients in similar circumstances.

### Key events

- 206 On 23 January 2006 three staff from the Community Learning Disability Team and the Care Home wrote to the Chief Executive asking for a meeting to discuss their concerns with the aim of finding ways to work more collaboratively with Trust staff. On 22 March 2006 a meeting took place where the Community Learning Disability Team staff put forward a number of concerns, including staffing levels, breakdown in communication, lack of feeding, medication not being given on time and liaison with the Community Learning Disability Team and Mr Ryan's carers.
- 207 Meanwhile, on 27 February 2006, Mencap complained to the Trust on behalf of Mrs Ryan. They raised concerns about the treatment Mr Ryan received in hospital and '*lack of communication with his family about his condition and possible treatments*'. They listed five specific areas of concern with multiple questions in each area. The key areas were: insertion of a feeding tube; communication with the family; epilepsy medication; lack of skills in dealing with people with learning disabilities; and inclusion of Down's syndrome on the death certificate.
- 208 On 26 April 2006 the Trust responded giving details about Mr Ryan's care and treatment. The response included a description of the sequence of speech and language assessments as well as information on decisions about nasogastric feeding and inserting a PEG feeding tube.
- 209 The Trust said there was '*no delay in appropriately considering the feeding tube*' and that there was liaison with the Community Learning Disability Team, Mr Ryan's carers and his family about feeding. It also explained that it had not always been possible to give epilepsy medication on time because staff resources were limited and there were difficulties in keeping an intravenous cannula in place. It also said that when Mr Ryan's condition deteriorated, the way in which staff had communicated with his family and the Community Learning Disability Team had been appropriate.
- 210 The Trust said nurses on the Ward had received training on caring for vulnerable adults, but not in caring for patients with learning disabilities. However, it said Mr Ryan's carers had provided specialist knowledge to support the ward nurses. In terms of the death certificate the Trust explained that the Consultant (who had not written the certificate) thought the information '*would help in the recording of accurate statistics reflecting the morbidity and mortalities associated with this syndrome*'.
- 211 The Trust offered to meet with Mrs Ryan to discuss her concerns.
- 212 On 15 May 2006 Mencap wrote again to the Trust raising some points about accuracy and validity of some information in the Trust's letter of 26 April 2006. They also asked the Trust to comment about why no attempt was made to feed Mr Ryan and why the Community Learning Disability Team had not been consulted about the possibility of using '*minimal restraint*' to help the Speech and Language Therapist with her assessments. They also questioned the Trust's response about communication with Mrs Ryan because she did not remember speaking to the Palliative Care Team and she

said no doctor or nurse spoke to her when she arrived on the Ward on 16 December 2005.

- 213 On 12 July 2006 the Trust responded to Mencap's second letter. In this response the Trust admitted there had been a breakdown in communication between the Consultant and the ward nurses because the Consultant thought nurses were attempting to insert a nasogastric tube when they were not. However, nurses thought the Community Learning Disability Team had advised that Mr Ryan would not tolerate a nasogastric tube so this method of feeding would not be possible. Therefore, they had not attempted to insert a tube. The Trust reported that the Head of Speech and Language Therapy had reviewed the actions of the Speech and Language Therapist who had assessed Mr Ryan and found no fault with her actions. The Trust also said the Consultant did not believe the medical team were at fault because they had followed usual procedures for arranging insertion of a PEG feeding tube. The Trust maintained that it would have been '*clinically inappropriate to force Mr Ryan to eat with any restraint*'.
- 214 In terms of communication with Mrs Ryan at the time when palliative care was introduced, the Trust said there was a record that the Palliative Care Team had spoken to her and the medical team spent '*a considerable amount of time contacting Mrs Ryan at home and speaking to her on the telephone*'. It said the Consultant would have been available to speak to her had she asked to meet him.
- 215 On 31 July 2006 Mencap wrote to the Trust for a third time. On this occasion Mencap said the failure to feed Mr Ryan was one of the direct causes of his death. They raised further points about feeding (lack of communication, risk/benefit of using restraint, whether or not nasogastric feeding was attempted, national guidelines on feeding and the Trust's Eating and Drinking Policy) and made some points about treating patients who lack capacity to consent.
- 216 The Trust tried to arrange a meeting with Mencap and Mr Ryan's parents in October 2006, but this offer was declined. On 18 October 2006 the Trust responded to Mencap's third letter. Its response included the draft report of a 'mini review' which had been conducted by the Trust's Medical Directorate.
- 217 The 'mini review' included an acknowledgement that multidisciplinary communication on the Ward had been poor, especially between doctors and nurses. It described action which had been taken to address this problem, for example, the introduction of weekly multidisciplinary meetings. It also included an acknowledgement that there was poor communication between the multidisciplinary team about feeding Mr Ryan and no one had taken responsibility for raising concerns or taking action about those concerns. Furthermore, the 'mini review' found there was no nutritional management plan in the medical notes and there had been confusion between doctors and nurses about whether or not an attempt had been made to pass a nasogastric tube. The Trust acknowledged it had been '*wholly unacceptable*' that no attempt had been made to pass a nasogastric tube. It also acknowledged the failure to complete the Malnutrition Universal Scoring Tool assessment, saying this was also unacceptable and contributed to Mr Ryan's lack of nutrition. The Trust also said staff had lacked understanding about appropriate use of restraint.

- 218 The Trust's response included the Chief Executive's apologies for delay, inaccuracies and confusion arising from previous responses. She also offered her *'heartfelt apologies to Mr Ryan's parents for the poor treatment that Mr Ryan received'* and she offered to meet with his family. The Chief Executive also told Mencap that she had reported Mr Ryan's death as a Serious Untoward Incident to the strategic health authority and launched an internal inquiry into his care and treatment.
- 219 On 9 November 2006 Mencap wrote a fourth letter to the Trust. This raised one principal query about Mr Ryan's congenital heart condition which was mentioned in the 'mini review'. Mencap said neither Mr Ryan's parents nor his carers knew about this condition and they questioned whether this had influenced the decision not to insert a PEG feeding tube.
- 220 On 22 November 2006 the Trust responded explaining that the doctor who had admitted Mr Ryan had heard an abnormal heart sound and wondered whether this resulted from congenital heart disease. However, Mr Ryan's heart function was found to be normal and this had no bearing on the decision not to insert a PEG feeding tube.
- 222 The findings of the inquiry are set out at Annex D. Key findings on management of the complaint included: there was a reasonable conclusion to the complaint from the Community Learning Disability Team; responses to Mencap showed inconsistencies and inaccuracies; significant delay in providing the first response; no challenge to written statements; failure to trigger a Serious Untoward Incident; and no developed governance framework in the Directorate of Medicine.
- 223 The report made nine recommendations which I have set out at Annex E. In summary, they related to clinical leadership; medical cover in the Directorate of Medicine; the work of the Trust's Nutritional Review Group; arrangements for Clinical Governance in the Directorate of Medicine; use of a nursing staff dependency tool; the relationship of ward staff to carers; speech and language therapy team working; whistle-blowing; and review of specific aspects of the complaints policy.
- 224 On 8 January 2007 an informal seminar was held by the Trust Board to consider the results of the inquiry. By this time several developments had already occurred including: establishment of a Nutritional Working Group; the stroke unit had been opened; the Ward Sister had revised the system of nursing handover and was going to attend a leadership course; the Consultant had attended a course on the care of people with learning disabilities; a regular multidisciplinary morbidity and mortality meeting had been set up and Mr Ryan's case had been discussed there; changes to organisation of services, including 'Hospital at Night'; and initiation of joint working with the local Community Learning Disability Teams.

### The internal inquiry

- 221 I have described above the nature and purpose of the Trust's internal inquiry. One of the aims of the internal inquiry was:

*'To understand and consider the failure to escalate the complaint within the organisation.'*

225 On 31 January 2007 the Trust Board reviewed the report and accepted its conclusions and recommendations. It also added six more recommendations which included: disciplinary hearings for key staff; further action on ensuring nutritional standards were met; Trust-wide review of governance arrangements; complete review of the complaints procedure; review of the Trust's overall approach to patients with learning disabilities; and development of a formal action plan to address all the recommendations.

226 Throughout 2007 the Trust Board monitored actions taken in response to the recommendations. In January 2008 the Board accepted the final report on the action plan which showed that all actions had been completed.

227 The Trust met with Mr Ryan's parents in March 2007 to discuss the internal inquiry and, since then, it has continued to update them about changes and improvements resulting from the findings and recommendations. Most recently, the Chief Executive wrote to Mencap setting out progress against the action plan. Her letter included achievements in improving nutritional care across the Trust against Essence of Care benchmarks. She also sent information about the outcome of collaborative working between the Trust and the Community Learning Disability Team which has included development of a 'Joint protocol to support people with learning disabilities to access acute hospital services' and a 'Health Passport' for people with learning disabilities.

## The advice of my Professional Advisers

228 My investigator specifically asked my Professional Advisers for their views on the Trust's explanations about the failures in Mr Ryan's care and treatment, including the finding of the internal inquiry. She also asked for their views on whether the recommendations of the internal inquiry and the subsequent action taken by the Trust would address those failings and, where possible, prevent a recurrence of what happened to Mr Ryan.

229 My Medical Adviser said he agreed with the findings of the internal inquiry. He also said that there is evidence that the Trust is addressing the problems; for example, there is now a stroke unit. He said:

*'I am reassured by the statement that multidisciplinary meetings are now a regular feature of care.'*

230 My Acute Nursing Adviser said the internal inquiry was thorough and identified key aspects about failings in Mr Ryan's clinical care. In terms of the Trust's actions to address failings it identified she said:

*'It is my opinion that the Trust has made considerable effort to learn from this case and has worked hard to put measures in place to address the failings identified. There is clear evidence encompassed in the recommendations of the internal inquiry panel and further recommendations of the Trust Board to demonstrate that the Trust are taking appropriate actions to address the clinical failings identified by the internal inquiry.'*

231 My Acute Nursing Adviser also reviewed additional information about the latest action taken by the Trust. She said the Trust has *'made really good progress'* and she commented that using the matrons and site managers as points of reference and expertise when people with learning disabilities are admitted was a particularly good idea. She also said the Trust had developed a clear pathway to escalate concerns and there was *'clear evidence of collaborative working'* between Trust staff and the Community Learning Disability Team.

232 My First Learning Disability Nursing Adviser said:

*'I believe the Trust has done everything possible to address this complaint and have taken full responsibility for their actions ...'*

233 My Second Learning Disability Nursing Adviser said the Trust has:

*'... really taken on board the lessons learnt from the tragedy regarding Mr Ryan and have pulled out all the stops to ensure people with learning disabilities get a better service in the future. The report back to their Board indicates they took the incident seriously and have put a lot of effort into getting things right for the future.'*

234 She also said that the Trust's protocol about admissions and discharges is *'excellent'* and *'should go a long way to improving things dramatically for people with learning disabilities'*. Furthermore, she said the *'patient passport'* which the Trust had developed is in line with national standards. In addition, she remarked on the positive relationship which had developed between the Trust and the PCT, particularly in terms of agreeing additional funding for services.

## My findings

235 Mrs Ryan remains dissatisfied with the way in which the Trust handled her complaint. Her main points are that the Trust failed to respond appropriately to her complaints and took too long to give her an explanation about how her son had died. She also wants to know why the Trust did not classify Mr Ryan's death as a Serious Untoward Incident as soon as he died. She believes this may have been for reasons related to his learning disabilities.

236 I can understand why Mrs Ryan is unhappy with the Trust's response to her complaint and why she feels the complaints process has been complex and prolonged. Although she first complained about Mr Ryan's care and treatment in February 2006, Mrs Ryan did not receive an open and comprehensive response from the Trust until it shared the results of the internal inquiry with her in March 2007. Even then, as we have seen, she has some outstanding queries, particularly relating to Mr Ryan's learning disabilities.

237 First, I consider the way in which the Trust responded to Mrs Ryan's complaint.

238 I have studied all the evidence about complaint handling by the Trust, including complaint correspondence and background papers provided by the Trust. I have assessed the Trust's actions against the Regulations, the *Principles of Good Administration* and *Principles for Remedy* and it is clear that there were significant failings in the Trust's management of this complaint.

239 In my view, the most serious shortcoming in complaint handling was the failure to recognise the seriousness of the matters complained about – the fact that the complaint concerned

the death of a man who had not been fed for 26 days. The significance of the complaint was not fully recognised until the Chief Executive declared a Serious Untoward Incident in September 2006 – over six months after the Trust received Mrs Ryan’s first complaint letter. The internal inquiry panel recognised the significance of this failing and explored the reasons why the complaint was not singled out as being particularly serious and significant. Although the initial complaint investigation and response followed the basic process set out in the Regulations, there were failings in the way in which the investigation was conducted.

240 In particular, it is clear that the investigating officer did not have the medical experience or authority to conduct an effective, in-depth investigation involving senior clinicians. This is illustrated in the first two responses from the Trust (26 April and 12 July 2006). The content of the letters is apparently based mainly on the Consultant’s view of events. It seems there was some input from the speech and language therapy team, but very little input from the senior nurses, especially the Ward Sister, who should have had a key role in responding to the complaint. Furthermore, it appears that the investigating officer did not challenge the Consultant’s contention that there had been no failings in Mr Ryan’s care and treatment, when the most basic failing, lack of nutrition, would have been obvious to anyone reviewing the case. However, it appears the investigator did not question the Consultant’s view. This meant that, in its first response, the Trust even denied there had been a delay in inserting a feeding tube. In the second response the Trust accepted there had been a breakdown in communication about feeding, but continued to maintain that the medical team was not at fault regarding the failure to feed Mr Ryan. Instead, a series of different explanations, such as limited

resources, problems with consent and Mr Ryan’s deteriorating physical condition, were put forward as reasons why he was not fed. It is clear that the investigation was not carried out in line with the requirements of Regulations 12 and 13. This was **maladministration**.

241 Turning to the nature of the responses themselves, I find the tone of the first two letters was inappropriate and very defensive. This is illustrated by the responses about communication with Mr Ryan’s family. Based principally on the Consultant’s view, the Trust condoned the frank way in which the Specialist Registrar had informed Mrs Ryan over the telephone that her son was dying. Moreover, the Trust robustly defended the Consultant’s approach to communication, saying he had been available when the decision to commence palliative care was made, but the family had not asked to speak to him. At this stage, the Trust did not acknowledge any major failings and its approach was far from conciliatory. The Trust’s responses were not in line with the overall thrust of the Regulations which focus on effective local resolution or the specific instructions on responses to complaints in Regulation 13. This was **maladministration**. In these circumstances I do not find it at all surprising that Mrs Ryan declined a local resolution meeting.

242 Mencap recognised that there were inaccuracies and inconsistencies in the Trust’s first two responses, for example, about whether or not nurses had attempted to pass a nasogastric tube and the length of time Mr Ryan had been without food. This led them to question other aspects of the Trust’s responses, including explanations about epilepsy medication. Inaccuracy and inconsistency were key failings in the initial management of this complaint. This was **maladministration**.

- 243 It is clear that the Trust's initial investigation into Mrs Ryan's complaint was wholly inadequate and its first two responses to the serious matters complained about were wholly inappropriate. I find that, up to this point, its approach to complaint investigation and response was not in line with that set out in the detail of the Regulations or the *Principles of Good Administration*.
- 244 Having made these criticisms of the initial attempts to address Mrs Ryan's complaint, it seems to me that some time in the summer of 2006 there was a turning point in the Trust's approach. This was when the 'mini review' was instigated. It is not entirely evident who or what prompted the 'mini review', but it is clear that the findings of this second investigation led the Trust to recognise the major failings in Mr Ryan's care and treatment. As a direct result the Chief Executive contacted the strategic health authority about Mr Ryan's death and set up the internal inquiry.
- 245 Following the 'mini review' there was a turnaround in the Trust's approach. The Trust's letter of 18 October 2006 is very different in content and tone from its previous two letters. It included detailed explanations, acknowledged failings, offered apologies and provided information about the internal inquiry.
- 246 I have studied the Trust's subsequent actions in depth and I have found no further faults with its approach to managing the complaint. On the contrary, I agree with Mencap and my Professional Advisers that, once it realised the seriousness of the issues complained about, the Trust was open and transparent about its failings. In terms of the inquiry itself, I draw attention to the appropriate senior independent advisers who were asked to join the inquiry panel, the range of papers they studied, the in-depth interviews they conducted and the clear, concise report they produced.
- 247 In terms of the Trust's response to the outcome of the internal inquiry, I note the effort which has been made to implement the expanded recommendations and the keen interest of the Trust Board in tracking progress with actions to meet those recommendations. I also note that the Chief Executive has maintained her personal interest in the case and has remained the key contact for Mr Ryan's parents and Mencap. Mencap have acknowledged that the Trust has worked hard to correct the failings identified in this case. Following the internal inquiry, the Trust has openly acknowledged failings, offered sincere personal apologies to Mrs Ryan and kept her and Mencap informed of progress with initiatives to address the failings identified. At this stage its actions reflected the *Principles of Good Administration*.
- 248 Secondly, I consider whether the failure to declare Mr Ryan's death as a Serious Untoward Incident at an earlier stage was related to his learning disabilities.
- 249 The Trust should have reported Mr Ryan's death to the strategic health authority as soon as he died because events associated with his death fulfilled the criteria to trigger a Serious Untoward Incident (which I have set out above). The Trust missed a second trigger when it received Mrs Ryan's complaint in February 2006. However, in my view, the Trust's failure to report Mr Ryan's death was due to the failings in both clinical and management systems which I have described in detail elsewhere in this report. In reviewing the sequence of events in the Trust's management of the complaint, I have seen no evidence to suggest that this failing, or any of the shortcomings in complaint handling, were related to Mr Ryan's learning disabilities.

## Complaint management: my conclusion

250 In conclusion, I agree with Mrs Ryan that there were major failings in the way in which the Trust handled her complaint. Specifically, these were:

- i. failure to recognise the seriousness of the matters complained about, in particular the failure to feed Mr Ryan;
- ii. failure to declare a Serious Untoward Incident at an early stage;
- iii. failure to conduct a proper, in-depth investigation; and
- iv. failure to provide appropriate responses which were accurate and consistent.

251 In these respects the Trust failed to comply fully with the applicable Regulations; its actions did not accord with principles of good administration; and it did not provide an appropriate or adequate remedy. These failings amount to **maladministration**.

252 However, I have found no evidence which indicates that the Trust's maladministration in the handling of Mrs Ryan's complaint was for disability related reasons.

## Section 4: the Ombudsman's final comments and overall conclusion

### Introduction

253 Mrs Ryan's overarching complaint is that her son's death was avoidable and that he was treated less favourably for disability related reasons. She has told me she has not had full answers to all her questions about Mr Ryan's care and treatment and she hopes my investigation will provide her with those answers. She seeks recognition for her view of events and she hopes other people will not go through the same experiences as her son. In this final section of my report I address Mrs Ryan's overarching complaint and set out my overall conclusion.

254 In assessing the actions of the Trust I have taken account of relevant legislation and related policy and administrative guidance as described above. I have taken account of available evidence and considered the advice of my Professional Advisers.

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

255 Mrs Ryan believed her son was treated less favourably for reasons related to his learning disabilities.

256 I have found service failure in respect of the inadequate care and treatment provided to Mr Ryan by the Trust. I have concluded that the key reasons for the significant shortcoming in Mr Ryan's care and treatment, and in particular his nutritional care, were failings in provision of stroke services, as well as failings in clinical leadership, communication and multidisciplinary team working.

257 In addition I have found maladministration in the way in which the Trust handled Mrs Ryan's complaint.

258 The Trust does not dispute the fact that Mr Ryan received inadequate care and treatment. However, when the Trust's internal inquiry looked at whether Mr Ryan was disadvantaged with regard to his learning disability it concluded:

*'There was no evidence supplied which led the Panel to believe that [Mr Ryan's] care was hampered by the nature of his learning disability. Many of his behaviours (including agitation intolerance of IV cannulation etc) would be typical of many stroke patients who might be agitated and confused.'*

259 Mrs Ryan does not accept the Trust's conclusion on this issue. Mr Ryan's sister said she thought the Trust *'didn't bother feeding [Mr Ryan] because he had Down's Syndrome'*.

260 I have described above the nature of Mr Ryan's learning disabilities and some of the possible mental and physical consequences for people who have suffered a stroke. We do not know the precise impact of the stroke on Mr Ryan's mental and physical health. However, it is clear that during his admission to the Trust he was not only disabled for reasons related to his learning disabilities, but also because of his stroke.

261 I am not persuaded by the Trust's argument that Mr Ryan was not disadvantaged for reasons related to his disabilities. Rather, from the evidence I have seen and the advice I have received, I conclude that the acknowledged failings in care and treatment cannot be separated from the fact that Trust staff did not attempt to make any reasonable adjustments to

the way in which they organised and delivered care and treatment to meet his complex needs. Trust staff failed to meet Mr Ryan's needs as a person disabled by his learning disabilities and his stroke. Therefore, I conclude that in some significant respects the Trust's service failures were for disability related reasons.

262 The evidence I have seen strongly suggests that the Trust failed to respond to any of the guidance such as Valuing People, Signposts for Success and Doubly Disabled which had been in place for some years before Mr Ryan was admitted to the Trust in November 2005. As I have explained in Section 2, this guidance required the Trust to ensure arrangements were in place for appropriate care and treatment of people with learning disabilities.

263 In Section 2 I set out my approach to human rights. On that basis, I also conclude that the Trust's actions and omissions constituted a failure to live up to human rights principles, especially those of dignity, equality and autonomy.

264 By failing to care properly for Mr Ryan, in particular by not feeding him, the Trust failed to have due regard to his status as a person, to the need to avoid the infringement of his dignity and wellbeing that would arise from a lack of attention to his needs, in particular his need for food, and to observance of the principle of equality in the way these rights were to be protected. There is no evidence of any positive intention to humiliate or debase Mr Ryan. Nevertheless, the standard of service does at the very least constitute a failure to respect Mr Ryan's human dignity.

265 In these respects the service failures I have found touched upon and demonstrated inadequate respect for Mr Ryan's status as a person.

### Was Mr Ryan's death avoidable?

266 Mrs Ryan believes that her son '*starved to death*' because staff at the Trust failed to feed him for 26 days. I can fully understand why she takes that view and I share her concerns.

267 In considering whether to make a finding about avoidable death I assess whether the injustice or hardship complained about (in this case Mr Ryan's death) arose in consequence of any service failure or maladministration I have identified.

268 I have concluded that it is impossible to say for certain whether Mr Ryan would have survived if he had been fed. However, whilst I cannot categorically say that Mr Ryan died because he was not fed, I am not persuaded that the Trust can categorically say that this was not the reason for his death.

269 My Medical Adviser has told me that on the basis of available information the stroke which Mr Ryan suffered '*sounds like the sort of stroke that one would normally expect the patient to survive, although often with long-term [problems with physical and mental functions]*'. The combination of failures in Mr Ryan's care and treatment, particularly the lack of specialist stroke services and the clinical failings in leadership, communication and multidisciplinary team working, put him at risk. Added to this the Trust's failure to feed him meant he was more likely to develop infections and less likely to survive them.

270 Taking into account the professional advice I have received, I conclude that, had the care and treatment Mr Ryan received not fallen so far below the standards which I have identified earlier in this report, it is likely that his death could have been avoided.

## Injustice

271 The Trust's internal inquiry established failings in the service provided for Mr Ryan and it openly acknowledged and apologised for those failings in a face-to-face meeting with Mr and Mrs Ryan. The Trust informed me of the actions it took to address the shortcomings identified as well as subsequent developments, in particular improvements related to services for people with learning disabilities. I have set out these actions above. My Professional Advisers have told me that these actions and initiatives were appropriate and would address the key failings in Mr Ryan's care and treatment identified at that time.

272 In her response to my draft report the Trust's Chief Executive said she would like to give:

*'... the Trust's sincere apologies for the shortcomings identified in your Report. Many of these were the conclusions of the Internal Review established by the Trust and to that extent reflect the dismay experienced in the hospital for the distress and sadness that we are aware has been experienced by Mr and Mrs Ryan.'*

273 She also offered to meet Mr Ryan's parents if they wished.

274 She went on to detail further changes which the Trust has made including changes to the complaints procedure and developments in services for people with learning disabilities. These included collaborative working with the Community Learning Disability Team and participation in the London Network for Learning Disability Nurses. She also gave details of the ways in which the Trust's focus on nutrition has impacted on staff and patients. Her examples included recruitment of a nutritional nurse specialist, staff training, policy review and audit.

275 Having considered the evidence put forward by the Trust about changes which have occurred since Mr Ryan was a patient there I find the Trust has taken and continues to take, reasonable action to address the shortcomings identified by its own inquiry. In particular, I recognise that the Trust has, as Mencap have acknowledged, taken an open and honest approach to the failings in the service provided for Mr Ryan. I also find that its actions will address many of the failings identified in this report with regard to the care and treatment provided for Mr Ryan and to complaint handling.

276 That said, I consider Mr Ryan's parents still have reason to be aggrieved by the failings in the Trust's care and treatment of their son and, in particular, those failings which I have concluded occurred for disability related reasons. Furthermore, they should not have had to wait for an investigation by me to fully establish the facts about the service provided for their son. Partly due to failings at the Trust, Mr Ryan's parents have had to wait over two years for answers to their questions. These findings represent **unremedied injustice**.

## My overall conclusion

- 277 I have found **service failure** and **maladministration** which have led to an **unremedied injustice** to Mr Ryan and his family. In the avoidable death of their son, Mr Ryan's family have suffered an injustice which can never be remedied.
- 278 Therefore, I **uphold** Mrs Ryan's complaint against the Trust.

## My recommendations

- 279 I recognise that the Chief Executive of the Trust has already met with Mr Ryan's parents and with Mencap to apologise for failings identified by the Trust's own internal inquiry, and that she has offered her apologies for those failings. However, my investigation has uncovered significant additional failings, particularly in relation to Mr Ryan's death, his human rights and his learning disabilities. These failings have not previously been recognised by the Trust. Therefore, I **recommend** that the Chief Executive of the Trust apologise to Mr Ryan's parents for all the failings I have set out in my report.
- 280 I also **recommend** that the Trust offer compensation of £40,000 to Mr Ryan's parents in recognition of the injustice they have suffered in consequence of the service failure and maladministration I have identified.

## The Trust's response to my recommendations

- 281 The Chief Executive of the Trust acknowledged the failings identified in this report and said:

*'The Trust unreservedly apologises to Mr and Mrs Ryan for the failings identified in the Ombudsman's report. We know that nothing can be done to take away the pain and anguish caused to their family, but hope that our commitment to have learnt from our mistakes will offer some comfort. The Trust accepts the remedy proposed by the Ombudsman.'*

I have outlined above some of the actions taken by the Trust in respect of its failings. I have already commented that I find these actions appropriate and I am reassured that lessons have been learnt from this case. The Chief Executive accepted my recommendation regarding a compensation payment and offered to make that payment as soon as possible.

## Mr Ryan's parents' response to my report

- 282 Mr Ryan's family and Mencap have said the outcome of my investigation is that *'justice has been done'* because my report exposes the failures that led to Mr Ryan's death. They also welcomed my conclusion that some of the failures in care and treatment were for disability related reasons. They told me they believe my report will have a positive impact on future care of people with learning disabilities. In particular, they have said that my report shows how *'proper care, using multidisciplinary working, personalised care planning and good communication within teams and with families and carers would greatly improve the outcome for people with a learning disability in our hospitals'*.

283 Mr Ryan's family have also welcomed the information provided by the Trust regarding changes which have been put in place to prevent a similar event occurring and they hope this work can be used to benefit other hospitals. Mr Ryan's family welcomed the personal apology which they received from the Chief Executive of the Trust.

### **My concluding remarks**

284 Mrs Ryan's complaints have been thoroughly and impartially investigated and my conclusions have been drawn from careful consideration of the detailed evidence, including the opinion of independent professional advisers. I hope my report will provide Mrs Ryan with the answers she seeks and will reassure her that lessons have been learnt and learning shared so that others are now less likely to suffer the same experiences as Mr Ryan and his family. I also hope that my report will draw what has been a long and complex complaints process to a close.



Ann Abraham  
**Parliamentary and Health Service 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.'

### Leading teams (section 37)

'If you lead a team, you must ensure that:

- medical team members meet the standards of conduct and care set out in this guidance;
- any problems that might prevent colleagues from other professions following guidance from their own regulatory bodies are brought to your attention and addressed;
- all team members understand their personal and collective responsibility for the safety of patients, and for openly and honestly recording and discussing problems;
- each patient's care is properly co-ordinated and managed and that patients know who to contact if they have questions or concerns;
- arrangements are in place to provide cover at all times;
- regular reviews and audit of the standards and performance of the team are undertaken and any deficiencies are addressed;

...'

### 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.'

## ANNEX B

### National Clinical Guidelines for Stroke, 2nd Edition, 2004 (extracts)

#### Organisation of stroke services

a. Stroke services should be organised so that patients are admitted under the care of a specialist team for their acute care and rehabilitation.

b. Stroke services should have:

- a geographically identified unit as part of the in-patient service
- a co-ordinated multidisciplinary team that meets at least once a week
- staff with specialist expertise in stroke and rehabilitation
- educational programmes for staff, patients and carers
- agreed protocols for common problems
- access to brain and vascular imaging services.

#### Assessment of acute stroke

a. Brain imaging should be undertaken as soon as possible in all patients, at least within 24 hours of onset.

b. The diagnosis should always be reviewed by an experienced clinician with expertise in stroke.

c. If the underlying pathology is uncertain, or the diagnosis of stroke is in doubt after computed tomography scan, magnetic resonance imaging should be considered.

d. The patient should be assessed on admission for:

- their risk of aspiration, using a validated 50ml water screening tool, administered by an appropriately trained professional
- their needs in relation to moving and handling, and their risk of developing pressure sores.

#### Acute interventions

a. Blood glucose, arterial oxygen concentration, hydration and temperature should be maintained within normal limits.

b. Blood pressure should only be lowered in the acute phase where there are likely to be complications from hypertension, for example hypertensive encephalopathy, aortic aneurysm with renal involvement.

c. Patients should be mobilised as soon as possible.

d. Aspirin (300mg) orally or rectally should be given as soon as possible after the onset of stroke symptoms if a diagnosis of primary haemorrhage has been excluded.

## ANNEX C

### Summary of key events (from medical and nursing records)

#### 26 November 2005

##### Day 1

Mr Ryan was admitted to the Trust at around 5.45am, after he had suffered a stroke.

Mr Ryan was reviewed by an A&E junior doctor and later by another junior doctor. Tests and investigations, including a chest X-ray and blood tests, were carried out.

Mr Ryan was reviewed by a consultant (not the Consultant) at 8.00am and transferred to the Ward at 12.30pm. He was reviewed by a junior doctor at 6.00pm. This junior doctor decided Mr Ryan may have aspirated after eating, and therefore should be designated 'nil by mouth'. A course of antibiotics was started and a weakness was noted on Mr Ryan's left side.

#### 28 November 2005

##### Day 3

A junior doctor saw Mr Ryan because he was drowsy but 'awake and rousable'. He was also not moving his left side. This junior doctor asked for an urgent CT scan, and a repeat chest X-ray. Intravenous infusion and antibiotics were continued and a speech and language therapy review was suggested.

The Community Learning Disability Team Nurse made an entry in the notes in which she explained that she was Mr Ryan's community nurse and provided two telephone contact numbers. In her note she asked to speak to the Consultant, expressed concern about the fact the CT scan had not been done and asked if she could liaise with a speech and language therapist and a physiotherapist after the CT scan had been done.

#### 29 November 2005

##### Day 4

Mr Ryan was referred to speech and language therapy.

Mr Ryan was reviewed by the Consultant.

The Specialist Registrar in Radiology reported that the CT scan showed a recent infarct in the right side of Mr Ryan's brain.

#### 30 November 2005

##### Day 5

A junior doctor noted that he had discussed the CT report with the Community Learning Disability Team Nurse but there is no record of what was said.

The physiotherapist reviewed Mr Ryan's position in bed.

A senior house officer said that Mr Ryan should remain nil by mouth and the intravenous infusions should continue. He also ordered further blood tests.

With his carer present, Mr Ryan was reviewed by a physiotherapist. Mr Ryan was unable to co-operate with chest exercises.

Also, while his carer was present, Mr Ryan was reviewed by a speech and language therapist and a note was made of Mr Ryan's normal eating and drinking habits. Mr Ryan tried to take sips of thin and syrupy fluids, but his swallowing was difficult to assess because Mr Ryan could not co-operate with instructions. Mr Ryan also coughed immediately following attempting to drink thin fluids. This speech and language therapist decided there was a high risk of aspiration and Mr Ryan should be given nothing orally.

The Community Learning Disability Team Nurse made an entry in the notes. She asked the medical team to review Mr Ryan's hydration and nutrition, and suggested that there had been breaks in the intravenous fluid regime. She said she thought the intravenous infusion should run continuously. She also asked if intravenous feeding could be considered.

### **1 December 2005**

#### **Day 6**

Mr Ryan was reviewed by a junior doctor who said he should continue nil by mouth and should have physiotherapy. This junior doctor ordered additional tests, including tests of heart activity. He made note of a conversation with Mr Ryan's parents during which he had discussed '*diagnosis and management*' with them. There are no recorded details of this conversation.

### **2 December 2005**

#### **Day 7**

The consultant reviewed Mr Ryan and said he should be given aspirin.

Mr Ryan was reviewed again by a speech and language therapist who tried him with teaspoons of creamy thick fluid. She decided there was still a high risk of aspiration and he should remain nil by mouth. She questioned whether Mr Ryan would tolerate alternative feeding methods.

Mr Ryan was reviewed twice by a physiotherapist who thought he may be aspirating his chest secretions. She also tried to seat him in a wheelchair but this was unsafe and the Care Home were asked to bring in his own wheelchair.

### **5 December 2005**

#### **Day 10**

A speech and language therapist tried to assess Mr Ryan but was unable to because he was drowsy.

### **6 December 2005**

#### **Day 11**

Following review, the Consultant decided Mr Ryan should sit out of bed during the day. Subsequently, the Consultant went on leave. He next saw Mr Ryan on 13 December 2005.

A speech and language therapist tried Mr Ryan with teaspoons of yoghurt. She decided there was still a high risk of aspiration and he should remain nil by mouth.

Mr Ryan was reviewed by a physiotherapist who transferred him into his wheelchair.

### **7 December 2005**

#### **Day 12**

A junior doctor carried out a review of Mr Ryan and noted that alternative feeding methods should be considered.

A physiotherapist noted no change in Mr Ryan's condition.

A speech and language therapist again reviewed Mr Ryan and decided he should remain nil by mouth. She wrote:

*'Team pls [please] consider this pts [patient's] long term nutrition as pt has been on NBM for 11 days with no improvement to swallow so far.'*

### **8 December 2005**

#### **Day 13**

Mr Ryan was reviewed by a junior doctor who noted a further improvement in movement in Mr Ryan's left arm. He decided to keep Mr Ryan nil by mouth and to discuss the situation with the Specialist Registrar.

A speech and language therapist tried to review Mr Ryan but he was too drowsy to co-operate.

A junior doctor noted he discussed the result of a heart test with Mr Ryan's sister. There are no recorded details of the discussion.

### **9 December 2005**

#### **Day 14**

A junior doctor reviewed Mr Ryan and noted he would discuss his feeding with the Consultant.

A speech and language therapist tried to review Mr Ryan but he was too drowsy to co-operate.

A chest X-ray was taken.

### **12 December 2005**

#### **Day 17**

A speech and language therapist reviewed Mr Ryan and wrote that she had discussed his condition with the Community Learning Disability Team Nurse, the Community Social Worker, the Manager of the Care Home and the Ward Sister. She said they had talked about feeding and a discharge destination for Mr Ryan. She explained her role and her opinion about the danger of aspiration. She said she was concerned about Mr Ryan's nutrition and that the team was going to discuss this with the Consultant the following day, with a view to alternative feeding methods.

A speech and language therapist saw Mr Ryan again and tried him with teaspoons of yoghurt. She noted that he did not try to swallow at all, but coughed on the yoghurt. She decided the risk of aspiration remained high and mentioned she was waiting for a decision about alternative feeding.

A Specialist Registrar reviewed Mr Ryan's condition and noted that the intravenous infusion should continue, Mr Ryan should remain nil by mouth and the Consultant would conduct a review the following day.

Mr Ryan's situation was reviewed by a dietician who had discussed him with a speech and language therapist. The dietician noted that Mr Ryan had been without food for 16 days.

### **13 December 2005**

#### **Day 18**

The Consultant reviewed Mr Ryan and decided that he should be referred to gastroenterologists for the placement of a PEG feeding tube. A dietician noted that a senior dietician would provide a feeding regime once the PEG feeding tube had been inserted.

### **14 December 2005**

#### **Day 19**

Mr Ryan was reviewed by a speech and language therapist who tried him with teaspoons of yoghurt but decided he was severely dysphagic and at high risk of aspiration.

A junior doctor noted that he had discussed the plan to insert a PEG feeding tube with Mrs Ryan.

### **15 December 2005**

#### **Day 20**

A medical student recorded that he had been told there was no space in the operating theatre schedule for five days. He had therefore discussed the possibility of feeding Mr Ryan using a nasogastric feeding tube with a speech and language therapist who had told him this would not increase the risk of aspiration but Mr Ryan might pull the tube out. This medical student suggested a nasogastric tube should be used to try to feed Mr Ryan.

A review was carried out by a junior doctor at 11.30pm because Mr Ryan had suddenly deteriorated, with a raised temperature, sudden shortness of breath and increased agitation. This junior doctor noted Mr Ryan had either developed

an aspiration pneumonia, become overloaded with fluid or suffered a pulmonary embolism [clot in the lung]. He arranged blood tests and prescribed antibiotics and oxygen.

## 16 December 2005

### Day 21

The Consultant carried out a review and decided Mr Ryan's condition had deteriorated so much he was now not fit enough to have the PEG feeding tube inserted and so palliative care should be instituted.

A Specialist Registrar discussed Mr Ryan's condition with Mrs Ryan in a telephone conversation. He recorded that:

*'She agrees that despite our best efforts over the last 19 days he has not improved + had in fact deteriorated despite our best efforts.'*

He recorded that he went on to discuss specific decisions with Mrs Ryan including the palliative care decision (no antibiotics, no intravenous infusion, no PEG feeding tube, no Intensive Care Unit or resuscitation) and that Mrs Ryan agreed with these decisions.

Mr Ryan was reviewed by the Palliative Care Team who suggested intravenous fluids should be stopped, and sedation and pain relief given.

Mr Ryan was also reviewed by a speech and language therapist and a physiotherapist who decided no further intervention from them was appropriate because of the decision to give palliative care only.

Mr Ryan's care was reviewed by a palliative care consultant who spoke to staff from the Care Home and noted their concerns about the decisions which had been taken. A palliative care nurse telephoned Mrs Ryan and also spoke with Mr Ryan's carers.

A case conference was held, involving the Consultant, his Specialist Registrar, staff from the Care Home, the Social Worker and the Ward Sister. An entry was made in the medical notes by the Consultant. It said:

*'Aim: to discuss care of patient + future mgt [management].*

*'Concerns from care staff regarding timely admin [administration] of IV fluids + attempts to feed patient. Explained that due to excessive work demands, there may be occ [occasional] delays in putting up IV fluids but this has never affected his medical health or prognosis.*

*'Feeding – (Ward Sister) reports attempts to pass NG tube were aborted due to patient's physical refusal + lack of understanding. Further attempts not carried out due to the need for restraint, risk of NG being pulled out + the risk of aspiration. In light of this a PEG was being planned but took extra time due to involvement of family, carers, GI [gastrointestinal] consultant + patient's fitness for procedure. However this was actively being pursued at all times.*

*' – We are all in agreement that palliative measures should be continued in light of his obvious distress + agitation, + the likely poor prognosis + low chance of recovery from stroke. The carers will discuss amongst themselves regarding whether they wish to complain about the feeding issue and IV fluids.'*

**17 December 2005****Day 22**

Nurses recorded that Mr Ryan's family had visited him until late in the evening.

**19 December 2005****Day 24**

Mr Ryan's care was reviewed by a junior doctor who noted the view of Care Home staff that they were unhappy with Mr Ryan's care and that they said the palliative care plan should be reviewed as Mr Ryan had survived the weekend.

A junior doctor discussed Mr Ryan's care with the Community Learning Disability Team Nurse on the telephone. This doctor noted that the Community Learning Disability Team Nurse said she was unhappy with the outcome of the decision taken at the case conference and that there were discrepancies between the doctors and nurses regarding nasogastric feeding. He also noted that she asked if the management plans should be reviewed because Mr Ryan had survived the weekend.

The Matron noted that the ward nurses were intimidated by Mr Ryan's carers who were making notes of what was happening to him.

**20 December 2005****Day 25**

Following review, the Consultant decided palliative care should continue.

**21 December 2005****Day 26**

Mr Ryan's death was confirmed at 1.10am.

## ANNEX D

### The Trust's internal inquiry: summary of findings

The findings about clinical care and treatment were:

- there was no stroke unit and there was no cohort of staff trained to respond to the specific needs of stroke patients;
- care was inadequate because Mr Ryan's nutritional needs were not met, for example there was no overall plan to meet these needs, there was an over-reliance on the hope that swallowing would return, and instructions about passing a nasogastric tube were unclear;
- no co-ordinated, multidisciplinary approach to Mr Ryan's overall needs and a '*complete lack of focus*' on the importance of basic nutrition;
- over-reliance on the outcome of speech and language therapy assessments in decision making about nutrition;
- a lack of continuity in both medical and nursing care, for example there were no daily ward rounds by senior doctors, information about test results was not passed on or actioned, the nursing shift pattern meant the nurse in charge had a caseload of patients as well as a co-ordinating role and the Modern Matron focused on bed management rather than care standards;
- communication difficulties both internally between members of the multidisciplinary team and externally with Mr Ryan's family and the Community Learning Disability Team;
- friction between Trust staff and carers, a possible confusion of responsibilities and a failure to grasp the benefits which the Community Learning Disability Team offered;
- no one acted as the patient's advocate because staff worked within their own professional roles and escalated their concerns; for example, the Speech and Language Therapist did not take a proactive approach to Mr Ryan's overall condition or care;
- medical care was fragmented; for example, there were no routine medical ward rounds at weekends; and
- there was no clear clinical leadership from the Consultant or the Ward Sister; for example, they did not recognise the need to seek advice or involvement from learning disability experts, or to find out about standards about stroke care.

The findings about complaint handling were:

- the complaint by the Community Learning Disability Team seemed to reach a reasonable conclusion;
- the Trust was too slow to recognise the seriousness of the issues complained about, in particular the basic issue of lack of nutrition;
- the Consultant persisted in maintaining Mr Ryan's care had been clinically appropriate and the investigating officer did not challenge this, or statements from other clinicians, possibly because she did not have a clinical background;
- there was a backlog of complaints and, although the basic steps of the complaints policy were followed, investigation of the original complaint was protracted and poorly organised;

- there were inaccuracies and inconsistencies in the responses to Mencap;
- a Serious Untoward Incident was not triggered early enough because clinical staff did not consider there had been significant failures in care (the usual trigger for a Serious Untoward Incident). Further triggers were also missed, specifically when Mencap became involved and during the Directorate of Medicine's 'mini inquiry'; and
- there was no evidence of a developed governance framework and no embedded system of multidisciplinary inquiry.

# ANNEX E

## The Trust's internal inquiry: recommendations

The report of the internal inquiry should be circulated to all those involved and the Medical Director should personally discuss its findings with the Consultant. The report should also be discussed with the Ward Sister. Arrangements should be made to discuss the findings with Mr Ryan's parents and Mencap.

1. Clinical leadership is essential to the wellbeing of all patients and was clearly lacking in this case. The Trust should:

- consider what additional skills in terms of clinical leadership, developing team working and the care of patients with needs the individual Consultant and Ward Sister require in this area. This might include mentorship;
- review the current arrangements for leadership development and their adequacy in respect of all clinical staff groups; and
- review and clarify the relative roles and responsibilities of the Head of Nursing, Matron and Ward Sisters with the Directorate of Medicine to ensure nursing leadership and the appropriate focus on quality. Ensure that the lead responsibility for quality is clarified.

2. The Trust should review the arrangements for medical staff cover with Medicine, considering the necessity for daily ward rounds of doctors of a suitable seniority, arrangements for annual leave and the adequacy of weekend cover.

3. The Nutritional Review Group should be charged with expediting its work and there should be a formal report back on progress to the Governance Committee at each meeting. This should include a rolling audit of Malnutrition Universal Scoring Tool, which should take place at least biannually until the Trust is assured it is fully embedded in practice.

4. The clinical governance arrangement within the Division of Medicine should be reviewed. This should include systems to assure that learning from complaints and incidents is identified and shared. A review of the triggers for clinical incidents should be undertaken with the Directorate and all staff reminded of the importance of incident reporting.

5. A review of the need for nursing staff dependency tools should take place.

6. A protocol should be developed to help define the relationship of ward staff to formal carers to ensure a mutual understanding of roles.

7. The complaints policy should be reviewed with a view to:

- assessing the value of grading complaints;
- reviewing the role and competencies for investigating officers, and the training available to them;
- considering the circumstances where peer review might be appropriate; and
- considering triggers for escalating complaints when the policy standards are not being complied with.

8. The Speech and Language Therapy Department should review its approach in relation to team working. There should be no hesitancy of bringing to the attention of clinicians any concerns in relation to a patient's care plan, or otherwise escalating concerns.

9. All staff should be encouraged to make known, in non-intimidating circumstances, any concerns that they may have about the clinical care of patients. This includes awareness of channels including the Whistle-Blowing Policy.

On 31 January 2007 the Trust Board added six more recommendations. These were:

1. That a formal disciplinary hearing should take place involving the Consultant and the Ward Sister.
2. That external advice should be sought to validate the Trust's approach to ensuring high nutritional standards for patients.
3. A thorough review of the complaints procedure should take place.
4. A review of the governance arrangements across all Clinical Divisions should take place.
5. That the Report should be presented to Mencap and the parents of Mr Ryan by the Chief Executive and Medical Director and that support from Mencap should be sought in undertaking a review of the Trust's overall approach to the care of patients with a learning disability.
6. That a formal action plan should be developed to address all the recommendations.

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