

Report by the Parliamentary and Health Service Ombudsman on complaints about disability issues

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Session 2010-12

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Foreword

I am laying this report before Parliament, under section 14(4) of the *Health Service Commissioners Act 1993* and section 10(4) of the *Parliamentary Commissioner Act 1967*, to share information about the Ombudsman's role in considering complaints about poor service and unfair treatment provided to people with disabilities and how we determine those complaints. Our approach and the outcomes we achieve are illustrated by summaries of five recently completed investigations. The five summaries cover complaints about a number of public bodies including the NHS and government agencies.

I hope that putting this information in the public domain will help people who have complaints about public bodies make informed decisions about where to take their complaints. I also want organisations within my jurisdiction to see how I consider complaints about poor service and unfair treatment provided to people with disabilities.



Ann Abraham
Parliamentary and Health Service Ombudsman

October 2011

Introduction

This report contains summaries of five recently completed Ombudsman investigations: three are complaints about the NHS and two are about government agencies.

What they have in common is that they all involved poor service to people with disabilities; and in each case that poor service included a failure by those public bodies to recognise and respond to those people's rights and their individual needs, leading to poor service and unfair treatment.

In recent years we have investigated a growing number of complaints where people's disability and equality rights are clearly engaged. It is not the role of the Ombudsman to adjudicate on matters of disability discrimination law or to determine whether the law has been breached: that is a matter for the courts.

That is not to say, however, that the Ombudsman has no role in addressing poor service and unfair treatment provided to people with disabilities when it happens, as the cases in this report clearly show. This report sets out the Ombudsman's distinctive role in the provision of justice and how we approach that role when addressing disability issues. This report also illustrates the outcomes which can be achieved when complaints are brought to the Ombudsman.

I am putting this information into the public domain so that someone who has a complaint that a public body has acted unfairly towards, or provided poor service to, a disabled person can make an informed decision about where to take their complaint. I also want organisations within my jurisdiction to see how the Ombudsman considers complaints about such matters.

The Ombudsman's approach includes an overall concept of fairness, a fundamental commitment to the humanity of individuals and their right to

equality in treatment and outcomes. Issues of discrimination and equalities underlie many of the complaints which come to the Ombudsman, and recourse to the Ombudsman is a very positive option for many people with complaints about disability issues. These issues are reflected in the *Ombudsman's Principles* (see below) and are always part of our consideration of complaints.

The Ombudsman's distinctive role

As I have said above, the Ombudsman is not empowered to determine whether the law has been breached. The Ombudsman system of justice provides an alternative to taking a case to court but it is not a substitute or surrogate court. The Ombudsman asks different questions from those asked in a court and looks at different issues.

While the courts determine whether people have suffered damage as a result of unlawful actions, the Ombudsman considers whether people have suffered injustice or hardship as a consequence of maladministration or service failure.

If the complaint is upheld and an injustice is unremedied, the Ombudsman will recommend an appropriate remedy for the injustice or hardship suffered by the complainants. The Ombudsman may also recommend changes in practice to prevent the same thing happening again. It is most unusual for these recommendations not to be complied with.

Some of the people whose stories are set out in this report might have been able to make a legal claim that the public body concerned had failed to comply with their statutory duty to make '*reasonable adjustments*' under disability discrimination law. Instead they brought their complaint to the Ombudsman. In accepting their complaints for investigation, we considered (as we are required to do by law) whether they had

an ‘*alternative legal remedy*’ and if so whether it was reasonable to expect them to resort to it. In each case we decided that the outcome they were seeking was not available to them through legal action, but was achievable by way of an Ombudsman investigation. The Ombudsman is able to recommend appropriate individual remedies as well as systemic changes which are not available through the legal process.

Although the Ombudsman does not determine or enforce the law she is nevertheless helping to give force to the principles that underpin the law as they affect the circumstances of the individual concerned. She is able to do this in a way that is often more accessible, flexible and far-reaching than that of the civil courts. The impact of this flexible approach can be seen in the outcomes achieved as a result of Mr R’s complaint which may assist him to rebuild his confidence.

The Ombudsman also has a wider range of remedies available to her than do the courts. The cases in this report illustrate the different sorts of remedies that the Ombudsman can provide.

The Ombudsman’s Principles

We want to be open and clear with both complainants and public bodies about what we expect when public bodies deliver services, and the questions we ask in deciding whether maladministration and service failure have occurred.

For those reasons we have published the *Ombudsman’s Principles*, which includes the *Principles of Good Administration*, *Principles of Good Complaint Handling* and *Principles for Remedy*. The *Principles of Good Administration* are particularly relevant here. These are the overarching principles which form the standard against which we assess the actions and decisions of public bodies.

Three of these six Principles are likely to come into play most often in our consideration of complaints that public bodies have acted unfairly towards, or provided poor service to, disabled people. They are:

- Getting it right
- Being customer focused
- Acting fairly and proportionately

Getting it right

‘Getting it right’ includes acting in accordance with the law and with regard for the rights of those concerned. It also includes taking reasonable decisions based on all relevant considerations. In this context, of course, the *Disability Discrimination* and *Equality Acts*, together with the *Human Rights Act*, are of particular relevance, forming a specific element of the overall standard.

So, if it appears to us that someone’s disability rights are engaged in relation to the events complained about, we will expect the public body complained about to have taken account of those rights as a relevant consideration in its decision making and had regard to those rights in the way it carried out its functions and throughout the provision of services to the complainant. For Mr F, although Cafcass were aware of his disabilities, they had just ‘gone through the motions’ and did not take account of his right to support and adjustments during his involvement with their service. This had made Mr F reluctant to go back to court in relation to access to his daughter as it meant he would have to re-engage with Cafcass.

Similarly, we would expect the public body to have had regard to and have taken account of core human rights principles of fairness, respect, equality, dignity and autonomy.

If the public body is unable to demonstrate that it has had proper regard to all of these factors, we will take that into account when considering whether there has been maladministration and/or service failure. In Miss W's case a failure to consider these aspects of her care were so serious that they constituted service failure which resulted in unnecessary distress and considerable worry and inconvenience to her family.

Being customer focused

'Being customer focused' includes ensuring people can access services easily. It also includes dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances. Difficulties in communication are a frequent part of complaints which we consider. Ms T was profoundly deaf and had epilepsy. Following an operation, the failure to assess her needs and ensure that she could communicate left her isolated and depressed and meant that opportunities to diagnose and treat her illness were lost.

So, we will expect the public body to have planned, designed and delivered its services in a way that ensures disabled people can access them easily; and to have treated the individual concerned with sensitivity, bearing in mind their individual needs and responding flexibly to the circumstances of the case.

If the evidence shows that the public body has not done so, we will take that into account when considering whether there has been maladministration and/or service failure.

Acting fairly and proportionately

'Acting fairly and proportionately' means that public bodies should always treat people fairly, and with respect. They should understand and

respect the diversity of their customers and ensure equal access to services and treatment regardless of people's background or circumstances. They must ensure that their decisions and actions are proportionate, appropriate and fair. Mr L's story demonstrates the impact on an individual when a hospital consultant failed to treat him with respect and ensure that his care and treatment were based on an understanding of his needs.

So, we will expect the public body and its staff to be able to demonstrate an understanding of the diverse needs of their disabled customers and an ability to respond appropriately to them. We will expect the individual who has complained to us to have been treated fairly, with the result that there is equality in the outcomes for them.

If the evidence shows that this is not so, we will take that into account when considering whether there has been maladministration and/or service failure.

The Ombudsman's findings and recommendations

Maladministration and service failure

The Ombudsman has considerable discretion and flexibility to determine what constitutes maladministration and service failure.

When considering whether an organisation has acted properly or fairly in making its decisions or providing services, the Ombudsman will decide what was reasonable in all the circumstances, taking into account the applicable general principle or specific standard.

The Ombudsman assesses whether or not an act or omission by the public body constitutes a departure from the applicable overall standard

and, if so, whether in all the circumstances that act or omission falls so far short of the standard as to constitute maladministration or service failure. This means that technical errors or omissions may not constitute maladministration or service failure.

Injustice and hardship

The Ombudsman upholds a complaint only when she finds that injustice or hardship has arisen in consequence of maladministration and/or service failure. A finding of maladministration or service failure will not automatically result in a finding of injustice or hardship or a recommendation for remedy.

Recommendations for remedy

If the Ombudsman finds that a complainant has suffered injustice or hardship in consequence of maladministration and/or service failure – and that injustice or hardship has not already been remedied – the Ombudsman will uphold the complaint and will recommend an appropriate remedy.

Individual remedies may include an apology, an explanation of what went wrong and financial compensation for loss, inconvenience or distress. The Ombudsman may also recommend changes in practice to prevent the same thing happening again. It is of key importance that the relevant bodies think carefully about how to ensure that failings are not repeated.

Conclusion

The case summaries in this report demonstrate the difficulties faced by disabled people in accessing public services; the lack of awareness in some public bodies of their statutory obligations,

leading to poor service and unfair treatment; and the role that the Ombudsman can play both in righting individual wrongs and driving improvements in public services.

I hope that this report will be helpful to people, and their representatives, who may be considering whether to refer such cases to the Ombudsman; and will also help bodies in jurisdiction understand how we will consider complaints made about them in relation to such matters.

Ms T's and Mrs S's Story

Ms T, who was profoundly deaf, began to have epileptic seizures after the birth of her first child in 2002, and the seizures became worse after the birth of her second child two years later. Ms T was prescribed anti-epileptic medication, but she and her family believed that it was making her drowsy and contributing to her poor cognitive state. She asked for a second opinion on the management of her epilepsy, and in 2006 she was referred to a consultant at Barts and The London NHS Trust.

In April 2007 that consultant wrote telling Ms T that he did not favour reducing her medication because of the increased risk of seizures that involved, and pointed out that other drugs were not free of side effects. However, in October 2007, when Ms T collected her prescription, she found that the daily dosage of one of her anti-epilepsy drugs had been reduced by half. When she queried this in writing, the consultant simply confirmed her medication. The next month she was admitted to hospital with worsening seizures and confusion, and she remained there for over six weeks whilst her medication was slowly changed and a series of tests (EEGs, which record brain activity) were carried out. The last EEG, carried out on 4 January 2008, indicated that she was still having seizures leading to loss of consciousness.

Ms T was then discharged on 7 January 2008. However, the discharge summary updating her GP on her treatment and condition was not sent until 4 February. By that time Ms T had been admitted to another hospital (on 2 February), where she died later that month of peritonitis and a bowel problem.

In March 2008 Ms T's mother, Mrs S, complained to the Trust about her daughter's care and treatment. She asked why her daughter's medication had been reduced in October 2007 without explanation; why her daughter had been discharged in January when her seizures were not

under control; and why, when she (Mrs S) had tried to discuss with the hospital the family's concerns about Ms T's deteriorating health after her discharge, the nurse specialist had simply told her that the consultant was on holiday and there was no one else who could speak to her in his absence. Mrs S also complained later about the delay in sending her daughter's GP the discharge summary and the failure to provide Ms T with someone who could use sign language. She said that her daughter's speech had been very poor and she had found communicating with her doctors difficult. Yet her deafness had not been taken into account during her hospital stay; no assessment had been made of her communication needs, and although a sign language interpreter had been appointed on one occasion and Mrs S had done her best to act as interpreter when she was visiting, her daughter had felt increasingly isolated and had become depressed. Mrs S said that she believed that communication between her daughter and the doctors had been so poor that opportunities to diagnose and treat her daughter's illness had been missed, and that her daughter might still be alive if her doctors had listened to her.

The Trust took over six months to respond to Mrs S's final letter to them. They apologised for the fact that the change in Ms T's medication in October 2007 had not been discussed with her first, acknowledged that she should have been readmitted to hospital in January 2008 when Mrs S had contacted the nurse specialist, and also apologised for the delay in the discharge summary being sent to Ms T's GP.

What our investigation found

We found that the care and treatment Ms T received fell far so far below the applicable standard that it amounted to service failure.

Although the consultant had previously warned Ms T in writing in April 2007 about the risks attached to reducing her anti-epilepsy medication, he not only failed to discuss those risks with her when he reduced her dosage six months later, but he also failed to involve her in making the decision about her treatment. That was completely contrary to the professional guidance to doctors on effective communication with patients.

There were similar omissions when Ms T was discharged on 4 January 2008. Critically, the doctors who made that decision failed to take account of the EEG result three days earlier. Had they discussed the EEG results and their implications with Ms T and her family, they might well have decided to postpone her discharge. They should at the very least have advised her what to do if her condition deteriorated after she left hospital. That omission meant that Ms T was sent home ill-prepared, without important information about her condition. To make matters worse, the delay in sending her GP the discharge summary meant that he was equally in the dark and unable to offer her and her family appropriate support either. Then when Mrs S sought advice from the hospital, as her daughter's health declined, the hospital failed to recognise that Ms T needed to be readmitted.

It should also have been immediately apparent to the hospital, given that Ms T was profoundly deaf, that they had additional obligations to her under disability discrimination law. Yet there is no evidence to show that any of the clinical or nursing staff considered whether they needed to treat her any differently from any other patient, or whether they needed to provide additional support, such as a sign language interpreter. This would have helped them with day to day communication with Ms T and enabled her to be able to understand, and contribute to, the decisions regarding her care and treatment. Had they recognised her

legal rights and acted accordingly, although the outcome for Ms T might well have been the same, Ms T's care and treatment might have been better planned and delivered. At the very least, she and her family might have better understood the problems she was facing and the risks involved in her proposed treatment.

In determining whether there was service failure, we referred to the Ombudsman's *Principles of Good Administration*. In order to 'get it right' the Trust should have ensured that it had regard to Ms T's rights as a person with disabilities. We found minimal evidence that either doctors or nurses had regards to the law or guidance relating to the provision of service to people with disabilities when they planned or delivered Ms T's care, or that Ms T's rights under disability discrimination law were a relevant consideration in their decision making. We concluded that in providing care to Ms T, the Trust did not have regard to its obligations under disability discrimination law. We found the Trust's failings in this respect were so serious as to constitute service failure.

We also found maladministration in the way the Trust handled Mrs S's complaint.

We found that Ms T suffered injustice as a consequence of the service failure in her care and treatment and that Mrs S experienced injustice in consequence of the Trust's maladministration in complaint handling. We upheld the complaint about the Trust.

What happened next

The Trust wrote to Mrs S to acknowledge the failings in care and treatment and complaint handling identified in our report and to apologise for the impact those failings had on her and on her daughter. The Trust paid Mrs S compensation of £1,000 in recognition of the unnecessary distress she had suffered as a consequence.

The Trust also sent us details of how they intended to build on new policies and procedures already introduced to share the lessons learnt from the investigation with its clinical, nursing and complaint handling staff to prevent similar failings occurring in the future. This included a wide range of steps to improve communications between medical and nursing teams, patients and their families throughout the patient's hospital admission, and with their GPs on discharge, and the setting up of a Communications Group to look into and try to resolve any communication problems experienced by patients. In response to recommendations by that Group, one nurse and another staff member were attending sign language training. Steps were also being taken to try and improve booking systems for appointments where British Sign Language (BSL) signers were needed and the Trust now use two dedicated booking staff who are BSL signers. The Trust had also appointed an Equality and Diversity Manager to provide training and guidance on the *Equality Act* for all Trust staff. Finally, a new complaints policy had been introduced which allowed greater flexibility in the handling of complaints, robust quality assurance to ensure that all issues raised were fully responded to, and which used in-depth analysis of all complaints to inform service improvement.

Mr and Mrs F's Story

Mr F has dyslexia, dyspraxia and scotopic sensitivity (in which reading is impeded by distortions in print). As a result, he has difficulty communicating with people both orally and in writing. He finds it easier to express himself in face-to-face meetings, rather than by telephone, and needs to have written material provided on a certain colour paper and in a certain font in order for him to understand it. Even then he is a very slow reader, and he becomes anxious and nervous when he has to write something.

Mr F wanted to have a greater input into his daughter's life and, in November 2007, he applied to a County Court for a contact and residence order in respect of her. He said in his application form that he had dyslexia and might '*need some help with reading and writing material*'. The case was sent to the District Family Proceedings Court, and the following month Mr F was invited to discuss his application. Mr F said that at the meeting he had completed a diversity monitoring form saying that he had a disability (dyslexia) and that he needed support to use their services, and that he had explained his disabilities.

In March 2008 a Family Court Adviser from the Children and Family Court Advisory and Support Service (Cafcass) wrote telling Mr F that Cafcass had been asked to prepare a welfare report, and that she would therefore be visiting him in April. During a visit on 28 April, when both Mr F and his current wife were present, Mr F completed a second diversity monitoring form in which he repeated the information he had given in the first form. Mr F said that he had told the adviser the font, font size, and the colour the paper needed to be in order for him to be able to read any written correspondence, and that he preferred face-to-face contact. The records show that, following a home visit in May to observe Mr and Mrs F with Mr F's daughter, the adviser made two lengthy

telephone calls to Mr F later that day and the next explaining various issues to him.

Cafcass sent their welfare report in respect of Mr F's application to the Court in May, and copied it to Mr F (in the correct font size, but with the incorrect font and colour paper). The report said that Mr F was dyslexic and dyspraxic, that it therefore took him longer, when under pressure, to gather his thoughts and articulate his views, and that adjustments needed to be made to reading material to assist him to read it. The report said that those needs had been taken into account when producing the report.

Over the following 10 months Mr and Mrs F wrote several times to Cafcass to complain about aspects of the welfare report, and Cafcass responded saying that the Court had been the appropriate forum in which to challenge the report. None of Mr and Mrs F's letters mentioned Mr F's disabilities, and none of Cafcass's replies were in the font requested by Mr F.

In the meantime, in October 2008, the Court had made a contact order specifying a schedule of contact for school terms and vacations.

In March 2009 Cafcass reviewed their management of Mr F's case and found that diversity issues had been taken into account, in that monitoring forms had been completed and the copy of the report sent to Mr F had been in the requested font size. They said that there was no evidence that anything else had been requested. Cafcass then wrote to Mr F offering to meet him to discuss the review. At the meeting, which took place in May, Mr and Mrs F produced a lengthy document setting out their complaint. They contended that Cafcass had failed to respond to Mr F's disability appropriately in line with the *Disability Discrimination Act*. They said '*No assessment was made of [Mr F] to find out how his disability would affect him during the report*'

and that his wishes with regard to font size and so on, had initially been ignored. The remainder of the complaint then dealt with the content of the report.

Cafcass agreed to review the complaint document and meet Mr F again; but when they did so, they told Mr and Mrs F that they had reached the end of the complaints process.

In subsequent correspondence, Mr F said that he believed that Cafcass had collected the disability monitoring information for statistical analysis, rather than to make the necessary adjustments. He believed that if he had been given additional support from the outset, he would have been able to express himself properly and the Cafcass report might have reached a different conclusion.

What our investigation found

We found that, although Cafcass had assisted Mr F to complete diversity monitoring forms on two occasions, they had simply recorded his disability and not the changes that needed to be made for him to have fair and equal access to their services. There is evidence that the Family Court Adviser discussed those requirements with Mr F, but did not record what they had agreed anywhere on the files. That was contrary to their own guidance on equality and diversity, which said that any support needs should be clearly highlighted on the case file.

We could not be certain of exactly what Mr F had requested, but found it most likely, on the balance of probabilities, that he had told them of his preference for face-to-face meetings and his precise font and paper colour needs.

We found that that initial failure to record the action they needed to take to meet Mr F's needs was the predominant cause of the shortcomings in

all Cafcass's future dealings with Mr F. As a result they sent him written information in the wrong format, and had lengthy telephone calls with him, without apparently considering alternatives. We also found that Cafcass missed the point when they told us that their failure to meet Mr F's requirements had been prolonged because Mr F had not raised disability issues with them when he had first complained. Had Cafcass had proper regard to their own guidance and made proper records, it should not have been necessary for Mr F to remind them of his needs.

We did not find that, had Cafcass understood Mr F's disabilities and made appropriate adjustments, it would have resulted in a different welfare report. However, we were satisfied that Cafcass's failures in this regard had caused Mr F additional distress and upset in a situation which was already by its very nature difficult and emotional. It must have been deeply frustrating for him to not to feel able to get his point across adequately when discussing access arrangements for his daughter. Further, the experience had clearly made him reluctant to go back to court about those arrangements as it meant having to re-engage with Cafcass.

We found that Cafcass failed to 'get it right' in that they did not have proper regard to their own guidance or to the *Disability Discrimination Act* in their decision making on Mr F's case. This failure to get it right was so serious as to amount to maladministration. Mr F experienced injustice as a consequence of the maladministration. We upheld his complaint about Cafcass.

What happened next

Cafcass apologised for the poor service Mr F had received and said that they would highlight the adjustments that needed to be made for

him on current and any future files, and would review his needs with him on a regular basis in any future dealings they might have. Although we provisionally recommended that Cafcass pay Mr F £250 in recognition of the frustration, distress and upset he experienced as a result of Cafcass's maladministration, Mr F said he did not want any payment.

Cafcass reviewed the learning from the investigation for dissemination across its operations.

Mr R's and Mrs R's Story

Mr R has learning disabilities and a mental health condition which causes paranoia. In December 2006 he went overseas on holiday to stay with some family friends for a few days. His parents had meant to travel with him, but were unable to do so because of his father's ill health. This was the first time Mr R had travelled abroad on his own.

On his return Mr R was stopped by two trainee customs officers at his local airport because of the large amount of tobacco he was carrying. The officers then interviewed Mr R about his trip, his means of funding it, and the tobacco. Contrary to the UK Border Agency's guidance, the customs officers did not check at the start of the interview whether Mr R was fit and well, or whether he had any medical condition of which they needed to be aware, nor did they ask him to read and sign the notes of the interview. If they had done so, they would have discovered that Mr R could not read or write. Mr R told them that he received benefits, but could not tell them what they were. The officers strip searched Mr R, at one point leaving him naked. One of the officers noted that the reasons for the strip search had been that a drugs trace test (which was known to be unreliable) on Mr R's luggage had proved positive, and because Mr R had appeared '*nervous, evasive*' when questioned. Although Mr R had referred to his disabilities and one of the officers had written '*Mental health problems. Disability.*' in his notebook, the officers took no action in response to this and simply continued with the interview. No drugs were found. Mr R was later allowed to leave, but the tobacco he had been carrying was seized.

Mrs R subsequently complained about the way the UK Border Agency had treated her son. She said that he had found the ordeal frightening and humiliating, and had been left so traumatised that he refused to travel on his own, or from the local airport, again. In their initial response to

the complaint the UK Border Agency expressed cynicism about the extent of Mr R's disability and his needs. They continued to do this throughout the complaints process, despite Mrs R sending them evidence of the disability benefits Mr R was receiving and reports on his mental health and abilities from a consultant psychiatrist and a psychologist.

What our investigation found

We found that the UK Border Agency had not had regard to Mr R's disability rights in the way that it had carried out its functions, nor taken account of those rights as a relevant consideration when making decisions regarding Mr R. Those failings were apparent both in their treatment of Mr R and in their handling of Mrs R's complaint.

As soon as Mr R had referred to his disabilities, the customs officers should have stopped the interview and rearranged it for when an appropriate adult could be present to protect his rights. Instead, not only had they pressed on regardless, they had failed to follow proper interviewing protocols, which might have helped them to identify Mr R's disabilities, and deal with him appropriately as a vulnerable adult. Had the UK Border Agency done what they should have done and arranged for an appropriate adult to be present, that person would have been able to explain that Mr R's difficulties in answering questions were due to his learning disabilities and not evidence of evasive behaviour. Not only would the matter not have progressed as far as a strip search, but Mr R would have had support and protection in what was for him a terrifying situation.

The UK Border Agency's subsequent failure to acknowledge Mr R as a disabled person in their complaint handling, together with the loss of the

tape recording of Mr R's interview, only added insult to injury.

We found that Mr R experienced injustice as a consequence of the maladministration in the UK Border Agency's interaction with him and that Mrs R experienced injustice as a consequence of the maladministration in their complaint handling. We upheld the complaint about the UK Border Agency.

What happened next

The UK Border Agency apologised to Mr R and Mrs R and paid Mr R £5,000 compensation for the distress, humiliation, intimidation and anxiety they had caused him, and £1,000 to Mrs R for the offence and upset caused to her by their poor handling of her complaint. The UK Border Agency also agreed to explore with Mrs R and Mr R what the UK Border Agency might do to enable Mr R to feel comfortable using his local airport in the future. The UK Border Agency further agreed to review the disability awareness training provided to their customs officers, with a particular emphasis on identifying non-visible disabilities, such as learning disabilities and mental health conditions. They also agreed to review their policy on the storage of tape recordings.

Mr L's Story

Mr L, who was 21 years old at the time of these events, had severe learning disabilities and epilepsy. On 20 July 2008 he was vomiting and had abdominal pain and was admitted to Luton and Dunstable Hospital NHS Foundation Trust, where two days later a polyp was found in his stomach and removed. On 24 July Mr L's consultant reviewed his condition. The consultant noted that he understood from speaking to Mr L that he had stopped vomiting and was keen to go home. Mr L was discharged the next day but his father, Mr G, brought him back to hospital as Mr L was still vomiting. On 28 July, a CT scan revealed a tumour in Mr L's colon. This was removed and Mr L's condition initially improved, however by 30 July he had begun to deteriorate again. A further scan suggested that there was a leak from the site of the tumour surgery. On 1 August Mr L had further surgery, and was then transferred to the intensive care unit, but his condition worsened and he died on 4 August. On 23 August the consultant wrote to inform Mr L's GP of his death. The consultant said that he had not suspected a bowel obstruction during Mr L's first hospital admission '*because [Mr L] was a poor historian and I really could not tell what was going on. [He] was mentally subnormal...*'.

Mr L's father subsequently complained to the Trust about a range of matters relating to his son's care and treatment. During the local resolution process the Trust apologised for shortcomings in some aspects of Mr L's care, including failures in documenting care and in communicating with Mr L's family about his condition and arrangements for his care. The consultant also apologised for using the term '*subnormal*' to refer to Mr L and said he would not use it again. In the Trust's final letter of 28 April 2009 they referred to a discussion at the local resolution meeting when Mr L's parents had told the consultant that prior to his first admission Mr L had been experiencing symptoms that could indicate bowel cancer. They said that the consultant had not been aware that

Mr L had those symptoms because '*this was not communicated to him by Mr L at any time...*'. The Trust acknowledged that the consultant should have made time to speak to Mr L's parents.

Mr L's father was dissatisfied with the outcome of his complaint as he felt that the Trust had not identified Mr L's disabilities as a key factor. He was not convinced that the Trust had learnt from what had happened to Mr L, or done anything to prevent a recurrence. He specifically wanted the Trust to make changes to involve families and carers of patients with learning disabilities in a more structured way. Mr L's father pointed out that, had anyone told them how sick their son was on 3 August, he and his wife would not have left their son alone and would have been with him when he died.

What our investigation found

We found several instances where, in view of Mr L's learning disability, hospital staff could and should have involved Mr L's family to ensure the proper planning and delivery of his care and treatment, but failed to do so. This omission was contrary to the Department of Health's guidance, professional standards and the Trust's own guidance.

Mr L's family were the experts concerning their son and his needs, and yet the nursing staff failed to seek information from them when assessing Mr L's needs and planning his care. Nor did they seek the input of the learning disability nurse or any other specialist adviser, contrary to the Trust's guidance.

Similarly, by failing to consult the family when Mr L was first admitted, the surgical team were unable to evaluate Mr L's clinical history fully, which meant that their decisions about Mr L's care and treatment were not based on all relevant considerations. We found it astonishing that the consultant, knowing of Mr L's learning disability,

could have expected Mr L to be capable of providing all the relevant history of his presenting illness without his family's help. Yet it is clear that that is what the consultant did, as he described Mr L as *'a poor historian'*, and he commented at local resolution that Mr L had failed to tell him about symptoms which might have indicated bowel cancer. We also found it extraordinarily inappropriate that a consultant should refer to Mr L as *'mentally subnormal'* in writing to the GP.

Staff had also failed to follow the relevant guidelines in respect of consent to Mr L's surgery. As Mr L was judged to lack capacity to give consent himself, it was proper for the clinical staff to decide on his treatment based on his best interests. However, close relatives and carers should have been involved in discussions about such treatments, and those discussions should have been recorded. Again, that did not happen here.

Sadly, the failure to communicate effectively with Mr L's family about his clinical condition continued throughout, and as a result, the family had gone home for the night and were not with Mr L when he died. This undoubtedly remains a source of continuing and profound regret for them.

Although the Trust had acknowledged that there had been some failings in communication, they missed the point that, in view of Mr L's learning disabilities, communication with the family was not simply good practice, but was of vital importance and Mr L's right.

Mr L's rights under disability discrimination law were engaged and should have been a relevant consideration in the Trust's decision making. However, we found no evidence to demonstrate that either doctors or nurses had regard to the law or any guidance relating to the provision of services for people with disabilities when they planned and delivered Mr L's care. They failed to

'get it right'. The Trust's actions fell significantly below the applicable standards, that was service failure.

The Trust's failure to involve Mr L's parents appropriately in his care and treatment meant that Mr L suffered the injustice of being denied the opportunity of an appropriate standard of care, and his parents were caused considerable additional anxiety and distress, compounding their natural grief at their son's illness and death.

As injustices arose to Mr L and his family in consequence or service failure we upheld the complaint about the Trust.

What happened next

The Trust wrote to Mr L's parents acknowledging the service failings set out in our report and apologising for the injustices thereby caused to them and to their son. The Trust paid compensation of £3,000. They also told us what they had done to ensure that they and the consultant had learnt lessons from the failings we had identified and what they planned to do to prevent a recurrence of them in future. This included setting up a Learning Disabilities Focus and Task Group, made up of care providers, relatives and hospital staff to discuss how to ensure that the Trust provided the best standards of care for vulnerable patients. A range of relevant training programmes was also being undertaken. One example of these was that the Learning Disabilities Liaison Nurse was running study days for Trust staff, using specific case examples to make nursing staff aware of the need to work with families to understand the person they are caring for and to involve families in care. The Trust had also commissioned an external review of the care they were providing to patients with learning disabilities.

Miss W's and Mrs W's Story

Miss W, who is in her 40s, has learning disabilities and epilepsy. She is cared for at home by her parents and needs significant support with her personal care and everyday tasks. On 3 September 2008 her parents found it difficult to wake her, so she was taken by ambulance to A&E at United Lincolnshire Hospitals NHS Trust. Doctors noted that Miss W's anti-epilepsy medication had been changed during August 2008 and that since this change she had become drowsy. Miss W's parents explained that Miss W was normally only incontinent during seizures but recently had become incontinent at other times. They also explained that she had been eating and drinking less and had lost weight. Miss W was admitted to hospital and the dose of her anti-epilepsy medication was increased. She remained in hospital until 18 September when she was discharged home.

Shortly after her daughter's discharge Mrs W complained to the Trust about the care and treatment her daughter had received during her stay in hospital. She complained about a number of issues including: that nurses had not given her daughter her anti-epilepsy drugs and other medication at the right times; that her daughter had been moved to another part of the hospital without a proper handover and without the bed space having been cleaned and prepared; and, that her daughter had been given Clexane injections without her or her parents' consent or knowledge. (Clexane injections are used to stop blood clots forming abnormally in the blood vessels.) Mrs W was concerned that nurses' communication with the family had been poor.

Mrs W also complained that there had been a lack of basic nursing care and her daughter's learning disabilities had not been taken into account. She said that hot drinks and meals had been left on her daughter's bedside table without any regard for her inability to deal with a hot plate or hot

food without burning herself, open containers, or cut food up. She said that cold drinks were not prepared for her daughter unless the family poured one and that her daughter's personal hygiene needs (in terms of washing, bathing and menstruation) had not been met.

What our investigation found

We found that during her stay in the hospital Miss W did not receive appropriate nursing care. On admission doctors and nurses noted that Miss W '*normally understands and talks quite slowly*' but nurses did not carry out a proper assessment of her communication and other needs. They did not develop care plans to address Miss W's needs.

In addition, we found that the Trust did not deliver Miss W's care in line with guidance issued by the Royal College of Nursing. This guidance states that people with severe learning disabilities may be very dependent on ward staff and might have difficulty expressing needs, such as hunger, thirst and the need to use the toilet, so staff should anticipate these. It states nurses need to work in partnership with people with learning disabilities and their carers, but that the support of families and carers should not be relied upon. However, in her complaint Mrs W had described instances where her daughter's needs were not anticipated and where nurses had relied upon her family.

We also found that doctors and nurses did not give Miss W the help and support she needed to make her own decision about the need for Clexane injections and stockings designed to stop blood clots. By its own admission, there was no evidence that the Trust's staff talked to Miss W or her parents about these treatments at all. The Trust's staff failed to assess appropriately Miss W's capacity to consent to treatments. We found that the care and treatment the Trust provided for Miss W fell so far below the applicable standard that it amounted to service failure.

We found minimal evidence which demonstrated that either doctors or nurses had regard to the law or any guidance relating to the provision of services for people with disabilities when they planned and delivered Miss W's care, or that Miss W's rights under disability discrimination law were a relevant consideration in their decision making about Miss W's care or in the way that care was then provided. Therefore, we concluded that in providing care to Miss W, the Trust did not have regard to its obligations to her under disability discrimination law. The Trust's failing in this respect was so serious as to constitute service failure.

We found that when handling Mrs W's complaint, although the Trust did acknowledge and apologise for many of the failings in Miss W's care and treatment, it did not consider fully and seriously all forms of remedy. The failures in the Trust's complaint handling fell far short of the applicable standard. That was maladministration.

The hospital would have been a frightening environment for Miss W and the Trust's failure to explain procedures, like the administration of Clexane injections and the need to wear specialist stockings, would have added to Miss W's distress. It would have been equally distressing for Miss W to be transferred within the hospital without anyone helping her to put her personal belongings away or getting her something to drink. Nurses did not listen to Mrs W when she explained what they would need to do to get her daughter to take her drugs and to help her with her everyday tasks. Mrs W and other members of Miss W's family had to make special trips to the hospital to feed and look after Miss W.

We assessed whether injustice to Miss W and her mother arose in consequence of the service failure and maladministration we had identified and concluded that it had. Therefore, we upheld Mrs W's complaint about the Trust.

What happened next

In recognition of the injustice Miss W and her mother suffered, the Trust agreed to write to Mrs W with an open and honest acknowledgement of the failings we had identified and an apology for the impact these failings had on her and on her daughter. The Trust also agreed to pay Miss W and her mother £2,500 to remedy the injustice arising from the service failure and the maladministration.

The Trust also agreed to prepare an action plan that detailed what it had done, or planned to do, to share the lessons learnt from the failings in its care and treatment of Miss W with its clinical teams and to avoid a recurrence of these failings in the future; and to avoid a recurrence of the failings we had identified in its handling of Mrs W's complaint.

**Parliamentary and
Health Service Ombudsman**

Millbank Tower
Millbank
London SW1P 4QP

Tel: 0345 015 4033

Textphone: 0300 061 4298

Fax: 0300 061 4000

Email: phso.enquiries@ombudsman.org.uk

www.ombudsman.org.uk

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