



## Mencap response to the Health Ombudsman's investigations into the deaths of six people with a learning disability

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

#### A damning indictment of the NHS

Following the publication of ['Death by indifference'](#) (Mencap 2007) the government asked the Parliamentary and Health Service Ombudsman to investigate the deaths of the six people with a learning disability described in the report. The Ombudsman conducted detailed investigations into the events that led up to the deaths of Martin, Mark, Ted, Tom, Warren and Emma.

The government also set up an independent inquiry into the health care of people with learning disabilities. Sir Jonathan Michael, chair of the inquiry, published his findings in July 2008 in a report called ['Healthcare for all'](#).

This briefing is about the Overview report ['Six Lives: the provision of public services to people with learning disabilities'](#) which was published on March 24<sup>th</sup> 2009 and the six detailed investigation reports. Click [here](#) to read Mencap's briefings on the individual investigation reports on Martin, Mark, Ted, Tom, Emma and Warren.

#### Summary

*'The investigation reports illustrate some significant and distressing failures in service across both health and social care.....They show the devastating impact of organisational behaviour which does not and apparently cannot adapt to individual needs, or even consistently follow procedures designed to maintain a basic quality of service for everyone.'*

This powerful report reinforces the urgent need for systemic change within the NHS for people with learning disabilities. It supports Sir Jonathan Michael's inquiry report 'Healthcare for all', bolstering what has been said about the failure to understand the law in relation to disability discrimination and human rights. It supports Mencap's view, and the

findings of the independent inquiry, that the six tragic deaths described in ‘Death by *indifference*’ were not isolated and likely to be part of a wider problem.

The report makes three recommendations aimed at ‘*changing underlying attitudes on a lasting basis*’. These include actions for the NHS and social care organisations in England, actions for those responsible for the regulation and inspection of health and care services and actions for the Department of Health in their role of promoting and supporting the implementation of the recommendations. Each are given between 12 and 18 months to report progress.

### **The Parliamentary and Health Service Ombudsman said**

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

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

*‘No one took a proactive approach in owning and resolving problems by making reasonable adjustments and seeking urgent solutions. It is this aspect of the quality of the service they experienced that Mencap described as “indifference” and it is unacceptable’*

*‘Nevertheless, the recurrent nature of the complaints across different agencies leads us to the view that the understanding of the issues and the focus on the quality of care is at best patchy and at worst an indictment of our society’*

### **Mencap’s view**

Mencap welcomes this hard hitting report. It confirms what we said in ‘Death by *indifference*’ and should be a wake up call to the NHS.

The overarching report and detailed investigation reports identify a catalogue of serious failures which led up to the unnecessary deaths of the six people described in our report and subjected them to the most appalling pain and suffering. It confirms that they were discriminated against and that their human rights were violated.

Shockingly, the investigations also revealed actions and omissions by health professionals that we were previously unaware of. For example, Emma’s mother did not know that when her daughter was given the prognosis of 10% survival with treatment, this wasn’t actually based on the staging of the cancer but on a flawed view of the difficulty of treating someone with a learning disability. Tom’s family found that during his final stay in the acute hospital he had twice been overdosed with morphine.

Whilst Mencap believes that the Ombudsman’s reports are a significant contribution towards the systemic change we have been campaigning for, we also think that she has not gone far enough to reinforce the fact that NHS staff must act within disability and human rights legislation. In particular we are concerned that she has not fully understood the requirements to make reasonable adjustments and has not properly interpreted the guidance on best interest decision making.

The report also shows how the families of the six people who died were totally let down by the complaints process, both at the local and Healthcare Commission stages. The complaints process did not provide them with the answers they had a right to. This condemned the families to a battle for justice that has spanned up to five years and has had a profound emotional and physical impact on all their lives.

Mencap are very disappointed that the Ombudsman has not brought an end to this fight for all the families. We will continue to support those families until they do achieve justice. Mencap hope that they will all take comfort in knowing that the lessons that can be learned from the powerful combination of their stories, the subsequent inquiry and detailed investigations will result in changing practice in the NHS for the better for many thousands of people with a learning disability and their families.

**We want every person working in the NHS, from the nurses on wards to the chief executives of strategic health authorities, to treat this issue as a priority. This means ensuring that all of the recommendations from the Health Ombudsman's reports and from Sir Jonathan Michael's independent inquiry are fully implemented to make sure that people with a learning disability receive the care and treatment they have a human right to.**

## **Detailed analysis**

### **What have the Local Government and Parliamentary and Health Service Ombudsmen recommended?**

The Ombudsmen have recommended a number of actions for all NHS and social care organisations in England to review:

- NHS and social care to urgently address how they plan and commission services to meet the needs of people with learning disabilities, and particularly people with profound and multiple learning disabilities. They are required to report back on this in 12 months time.
- Care Quality Commission and Monitor to make sure their inspection systems enable them to assess whether health and social care organisations are meeting the needs of people with a learning disability. They are required to report back on this in 12 months time.
- The Department of Health should promote and implement these recommendations and publish a progress report in 18 months time.

### **Why has the Local Government Ombudsman been involved in the report?**

In some of the six cases there were complaints about the care provided in social care settings as well as in primary or secondary health care. For example, Mark broke his leg whilst receiving respite care and Tom's family complained about the lack of transition planning which led to him being admitted to an NHS assessment unit. In both cases the LGO upheld the complaints. In Mark's case the fact that he should not have broken his leg

in the first place was seen as an avoidable accident that contributed directly to his avoidable death.

### **How will the Ombudsman's report stop tragedies like this happening again?**

*'Taken together, the investigations demonstrate an urgent imperative for organisational and cultural change, coupled with individual leadership and commitment'*

Mencap knows that systemic change is a massive challenge. We also know that tragedies like the six set out in our report are still happening. We have already referred 5 more cases to the Ombudsman for investigation and are currently supporting others through the local complaints process.

However, since we published 'Death by indifference' in 2007, we have also heard about the work of many NHS and social care professionals who are already taking action to prevent tragedies of this kind.

We know that it will take time before we will see real change but by making strong recommendations to the organisations responsible for the provision and regulation of social care and health, the Local Government and Health Ombudsmen have contributed to the call for urgent systemic change. The Government has now accepted all the recommendations made by Sir Jonathan Michael and set out the actions it will take in 'Valuing People Now' (Department of Health 2009). The Ombudsman has recommended that the Department of Health publish a report on their progress in 18 months time.

Mencap will monitor the progress that is being made and we will not stop campaigning until we stop hearing about appalling accounts like those in our report.

### **Why are Mencap critical of the Ombudsman's approach to reasonable adjustments?**

The Ombudsman has supported what Sir Jonathan Michael said about NHS professionals breaking disability discrimination law. She has made a number of comments in the report regarding the failure of NHS staff to understand and to make reasonable adjustments and states that she has found no shortage of policy and guidance in regard to them.

The Ombudsman has not applied the requirement to make reasonable adjustments to all of the cases. In particular no service failure was found in the practice of any GP, where in our view they had not made appropriate reasonable adjustments. This is most striking in the case of Warren where, despite the fact that the Ombudsman's own clinical adviser sets out the steps that should have been taken, she does not conclude that the failure to do so was service failure.

Mencap suggests that as the Ombudsman has concluded in some individual circumstances that the practice of doctors did not amount to service failure because most doctors would have done the same in similar circumstances, she is in effect condoning the fact that doctors are currently breaking the law.

This seems to suggest a need for better advice and training on the practical implementation of the Disability Discrimination Act in practice by all health professionals. We believe that the Ombudsman should have recommended that this be addressed with more detailed guidance by the GMC.

## **What does the Ombudsman say about 'best interest' decisions?**

The Ombudsman says very little about best interest decision making and appears to have confused the defence that health professionals were 'doing their best' with the requirement to act within the law and the wealth of guidance available to them.

There was no evidence that any health professional intended to act maliciously, rather that they may have held misplaced assumptions about the degree of the disability or the quality of the individual's life. These attitudes may have influenced the actions of the health professionals, resulting in them acting in a way that they thought was 'for the best'. We feel that the Ombudsman's report should have made it clear that this is a long way off from acting within the very clear legislation and guidance, or following the required process for making a best interest decision.

Mencap believes that the way health professionals make best interest decisions cuts to the heart of what can go wrong for many people with a learning disability, particularly those with the most profound disabilities. Instead of weighing up the risks and benefits of the intervention, judgements are made about the value and meaning of someone's life. An example of this is Emma Kemp's case, where doctors based their prognosis of 10% not only on the staging of the cancer but also on their misunderstanding of the impact of Emma's learning disability on her ability to tolerate treatment.

## **What do Mencap think about the fact that the Ombudsman did not find service failure in all cases?**

Mencap believe that the Ombudsman has conducted a detailed and rigorous investigation that has provided answers to most of the questions we and the families asked. We also recognise the Ombudsman's task of weighing up the evidence objectively was difficult in some cases because of the passage of time and, in some instances, the absence of detailed clinical notes.

In some circumstances, where she has not found service failure, we accept this because her investigation has provided helpful clarification on the circumstances. For example in Ted's case the Ombudsman was asked to investigate the role of Ted's care team in following any discharge advice. However, the Ombudsman's investigation found that there were no discharge plans. The Ombudsman concluded that he should not have been discharged from hospital because it was not safe to do so. Ted's sister was pleased that the staff team from the care home, who she had always felt supported Ted so caringly, had not failed him.

However, where the Ombudsman has had to weigh up the evidence and recollections of the families against the recollections of the health professionals, we think that she has unfairly given greater credibility to the evidence provided by doctors. Mencap has heard the accounts of the families on many occasions and know that, because of the dreadful events that they experienced, they recall the events vividly. For example, Warren's parents have consistently recalled the traumatic events leading up to the night Warren died but do not think that the Ombudsman believed them, and found this especially unfair because the doctor concerned did not have detailed notes to back up his account.

## **The Ombudsman did not conclude that all of the deaths were avoidable, were Mencap wrong to say they had died unnecessarily?**

Mencap still believe that the six deaths were avoidable. We do accept that in some circumstances this was difficult to prove definitively. We also accept that there were a complex series of events that led up to the deaths and that it was difficult for the Ombudsman to identify which actions may have been pivotal in preventing the death.

However, in some circumstances we do think that she has misjudged this. For example, in Tom's case we refute the fact that he was in an '*inevitable decline*'. We maintain that if the fact he had an ulcerated oesophagus had been identified sooner and a PEG operation been arranged faster, this would have resulted in an improvement in his nutrition and health. There is every reason to believe that this would have given him some more years of good quality life. Tom's family and Mencap are very disappointed about the Ombudsman's finding that his death was not avoidable because we believe that there were several times when his life could have been saved.

## **Why do Mencap and the families believe that some professionals should be named and referred to their professional bodies?**

Mencap and the families believe that there were circumstances in which the care provided fell well below the standards set out in detail in their professional codes. The Ombudsman has been critical of many of the professionals concerned but has not recommended that they are referred to their professional bodies. We believe that this is wrong and that unless professionals are held to account for their actions there is a risk that this will give the wrong message to health professionals who will believe that they can get away with treating people with a learning disability in this way. For example, despite a catalogue of service failures which led to Martin being starved to death in an NHS ward not one of the professionals, who must have walked by his bed each day and seen him deteriorating in front of them, has been held to account.

Click [here](#) to read the Ombudsman's reports in full

[www.mencap.org.uk](http://www.mencap.org.uk)

Registered charity number 222377