



Death by *indifference*

Following up the *Treat me right!* report

MENCAP

Understanding learning disability

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Introduction

“We believe that Mark died unnecessarily. Throughout his life, we encountered medical professionals who had no idea how to deal with people with a learning disability or what it is like to be a parent of someone with a learning disability – to know their suffering, to see their distress. If only they would listen...”

Allan, father of Mark, who died in August 2003 of bronchopneumonia

Mark’s family believe that the doctors and nurses treating him failed to understand his medical needs or appreciate the seriousness of the condition that led to his death. They believe that this was mainly because Mark had a learning disability. They also believe that if the medical staff had listened to them and what they knew about Mark, his life could have been saved.

Mencap believes that Mark’s family is right. We believe that the real, underlying cause of Mark’s death – and those of many other people with a learning disability who die in hospital – is the widespread ignorance and indifference throughout our healthcare services towards people with a learning disability, and their families and carers.

We say that this is a national disgrace.

We say this is institutional discrimination.

About this report

This report will set out why we believe there is institutional discrimination within the NHS, and why people with a learning disability get worse healthcare than non-disabled people. We present the stories of six people who we believe have died unnecessarily. We do so because healthcare professionals need to realise the serious – even fatal – consequences of their lack of understanding. We do so to point out that these professionals must work to ensure that such tragedies can never happen again.

This report follows on from Mencap's *Treat me right!* report and campaign in 2004, which exposed the unequal healthcare that people with a learning disability often receive from healthcare professionals. The report made clear that much work needs to be done within the NHS to ensure that people with a learning disability are treated decently and equally.

Since the launch of our *Treat me right!* campaign, many cases of appalling treatment of people with a learning disability in hospitals around the country have come to light. The six cases presented in this report share common factors. In our view, they raise serious concerns about the way people with a learning disability are treated within our healthcare system.

The Disability Rights Commission (DRC) recently published the results of a formal investigation into physical health inequalities experienced by people with learning disabilities and mental health problems¹. The investigation showed that people with a learning disability receive fewer screening tests and fewer health investigations. It showed that people with a learning disability are less likely to get the healthcare they need. Commenting on the report, the Chairman of the DRC stated that the view of the inquiry panel was that 'early deaths in these groups are not acceptable' and that they had encountered 'complacency and a lazy fatalism that these groups just do die younger'².

But the fact is, that shocking and tragic as these reports are, there has been an astonishing lack of response to them at Government level. Health inequalities have been widely documented and the solutions clearly identified – including the need for a confidential inquiry into premature deaths, annual health checks and staff training. But nothing has been done. There has been no action to

prevent the disgracefully poor treatment that continues to be reported to Mencap. No action has been taken to stop other deaths like the six you will read about in this report. That is why this report is called *Death by indifference*.

This is a wake up call for the NHS. It is simply not doing enough to ensure a reasonable standard of treatment for people with a learning disability. Calling for discriminatory practices to be eliminated, the DRC¹ report states that ‘in the absence of systemic national action to close the gaps of inequality, service users remain caught in a policy Catch 22 situation’. Warning that the Government could face legal challenge under new disability equality laws,³ the DRC states that ‘a clear lead needs to come from the Department of Health and the Welsh Assembly Government in taking action and ensuring that others take action’.

It is clear that change needs to happen – without further loss of time.

Introduction to the case studies

After Mencap published the *Treat me right!* report we were contacted by the families of Emma, Mark, Martin, Ted, Tom and Warren. Each family has an understandable desire to fully understand why their family member died. What they also share is the motivation to achieve systemic change that will benefit others in the future.

Each case is currently at a different stage of the complaints process. The purpose in including them in this report is to show that they have common strands, and that a series of interwoven actions resulted in those concerned getting unequal treatment. The actions of the individual health professionals concerned are a matter for those individual complaints processes.

However, it is our belief, and that of their families, that their deaths were avoidable and that institutional discrimination is the underlying cause. We believe that they occurred because of discrimination, indifference, lack of training and a very poor understanding of the needs of people with a learning disability.

It is difficult to determine whether any of the individual doctors and nurses involved consciously discriminated against the people featured in this report. Many families known to Mencap report the words that health professionals have said to them, such as:

'If she had been a normal young woman we would not hesitate to treat her.'

'Wouldn't it be better for everyone if we just let him go?'

'In my opinion there is nothing wrong with him and I am not usually wrong. It's just the way he is.'

While families obviously vividly recall these statements, such words would not be recorded in case notes and are hard to prove. Neither would the attitudes displayed by healthcare professionals that result in such a level of fear and mistrust that some families feel the need to mount bedside vigils when their loved ones are in hospital. Direct discrimination is hard to prove, but this does not mean that it does not exist.

It could also be argued that the health professionals concerned did not intend to act maliciously, but held mistaken beliefs about patients with a learning disability. An example of the level of ignorance about patients with a learning disability is demonstrated in a recent report about responding to the pain experiences of people with learning difficulties and dementia⁴. The report explored the reason why some people did not receive appropriate pain control while in hospital. It found that 'a further barrier to pain recognition was the generalised but concerning belief that people with a learning difficulty have a high pain threshold'. It is important to remember that, under the Disability Discrimination Act (DDA), discrimination that is unintentional is still against the law.

In Mencap's view, it is this type of widespread ignorance that results in institutional discrimination. It means that the practice, policy, procedures and systems followed by the healthcare staff are not grounded in a proper knowledge of the needs of people with a learning disability. But there is absolutely no excuse for ignorance of this kind. It is not that the health and treatment needs of people with a learning disability are unknown. They have been recognised for many years. There is also evidence of some very good practice in the NHS but this has not been implemented more widely. We know that there is a growing awareness of the problems. However, there is also a lethargy in tackling them. It is our view that allowing this shocking level of ignorance to continue is further evidence that there is institutional discrimination within the NHS.

In the six case studies that follow, we have provided a short summary of the complex amount of information that we have gained from the families and the reports and correspondence relating to the complaints process. The information on each case is, to the best of our knowledge, accurate at the point of going to print. But we will only know what really happened and whether their deaths could have been avoided if there is a thorough independent investigation.



Emma

"Determined, fun, caring, loving... these are the things I think about when I think of Emma."

"She had a great sense of humour and loved pulling faces for a laugh!"

"she had wonderful smiles that could light up a room."



Emma died of cancer on 25 July 2004, aged just 26. She had a severe learning disability, which meant that she sometimes exhibited challenging behaviour and had difficulty in communicating how she felt. The hospital delayed treating her because they said she would not co-operate with treatment and therefore could not consent to treatment.

Emma's family has complained to the hospital and subsequently to the Healthcare Commission.





Emma's mother first took her to her GP because Emma had not eaten for eight days. Her GP suggested it might be a virus. Her mother was not satisfied, as Emma was very unwell and still not eating. She decided to find another GP.

A month later, Emma was admitted to a surgical ward at the hospital with a swelling in her groin. She had an X-ray, and a scan culminating in a biopsy. While she was in hospital, Emma was distressed and in pain. She was not eating and couldn't take a painkiller orally. The hospital found Emma's behaviour very difficult to manage. Emma was discharged from the hospital on the grounds that there was nothing more they could do for her. She was sent home without any help to control her pain.

Eleven days later Emma and her mother went back to the hospital to get the results of the biopsy. They were told that Emma had Lymphoma B1 type cancer and that, with treatment, she had a 50:50 chance of survival. But the doctors decided not to treat her, saying that she would not co-operate with the treatment. Emma and her mother were sent home with no advice about Emma's care needs and still no way of dealing with her pain.

Emma was back in hospital again five days later, as by this time she had stopped drinking. Again, the doctor wanted to discharge her. Her mother refused to take her home. Emma received no treatment at the hospital for two more days, with the doctors again saying they could not treat her as she was unable to consent. So her mother instructed a solicitor to serve notice on the doctors to start treatment for pain relief by 9am the following day. Treatment did not start, so the solicitor started an action in the High Court and the hospital finally agreed to treat Emma.

A second medical opinion was sought and this doctor said that as the cancer had advanced she now had only a 10% chance of survival with treatment. It was decided that palliative care was now the only course of action to take.

A few days later Emma was moved to a hospice where she received excellent care for about a month. She started drinking again and her pain was well controlled until she died.

The questions we want answered...

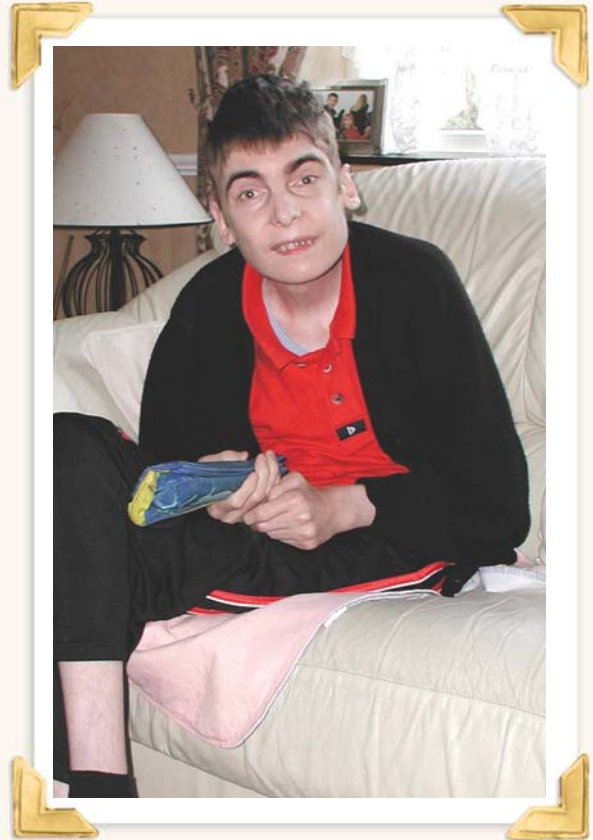
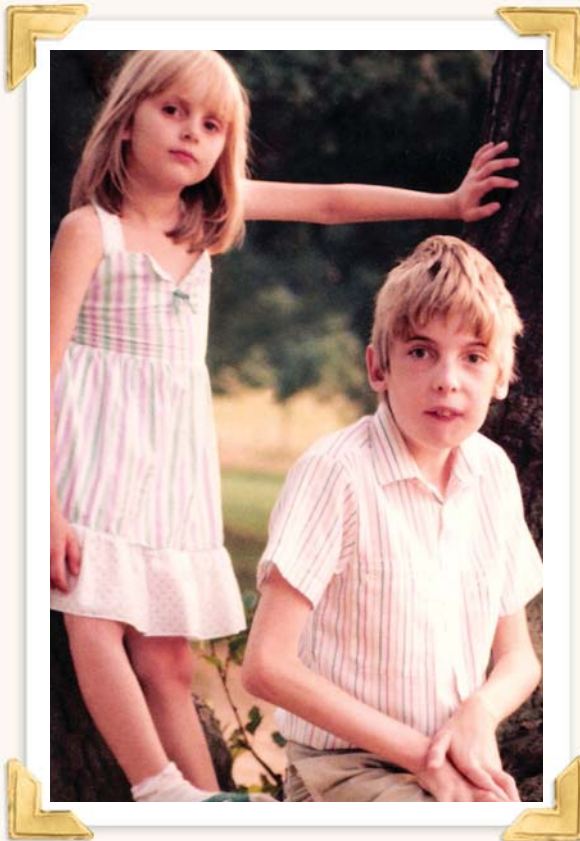
- If Emma had been diagnosed earlier and treatment started immediately, would her death have been avoidable?
- What assessment was made by doctors to show that treatment was not in Emma's best interests?
- What possible explanation can there be for failing to offer Emma pain relief?
- What training had hospital staff received to help them manage patients who do not co-operate well with treatment?





Mark

"Mark was very funny and often had all the family in stitches with his antics. He loved an audience!"



"Mark was always very close to his sister, Jane. She shared almost all his social events, clubs, birthday parties and school trips."

"We were blessed with a lovely son who was innocent, gentle and good natured."

Mark died on 29 August 2003 of bronchopneumonia. He was 30 years old. He had a severe learning disability and had very little speech, though he had his own way of communicating his needs which his family understood. Two months before his death, Mark had been admitted to hospital with a broken femur. After an operation in which he lost a lot of blood, Mark was discharged and re-admitted twice in two months, finally dying in intensive care eight and a half weeks after the operation.

Mark's family has complained to the hospital and subsequently to the Healthcare Commission.





Mark was just 30 years old when he fell and broke his leg. He was taken into hospital by ambulance. After the operation on his leg Mark lost 40% of his blood. He started to convulse and his body began to go into status epilepticus (i.e. continuous fitting). The hospital staff said he was just reacting to the operation, but his father realised that the hospital staff had failed to give Mark replacement epilepsy medication and insisted that they did this as well as give Mark a blood transfusion.

Mark was discharged from hospital after about a week. But he was clearly distressed and in pain. He was unable to sleep or settle at home and started to moan. He was re-admitted to hospital a few days later, but then had to wait three days to see the pain team.

He was discharged again, but on his way home the moaning started once more and he began to slap himself. Back home, this went on 24 hours a day. Mark didn't sleep at all – he began to deteriorate. His GP visited and prescribed antibiotics but Mark continued to deteriorate. He wouldn't eat and so was losing weight. He developed a high temperature and was having fits. Mark was clearly seriously distressed – he never usually behaved like this. He was taken to the Accident and Emergency department in a serious condition. He was malnourished, dehydrated and showing signs of kidney failure.

Mark was taken down to intensive care and put on a respirator. He was in the intensive treatment unit (ITU) for a few days, but was then moved back to a high dependency unit. He remained there one night, but by the time his family visited him the following morning he had suffered a serious relapse which culminated in a cardiac arrest. He was resuscitated and returned to the ITU, where the doctors decided that he would not be able to recover. The ITU staff showed genuine care and concern for his well-being. However, in the meantime, Mark had picked up septicaemia and finally developed multi-organ failure.

The questions we want answered...

- How was it possible for someone to go into hospital with a leg injury and die?
- Why didn't healthcare staff listen to Mark's family – who knew that something was terribly wrong and kept telling them this?
- How did doctors miss the extreme deterioration in his condition?
- Why did it take so long for the pain team to attend to Mark?





Martin

"Martin was often smiling – he loved to go out, liked the movement of the coach and listening to the music. When he was young, he liked being in our car as well. He loved getting behind the wheel and turning it around."

"Martin will always be the light of my life. He had a quirky sense of humour and oodles of charm."

Martin died on 21 December 2005, aged 43 years old, allegedly of a stroke. He had a severe learning disability and no speech. In the 26 days he spent in hospital following a stroke he went without food. The hospital failed to use a nasal feeding tube at the critical time to prevent his condition from deteriorating dangerously. This left him too weak to undergo surgery to have a PEG feeding tube inserted into his stomach.

Martin's family has complained to the hospital and to the Healthcare Commission.





Martin had a stroke and was sent to hospital. While there, he also contracted pneumonia.

Martin had trouble swallowing after his stroke and so was visited by a speech and language specialist. But Martin's swallow reflex did not return. He could not take food or water orally and so was put on a drip. Martin did not tolerate this well and sometimes pulled the drip out. In the second week at the hospital Martin was still unable to eat and the drip was not providing him with adequate nutrition. He was visited and tested by the speech and language team several times. They recorded in their notes that he should remain 'nil by mouth' and that 'alternative feeding methods should be considered'. However, no action was taken. This situation continued into a third week.

By this time, his veins had collapsed, which meant that the doctors couldn't get the glucose liquid from his drip into his body. So they decided they needed to insert a feeding tube into his stomach. This would have required a surgical procedure. However, by the time they had made this decision, Martin had been without nutrition for 21 days and his condition had deteriorated so much that he was in no state to undergo an operation. Five days later, Martin died.

The hospital admit that they did not act on the information that Martin was assessed as being at 'high risk' on the Malnutrition Universal Screening Test (MUST) scale, and that they did not follow their own enteral feeding policy. This policy states that alternative feeding methods should be considered after seven days.

The hospital carried out an internal investigation. This found that there had been a multidisciplinary communication failure, which resulted in the doctor being "under the impression" that the nurses had been feeding Martin via a naso-gastric tube when this was not the case. There had been a complete breakdown of communication, resulting in Martin being without food for 26 days before he died.

The questions we want answered...

- Why did the hospital fail to meet Martin's basic needs and leave him with no nutrition for 26 days?
- Who was ultimately responsible for ensuring that he received nutrition?
- Why did the hospital fail to give Martin food via a nasal tube while they waited for his swallow to return, or for a slot to become available in theatre to insert the PEG feeding tube?
- Given the urgency of the situation, why was the operation to insert the PEG feeding tube not brought forward?
- Why did the hospital fail to follow MUST and their own feeding policy?
- Why did the hospital's internal procedures and communications fail so badly?





Ted



"Ted may have had a learning disability, but he was still a human being and had rights. You hear people always ready to quote the Human Rights Bill. What happened to his rights?"



"Ted had a gentle nature. He loved to wander off to the playing fields behind our house where we grew up to watch the men playing cricket or the groundsmen cutting the grass on tractors."

Ted died on 27 May 2004. The death certificate stated that this was due to a heart attack, but this was changed after the inquest to 'aspiration'. He was 61 years old. He had a severe learning disability and virtually no speech. He had been admitted on 5 May 2004 hospital due to problems with urine retention. He was discharged three weeks later, despite the fact that his care staff raised concerns about his health. The following day he collapsed and died.

Ted's family complained to the hospital, the GP practice and subsequently to the Healthcare Commission.





Ted developed urine retention problems and was admitted to hospital for an operation. After the operation he got out of bed and fell. It was suggested that this could have been because he had a stroke or heart attack. He was then admitted to the intensive care unit with a post-operative infection. Here, it was confirmed later that he had suffered a mild heart attack. Ted made a good recovery and one week later he was transferred to a general medical ward.

The following day, the hospital contacted the NHS residential unit where he lived and said that they wanted to discharge Ted that day. This was despite the fact that his condition had been assessed as “concerning”. Ted had been agitated and wandering around the ward during the night. His sister said that this was unusual and in her view, a sign that he was distressed. The senior charge nurse at Ted’s residential care home was not confident that he was well enough to leave hospital. In particular, the care home staff were worried because Ted was not able to swallow properly and he was still bleeding when he urinated.

As Ted’s residential care home was an NHS unit, the hospital felt that it was appropriate to discharge him. A member of staff was sent to collect him. It is not clear what verbal or written instructions were given to explain Ted’s care needs.

All night, staff were concerned about his condition and Ted was watched closely. It was noted that he seemed chesty and unsteady. In the morning, the nurse in charge of the unit noted that he had a bloodshot eye, unsteady gait, chesty cough, was walking unusually fast and had blood in his urine. They called the GP the following morning and he arrived later that day. The GP assessed Ted’s condition and said that there was no need to return him to hospital. Ted sat down and ate a communal meal. He began to vomit and then collapsed. The care staff called an ambulance and Ted was sent back to the hospital where he died shortly afterwards.

An inquest was held and stated that Ted had died from aspiration pneumonia and that a simultaneous heart attack would have hastened his death. The post mortem report stated that he had aspirated a large amount of food into his lungs just before he died.

The questions we want answered...

- Was Ted discharged from hospital too early, given his special needs and the fact that the residential staff expressed concern about the state of his health?
- Was it reasonable for the hospital to assume that the care home had the skills to support him?
- Was a thorough assessment of Ted’s ability to swallow carried out by speech and language therapists before he was discharged?
- What information was the care home given about Ted’s swallowing ability?
- Were any instructions about how to feed Ted carried out correctly?





Tom

"Dear, unique, courageous Tom. You liked music – Robbie Williams, Blue, Jools Holland. You enjoyed BBQs and football matches, and, yes, famously you liked blondes."



"Your heart reached out to freedom, you loved being outside, in sunshine, or rain and cold, being near water, listening to the birds, feeling the touch of nature on you."

Tom died on 25 May 2004. He was just 20 years old. He had profound and multiple learning disabilities. He died of aspiration pneumonia and reflux oesophagitis. A hospice consultant recommended that the underlying causes of his pain were investigated by a gastroenterologist over a year before he died, but no action was taken on this issue until it was far too late. Medical assessments promised at the NHS assessment unit Tom was admitted to never took place, and Tom's parents found that the concerns they raised over Tom's expressions of pain weren't listened to.

Tom's family has complained to his GP, the primary care trust, the hospital and the Healthcare Commission.





Tom had profound and multiple learning disabilities and complex health needs. He attended a residential special school. His parents raised concerns on numerous occasions about planning for Tom's future after he left school. However, social services took no action until very late on. There then began a frantic search to find a suitable placement for Tom.

Prior to leaving the school, Tom was showing signs of distress. The school put this down to the fact that he was no longer happy there. Convinced that Tom was in pain, his parents had insisted that he was referred for medical investigations. Tom went to a hospice where the consultant recommended that further investigations were carried out to identify the underlying cause of the pain he was experiencing. The consultant suggested that the pain was likely to be related to Tom's digestive system. This advice concerning further investigations does not appear to have been acted on. Tom's GP decided that he should not have a PEG feeding tube inserted because of fears that Tom would not tolerate it. His parents were not involved in the discussion about how best to ensure that Tom was receiving adequate nutrition.

It soon became apparent that there was nowhere suitable for Tom to move to after leaving school, within the required timescale. Tom was eventually placed at an NHS psychiatric assessment unit. His parents were told that they would assess his needs, including his medical needs. However, no such assessment ever took place.

During this period, Tom's health continued to deteriorate. He was steadily losing weight and exhibiting highly unusual behaviour – such as gouging his head. Tom's parents were sure he was expressing the pain he was in.

Finally, a place became available at a social services residential home. The concerns raised by Tom's parents about his health were at last acted upon, and staff ensured that Tom was admitted to hospital. Following tests, they found that Tom had an ulcerated oesophagus. The hospital agreed to insert a PEG so that Tom could be fed by tube and the operation to do this was carried out. However, Tom died before receiving nutrition as by this time he was extremely weak.

The questions we want answered...

- Why was Tom not referred to a gastroenterologist when this was recommended by the hospice consultant?
- Why was no medical assessment carried out when Tom was in the NHS psychiatric assessment unit?
- How could it take such a long time before the underlying cause of Tom's pain was diagnosed?
- How did Tom fall through so many different hands and no one recognise the serious nature of his condition until it was too late?





Warren



"Warren had all the greatest qualities in abundance. He was a very happy and contented young man with a great sense of humour and a love for everyone."



"we will always treasure all the happy times we shared with warren and all the love he gave us. He will stay in our hearts and thoughts for evermore"

Warren died on 25 September 2004. He was 30 years old. He had a severe learning disability and very little speech, but he could make himself understood to his family. He died of aspiration pneumonia, paralytic ileus and peritonitis, following perforation of the appendix. His mother and father repeatedly asked whether Warren had appendicitis or a blocked bowel when doctors visited Warren. They were told that Warren had a virus.

Warren's family has complained to the hospital, the General Medical Council, the Healthcare Commission and subsequently to the Health Ombudsman.





When Warren first showed signs of distress, his doctor visited on three occasions. On each occasion, his parents asked the doctor if there was anything wrong with his appendix or whether he had a bowel blockage. At that point in time, the doctor did not consider there was any cause for alarm.

A month or so later, Warren was having difficulty sleeping, was fitting, and was clearly in severe distress. His parents called the doctor out. Warren was having trouble swallowing so was not eating. Warren's parents had never seen him look as ill as he did then. Certain that something was very seriously wrong, they again asked about his appendix and the possibility of a bowel blockage. They were told that he had a virus. His parents were also concerned that, as he was not eating and he took his medication in his food, he was not getting his epilepsy medication. The doctor prescribed paracetamol and diazepam to calm his fits.

The following day Warren's condition was worse. His parents called the out-of-hours doctor on duty. After examining Warren, the doctor advised them to take Warren to hospital to have a stomach X-ray. However, the doctor gave no indication that anything was seriously wrong with Warren. A few hours later, Warren's parents were so concerned they called the doctor again, and an ambulance was sent to take Warren to hospital. When they arrived there the staff also gave no indication of the seriousness of his condition. Warren's parents felt that certain members of staff had a negative attitude towards Warren. When his Mum noticed Warren's colour had changed she alerted a nurse, who realised Warren had stopped breathing.

Warren died within two hours of admission to the hospital. His death certificate lists two causes of his death as: peritonitis following perforation of his appendix, and a paralytic ileus (a bowel blockage caused by a paralysed bowel). These were precisely the conditions about which his parents had repeatedly voiced their suspicions.

Warren's parents feel robbed of their last precious moments with their son. They were rushed away from his bedside – and he died with a state of hurried confusion all around him.

The questions we want answered...

- Why did doctors fail to recognise Warren's serious symptoms and signals of pain and distress?
- Why didn't doctors consider the possibility of appendicitis when Warren's parents repeatedly raised this as a concern?
- Given that Warren was unable to communicate verbally, why did doctors not listen to his parents who knew him best and could provide vital information about his condition?



This report's main contentions

These six shocking and tragic cases demonstrate why it is Mencap's belief that there is institutional discrimination within the NHS against people with a learning disability – leading to neglect and, as we have shown, to premature death.

In this section of the report we explore what we mean by this.

The Stephen Lawrence Inquiry, which looked at race issues, can be equally applied to disability. It defines institutional discrimination as follows:

“Institutional racism consists of the collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racial stereotyping, which disadvantage ethnic minority people.”

In plain English, this means that institutional discrimination results when organisations fail to make changes in the way they deliver their services to take into account people's differing needs. Nor does the organisation deal with ignorance and prejudice within the workforce and culture of the organisation.

We believe that there is a fundamental lack of understanding and respect towards people with a learning disability and their families and carers. This lack of understanding and respect leads to – and is demonstrated by – the poor design of systems, policies and procedures to meet the particular and differing needs of patients with a learning disability. This is despite the fact that the NHS has been required to make ‘reasonable adjustments’ under the Disability Discrimination Act (DDA) since 1995. This is to ensure that people do not suffer discrimination.

The failure to tackle unequal access for people with a learning disability has resulted in institutional discrimination. The factors that contribute to this are:

1. People with a learning disability are seen to be a low priority

Senior management within the Department for Health, strategic health authorities, hospital trusts and primary care trusts see people with a learning disability as a low priority.

The *Our Health, Our Care, Our Say*⁶ White Paper states that ‘People with learning disabilities face particular inequalities. The NHS has historically not served such people well’. Despite this, the DRC report concluded that ‘there has effectively been no inclusion of the high risks to physical health among people with a learning disability in mainstream targets’ and that ‘government programmes to tackle health inequalities have tended to ignore disability related inequalities’. In our view the reason for this is that people with a learning disability are a low priority.

This contention is also borne out by the Healthcare Commission investigation report⁷ into provision of services for people with a learning disability at Cornwall Partnership NHS Trust in July 2006. The abuse that was identified in Cornwall occurred primarily because learning disability services had such a low priority and lacked any management focus. This, in our view, leads to neglect.

This Healthcare Commission report illustrates that no organisation in the social care or healthcare field was sufficiently concerned to identify what was going on in learning disability services. Even the inspection system failed to identify the shocking level of discrimination and abuse.

More recently the Healthcare Commission has published a report on the investigation into the service for people with a learning disability provided by the Sutton and Merton Primary Care Trust. This followed a series of serious incidents, including allegations of physical and sexual abuse. The report concluded that ‘institutional abuse’ was prevalent and was mainly due to ‘lack of awareness, lack of specialist knowledge, lack of training and lack of insight’. The report noted that, ‘Performance reports to the PCT’s board did not include any mention of the learning disability service and focused on accident and emergency and acute services’. Here again, the lack of priority accorded to people with a learning disability has led to neglect and abuse.

2. Many healthcare professionals do not understand much about learning disability

The DRC identified diagnostic overshadowing as a key barrier to people with a learning disability getting equal treatment. Diagnostic overshadowing is when

doctors make dangerous faulty assumptions about people with a learning disability, revealing an overall lack of training and skills in understanding learning disability. They may wrongly believe that a presenting problem is a feature of someone's learning disability and that not much can be done about it. This can often lead to wrong or no diagnosis of a medical condition that needs treatment. In its report the DRC calls for 'improved staff training' explicitly to reduce the risk of 'diagnostic overshadowing and unequal treatment'¹.

People with a learning disability may also find it hard to communicate their symptoms and to understand what they are being told. As a result, some people have to put up with a great deal of pain and discomfort before they get the right treatment. Sometimes people do not get the treatment they need. Warren died of appendicitis. In response to the complaint made by his parents, it was stated that the presence of his learning disability meant that his condition was 'more difficult to diagnose than in normal circumstances'. This is not an acceptable reason.

When assessing and managing patients with a learning disability, professionals are often ignorant of:

- the signs and behaviours expressed by people with a learning disability, and in particular the clues that indicate distress in an individual
- the key role that carers play in interpreting distress cues
- the need to be more suspicious that the patient may have a serious illness, and be more proactive in intervening and assessing the needs of a person with a learning disability
- the issues around consent and capacity
- the difference between a professional's opinion of a patient's quality of life, and a patient's opinion of their own quality of life
- the professional requirement to ask for help and/or refer on when faced with a novel or puzzling clinical situation
- the dangers of delaying or deferring action.

3. Many healthcare professionals do not properly consult and involve the families and carers of people with a learning disability

All the families in the case studies said that they were not listened to by the medical staff treating their sons and daughters. This was the case with Mark's family, who felt that they were consistently ignored when they expressed their concerns. Warren's mother and father asked doctors repeatedly if Warren might have appendicitis or a blocked bowel. But they too felt that their concerns were ignored.

Parents and family members can often provide vital information that can help doctors and nurses to decide on appropriate treatments for people with a learning disability. But there appears to be a tendency among healthcare professionals to discount this information, or not even to consult family members in the first place. It is often assumed that they are over-emotional, irrational and uninformed. By disregarding the views and information that family members provide, doctors can make wrong diagnoses, leading to premature, avoidable deaths.

Identifying distress is a key failing in each of the case studies. Research has shown that people with a learning disability give out many distress cues. Professionals who do not know the person with a learning disability will not pick up the distress cues, but in contrast, carers are very capable of recognising these cues and identifying distress.

4. Many healthcare professionals do not understand the law around capacity and consent to treatment

Professionals needing to treat people with learning disability are often ignorant of issues around consent and capacity to the extent that the person with learning disability is often denied treatment.

In Emma's case, there was a delay in starting treatment because the doctors said she would not co-operate with treatment and therefore could not consent to it.

Doctors and nurses can sometimes wrongly believe that someone is refusing treatment. For example, someone may pull out tubes or recoil from an injection

because they are frightened or in pain. But this does not necessarily mean they are refusing treatment and that they would rather die. It simply means they do not understand the consequences of either having or refusing to have the treatment. They may not even understand that they are receiving treatment.

Anyone without a learning disability who becomes non-verbal or unconscious for some reason – perhaps because of an accident – would hope that doctors would assume that they would wish to receive treatment to be kept alive. Doctors should start with the same presumptions in the cases of people with a learning disability. In such cases they must be able to clearly establish someone's incapacity to consent to treatment. They must then act in that person's best interests, paying due regard to the opinions and wishes of those closest to the patient – their family and carers.

5. Health professionals rely inappropriately on their estimates of a person's quality of life

Best interest decisions can be highly biased. The doctors who make them have to be very clear about their attitudes to the quality of life assumptions they make about someone with a learning disability. The report of the independent inquiries into paediatric cardiac services at the Royal Brompton Hospital and Harefield Hospital concluded that 'some doctors at the Royal Brompton Hospital had failed to provide a balanced view of all treatment options available to children with Down's syndrome and congenital heart disease in the early 1990s' and that there was 'evidence of discriminatory attitudes'. It said that doctors did act in 'good faith', believing that what they were doing was acting in the best interests of the patient and 'did not intentionally discriminate against the Down's patients'.⁹

This illustrates how health professionals often make personal assessments of a patient's quality of life and view this as a caring step to take in their decision-making process. This is despite good-quality evidence demonstrating the very poor correlation between a professional's opinion of a patient's quality of life, and a patient's opinion of their own quality of life and the level of ignorance that exists among professionals about people with a learning disability.

6. The complaints system within NHS services is often ineffectual, time-consuming and inaccessible

When tragedies happen like those outlined in this report, relatives and carers have recourse to a complaints system, but this process is fundamentally flawed. When investigations are carried out by health professionals, who are ignorant of the needs of people with a learning disability, they are unable to conceive of an alternative way of assessing and treating patients with a learning disability.

For families the whole process is extremely complex. They want to know how their relative died and for the NHS to take responsibility for the things that went wrong. As matters proceed more information comes to light. How do they make sense of it all? Have they asked the right questions? Have they missed something crucial? In Ted's case, his sister complained that the GP must have missed some serious symptoms as he said that Ted was well enough to remain at the care home just an hour or so before he died. However, as more information has emerged, so have other questions – such as those concerning the assessments that were made of Ted's swallowing ability and what instructions were given to care staff when he was discharged. Confused and distressed, his sister is left wondering if she will ever really understand what happened.

The initial complaint is addressed to the local NHS service or hospital trust concerned. If their response is unsatisfactory, the complaint can be passed to the Healthcare Commission. However, since the Healthcare Commission took on responsibility for the independent stage of the complaints process in July 2004, it has been inundated with complaints.

Many of the cases Mencap has been involved with have taken over a year to receive even an initial response. They therefore miss the Healthcare Commission's own timescale target by over six months. Many of these initial responses indicate that the hospital trust or primary care trust has not properly answered the complaint and so it is returned to them for further comment. For example, Mark's family complained to the Healthcare Commission in July 2005. They received the decision following the review of his case in December 2006. The Healthcare Commission has referred a total of 15 issues back to the trust.

If, when the trust has responded a second time, the complainant is still not satisfied, they have to complain to the Healthcare Commission all over again. By this time grieving families are discouraged, disturbed and unable to comprehend why this process feels so unhelpful. Mark died on 1 September 2003. Over three years later his family remains, like the other families in this report, unable to grieve properly or move on in life because they are still no closer to understanding why their loved one died.

What Mencap wants to happen

Mencap is demanding an independent inquiry into the six cases outlined in this report. We want them investigated together – not in isolation

Mencap is calling for an urgent independent inquiry into these six cases. We want the NHS to accept that there is institutional discrimination and do something about it. We want the underlying common causes identified and acted on. We and the families who have lost loved ones want to understand why they died and exactly what lessons the NHS needs to learn to avoid further tragedies. This is not to apportion blame but to encourage an honest and open debate that will lead to change.

An independent inquiry is needed to bring about cultural change. It will put pressure on ministers, and senior management in all parts of the NHS to focus on the treatment of people with a learning disability. It will reinforce the need for increased training for all medical professionals, and the need to revise policies and procedures for treating people with a learning disability.

Mencap wants confirmation that the confidential inquiry into the premature deaths of people with a learning disability will take place

In 2001, *Valuing People* called for a feasibility study into such an inquiry. In June 2004, Mencap's *Treat me right!* report called for the confidential inquiry into premature deaths. It has still not commenced. A feasibility study has been conducted, but no announcement has been made as to when or if the confidential inquiry will take place.

A confidential inquiry is important because until all those people who died prematurely can be identified, no one will really know the size and scope of the problem.

However, even when this happens it is likely to be a further five years before systemic change might take place in the NHS. Our proposal for a formal investigation does not negate the need for a confidential inquiry. In fact, it would be a very useful precursor to it, and would act to speed up the pace of change.

Mencap wants major improvements to the investigation of complaints against the healthcare system

We want the complaints system to be able to get to the heart of the matter. When somebody dies it is crucial to know how they died and whether their death was avoidable. The current system investigates the specific, often narrow complaint that is made, and fails to deal with these underlying questions.

In particular, the Healthcare Commission's complaints procedures and funding should be reviewed. The Commission should be resourced to carry out its functions efficiently. We want the Healthcare Commission to simplify and speed up the complaints system, so that families can understand what happened and why – within a sensible time frame, and with the least possible additional stress. It should be able to take responsibility for the complaint until it is concluded or sent on to the Ombudsman, rather than pass the responsibility back to the complainant.

Mencap has supported the families of the six people presented in this report at all stages of the complaints process, some from the first stage of the complaint through to the conclusions made by investigations carried out by the Healthcare Commission. We know how appalled they are by the time it has taken, how confused they are by the process, and how angry and disappointed they are when the investigation concludes having not answered the fundamental questions – did their loved one die unnecessarily and if so how could that have happened?

Nothing can bring back much-loved family members – like the six people featured in this report.

“We will never get over the terrible sadness of so suddenly losing our son Warren and the severe pain he had to suffer. We weren’t even there to comfort him as no one would tell us how dangerously ill Warren was. All we have left is his grave.” Warren’s parents

But a full understanding of what happened can help parents and families come to terms with their loss – in the knowledge that the lessons of their stories will be truly learnt, and future avoidable deaths prevented.

“We hope, that by hearing these stories, policymakers and professionals will make the changes needed to help prevent many more such avoidable tragedies. Events as catastrophic as these just cannot be allowed to continue unchallenged.” Tom’s parents



Appendix

Treat me right! – the story so far

In 2004, Mencap launched *Treat me right!* – a major campaign for better healthcare services for people with a learning disability.

Here is a summary of the key findings and recommendations of the campaign's report, together with an update of what has happened as a result of the campaign, and likely future developments.

Treat me right! – the main argument

People with a learning disability have poorer health than the general population. This is partly due to:

- conditions that can be related to their disability (for example, epilepsy, thyroid problems, sight and hearing problems)
- socio-economic factors – people with a learning disability are generally poor – living on benefits or a low income. As a result, they are more likely to have unhealthy lifestyles.

But it is also due to a poor standard of treatment within NHS services, which often seems to stem from ignorance and prejudice among healthcare professionals towards people with a learning disability.

In *Treat me right!* we called for:

- more learning disability training for all medical staff
- all NHS organisations to comply with the Disability Discrimination Act (DDA)
- annual health checks for people with a learning disability
- all hospitals to fulfil their duty of care and provide appropriate levels of support to patients who have a learning disability.

The DRC acknowledge exactly the same problems and agree with the solutions outlined above. They did not look into secondary care so did not include the recommendation concerning a hospital's duty of care.

Treat me right! – the main findings

- People with a learning disability have poor access to GPs and other primary healthcare practitioners. In a survey for the *Treat me right!* report, 75% of GPs said that they had received no training to help them treat people with a learning disability, while 90% felt that a patient's learning disability had made it more difficult for them to give a diagnosis.
- Health professionals have not had appropriate training to understand learning disability. This can lead to 'diagnostic overshadowing' – when doctors wrongly believe that a presenting problem is as a result of the learning disability and that not much can be done about it. Doctors and nurses also do not understand the different ways that people with a learning disability may communicate.
- People with a learning disability receive particularly poor-quality care in hospitals. Again, this is often due to a lack of understanding and training among staff. Hospitals also sometimes fail to meet their legal duty to provide basic care for patients with a learning disability and assume that family members or care home staff will do this.
- At worst, there appear to be cases of blatant discrimination – when healthcare staff seem to make arbitrary value judgements about people with a learning disability having less worth than people without a disability.

Treat me right! – the recommendations

- Health staff should get learning disability training, involving people with a learning disability themselves.
- All NHS organisations must fully comply with the DDA so that they fulfil their legal responsibility to provide equal access to healthcare. This should include:
 - longer and more accessible appointments
 - accessible information
 - identifying people who have a learning disability.

- Primary care services should proactively identify people's health problems. They should do this by offering annual health checks to all people with a learning disability and by ensuring that they have the same access to screening services as the rest of the population.
- Healthcare services must address the problem of health inequalities. They should do this by ensuring that the health equity audit:
 - addresses the extent to which people with a learning disability are accessing mainstream services
 - proposes action to reduce the gap in life expectancy.
- Hospitals must fulfil their legal duty of care and provide appropriate levels of support to patients who have a learning disability.
- There must be an inquiry into the premature deaths of people with a learning disability.

Treat me right! – what has happened since 2004

- The Government agreed that the National Patient Safety Agency would carry out a feasibility study into a confidential inquiry into the premature deaths of people with a learning disability. This has now been completed, but no decision has yet been made about whether to proceed with the inquiry.
- The Welsh Assembly agreed to provide a financial incentive to GPs to introduce regular health checks for people with a learning disability from April 2006. In England the Department of Health has supported the principle of health checks, but has not yet given the go ahead for them.
- The findings of the Disability Rights Commission's (DRC) formal investigation, published in September 2006, into the health inequalities experienced by people with a learning disability or mental health problems mirror our own in *Treat me right!*.
- Mencap will keep pressing both the Healthcare Commission and the Department of Health to have rigorous performance indicators that should

ensure marked improvements in the quality of care provided. We will continue to support the Valuing People Support Team in the work it is doing in this area.

- Under the Disability Discrimination Act 2005 there is a new Public Sector Duty requiring all public sector bodies to produce disability equality plans. These plans will have to address how health inequalities can be reduced. This should have a major impact on the quality of healthcare services for people with a learning disability.
- The White Paper on health and social care services in England, *Our Health, Our Care, Our Say*, aims to give people with a learning disability much greater control of their own well-being. It also makes crucial reference to the need for regular health checks for people with a learning disability.

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the 1990s, the number of people in the world who are malnourished has increased from 1.1 billion to 1.5 billion (FAO 2001).

There are a number of reasons why the world's population is becoming more malnourished. First, the world's population is growing rapidly. The world population is projected to reach 8 billion by the year 2025 (United Nations 2000). Second, the world's population is becoming more urbanized. The number of people living in urban areas is projected to increase from 3 billion in 1990 to 5 billion in 2025 (United Nations 2000). Third, the world's population is becoming more dependent on food imports. The number of people who are dependent on food imports is projected to increase from 1 billion in 1990 to 2 billion in 2025 (United Nations 2000).

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