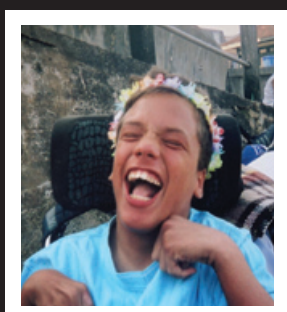
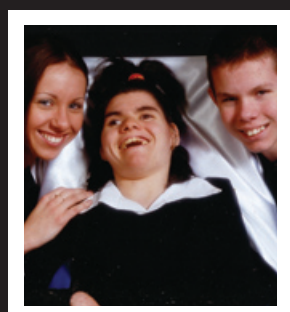
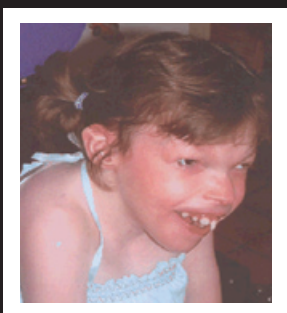
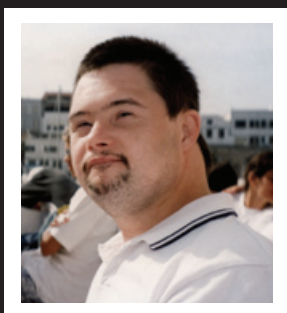
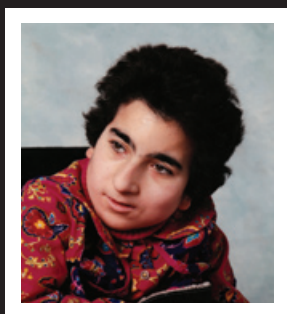
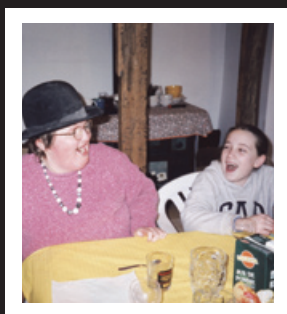


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# Mencap submission to the independent inquiry into access to healthcare for people with a learning disability

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# Introduction

The publication of *Death by indifference* put into the spotlight the tragic consequences of the healthcare inequalities that people with a learning disability experience. These inequalities have been clear for years<sup>1</sup>, but it has taken the deaths of Emma, Mark, Martin, Ted, Tom and Warren – and the bravery of their families in telling their stories – to bring about this inquiry. The cases of the six people whose stories we highlighted in *Death by indifference* are not isolated. Mencap hopes that this inquiry will act as the catalyst for the change that is so clearly needed. We hope it ensures that such tragic deaths never happen again.

Family carers can all share experiences of situations where their son or daughter did not receive the care they needed in the health service. Such experiences include occasions where adjustments, such as side rooms, weren't made available. They also include clear examples of healthcare professionals failing to understand what it means to have a learning disability. But too often these negative experiences go much further – and are far more dangerous.

Since the launch of *Death by indifference*, more families have approached Mencap to tell us about their sons, daughters, brothers and sisters. Loved ones who they watched suffer and die in the very place they assumed would provide the care and treatment they needed. Instead, basic care needs were not met. People were left in their own excrement, pain was left untreated, symptoms dismissed and judgements made that this person was not really worth treating.

It is these experiences, as well as those of Emma, Mark, Martin, Ted, Tom and Warren, that this submission is based upon. In some cases names have been changed for legal reasons, or at the request of families – but all the people mentioned are real. And so are their experiences, which families and carers of people with a learning disability all over the country have described to Mencap.

This is not to say that there aren't individuals and organisations making real efforts to address the problems of access to equal healthcare for people with a learning disability. Some of the solutions found by those seeking to deal with this issue are mentioned in this submission.

But equal healthcare is a legal obligation that should be embedded in the every day running of the NHS, not an exercise in identifying pockets of good practice. The Department of Health needs to take a firm lead in making substantive changes to the way that people with a learning disability are treated in the NHS. These changes are vital to the prevention of more tragic deaths and unnecessary suffering.

The number of people with a learning disability in the UK is increasing. In particular, the number of people with profound and multiple learning disabilities is growing.<sup>2</sup> These demographic trends add weight to the need for the NHS to tackle the health inequalities that people with a learning disability

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<sup>1</sup> *Valuing People*, Department of Health (2001) p.61

<sup>2</sup> *Ibid* p.16

face – NHS staff are ever more likely to be treating people with a learning disability on a regular basis, including those with increasingly complex health needs.

## Value of life

*‘Wouldn’t it be better for everyone if we just let him go?’*

With every death and serious incident brought to our attention, the lack of value placed on the lives of people with a learning disability is implicit. It may not be recorded in medical notes, but it is unmistakably clear in the experiences that families of people with a learning disability have shared with us.



Emma’s mother, Jane, was told ‘if she had been a normal young woman, we wouldn’t have hesitated to treat her’. The mother of Daisy Healy, who died when she was just nine years old, explained how the family had assumed that hospital staff would do all they could to save her daughter: ‘everyone who met Daisy fell in love with her’. Instead, a ‘do not resuscitate’ order was organised, and Daisy’s family could only watch as she died slowly. They were given no explanation, or even a diagnosis. An independent medical advisor who looked at Daisy’s case described her medical notes as a poorly kept ‘document of her decline’ rather than an attempt to record and tackle any of the medical issues affecting her.

For the family of Tom Wakefield, the photographs of the unit where he was placed speak a thousand words.



Here, Tom’s needs were meant to be assessed, but instead Tom’s family feel he was ‘dumped’, like the rubbish that surrounded the building. The medical assessment recommended by a consultant never took place, and Tom’s health needs were ignored.

Families should never have to fight to convince doctors that their loved ones’ lives are worth saving. Assuming that the life of a person with a learning disability is a burden – both to themselves and their carers – and that it would be better for everyone if they were just ‘let go’, leads their families to absolute desperation.

The parents of Maria Manitarra found it impossible to convince the doctors that they wanted to take their daughter home after she suffered further brain damage while in hospital. Instead, they felt that doctors weren’t fighting for Maria’s life because they thought it would be better to remove the ‘burden’ she was placing



on their lives. For Maria's family, this was a shocking and incomprehensible assumption. But one they were unable to persuade the doctors was incorrect. They were never able to take Maria home, and she died in the hospital.

Many people with a learning disability do not have family and carers to advocate for them. It is vital that all NHS staff take responsibility for challenging underlying assumptions. They must give equal care and treatment to patients with a learning disability.

## Duty of care

The insidious assumption that the lives of people with a learning disability are not of equal worth results in a neglect of even basic care. Duty of care is a legal requirement due to all patients, but for people with a learning disability it is often over-looked.

Angela Leech was in hospital for a couple of weeks before she died. Her family felt the need to be with her around the clock. They complained because Angela was not given basic checks, for example, temperature and blood pressure checks. No-one checked what medication Angela was on, and staff ignored the family's questions about how her medication was being administered. Nursing staff even asked Angela's mother to assist with removing a needle from her daughter's arm. Angela's mother gave repeated reminders that her daughter needed altered textured meals, but these were ignored. The most basic care – keeping Angela clean and fed, and ensuring that her necessary medication was administered – was not provided by nursing staff. This resulted in Angela's family feeling that the only way to keep her safe was to remain at her side at all times.

Patients with a learning disability are more likely to have additional care needs. But these care needs are still the responsibility of the hospital where the person is a patient. Staff need to be able to assess the care needs of patients with a learning disability, and they must have the resources available to meet them. This may involve paying care staff or arranging additional nursing cover on the wards. If family carers want to take on caring responsibilities in the hospital environment, then staff should support them to do so, but clear definitions of exactly what they are taking on must be drawn up. Administering medication and other medical procedures should never fall to families or carers.

John<sup>1</sup> died the night his family were not able to stay with him on the ward – despite requesting permission to do so. He had a severe learning disability, but staff failed to make an adequate assessment of his needs, including fixing appropriate 'bed bumpers' to the sides of his hospital bed. He was left unobserved, and his continence pads were not changed. The required two-hourly PEG feeding tube observations were also not carried out. John was found by the tea lady the following morning, asphyxiated between the bars of his bed.

The response from the hospital where John died (which is currently being investigated by the Health and Safety Executive) abdicated its responsibility to severely disabled patients by saying that they do not have access to the necessary expertise:

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<sup>1</sup> *Not his real name*



*“like most acute hospitals, the skills of registered nurses in learning disabilities, and other professionals who have been educated and trained in these specialities and have advanced experience with these patient groups, are not readily available.”*

All health professionals must receive sufficient training to meet the basic care needs of all their patients. Staff must have access to specialist knowledge where needed. It is shocking that a hospital would view a patient’s learning disability as an excuse for not having met their care needs.

The 2004 National Patient Safety Agency (NPSA) report, *Understanding the patient safety issues for people with learning disabilities (2004)*, highlighted these issues:

*‘One carer had observed many patient safety incidents involving her son; her and her husband have to constantly advocate on his behalf. Her concerns about the risk of harm are so great, that she said “It makes me hope that he dies before we do.”’<sup>3</sup>*

All hospital staff need to be issued with formal statutory guidance that reminds them of their responsibilities in relation to duty of care for people with a learning disability. Any failures to meet the duty of care must have serious consequences. It was only when Mencap became involved that the death of Martin, who died after being left on a ward without nutrition for 26 days, was escalated as a serious incident within the trust, and the chief executive was made aware of this catastrophic failing within the hospital. Without the spotlight afforded by our report, the starvation of a young man with a learning disability on an NHS ward would not have had any consequences for staff – and no lessons would have been learnt.

## Understanding learning disability

*‘We’re not geared up for people with a learning disability’*

The move for people with a learning disability from living in isolated institutions to living in the community began over 30 years ago. The closure of the last NHS campuses will shortly be realised.

All people living in the community need access to mainstream services. But while the social care sector has been changing to reflect the de-institutionalisation of people with a learning disability, the NHS has failed to adjust to this shift. Staff still see people with a learning disability as a problem that specialist learning disability services will ‘deal with’. They must accept that people with a learning disability form a section of the community whose health needs must be met as part of the mainstream NHS.

A family carer attempted to have her daughter, who was seriously ill, admitted to hospital. They were sent away three times, told by staff that the hospital wasn’t ‘geared up for anyone with learning disabilities’. Only with the help of their GP and community learning disability team were they able to arrange admission to the high dependency unit.

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<sup>3</sup> NPSA, *‘Understanding the patient safety issues for people with learning disabilities’ (2004)*, p.12

Another family carer told us how upsetting it was when a senior consultant referred to his son as 'sub normal' while treating him. Warren's parents were similarly distressed when the radiologist treating their son asked: 'does he bite or scratch?'. This language and attitude illustrates the ignorance and fear among some members of staff when they encounter a patient with a learning disability.

Staff lack the confidence and understanding necessary when treating patients with a learning disability. The training that mainstream medical and nursing staff receive is clearly insufficient to ensure that all their patients are treated equally and cared for appropriately.

## Listening and communicating

If medical staff had listened to the concerns of Warren's parents, his appendicitis might have been diagnosed quickly enough to save his life. Instead, they were told that the clear signs of distress they were seeing in their son were 'just Warren being Warren'.



Martyn Evans was intubated while awaiting a tracheotomy. His family repeatedly requested that they were with Martyn for any attempt at extubation, as he would be distressed, and would react badly without familiar faces there to reassure him. But the hospital refused this request, and Martyn was extubated without his family present. The attempt failed, with Martyn becoming distressed. He was deprived of oxygen and had to be reintubated.

Martyn never regained consciousness. His family believe that during his last moments of consciousness he was left scared and alone, and that if they had been able to calm him, the extubation attempt was more likely to have been successful. The knowledge of family and carers should always be taken onboard by health professionals. Rather than seeing attempts to share such knowledge as a hindrance, professionals should use it to assist them to meet the needs of their patients.

The parents of one young girl were labelled 'stropky' by ward staff because of their efforts to advocate for their child. Once the label was given, they felt their comments were dismissed by those caring for their daughter, even though the staff were struggling to understand or meet her needs. The knowledge of family carers was clearly also dismissed in Mark's case, and in Warren's case. When this happens, families are left unable to advocate for their loved ones – people who are unable to articulate concerns for themselves.

Better communication improves treatment. It could save lives. There are many good practice examples, often developed by people in a learning disability liaison or health facilitation role. These tools, like the Hospital Communication Book<sup>4</sup>, or Patient Passport,<sup>5</sup> provide simple information about the person with

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<sup>4</sup> The Hospital Communication Book was originally developed by Surrey Learning Disability Partnership Board. For more information visit:

[www.mencap.org.uk/html/campaigns/deathbyindifference/hospitalcommunicationbook.pdf](http://www.mencap.org.uk/html/campaigns/deathbyindifference/hospitalcommunicationbook.pdf)

<sup>5</sup> The Patient Passport is a CD-ROM, which can be downloaded on to a PC, either at the patient's home or at a day centre. A carer, with input from the patient where possible, fills in a form on the computer. The form is then printed out and can be given to staff on admission to hospital. For more information visit:

[www.humber.nhs.uk/templates/page.aspx?id=3343](http://www.humber.nhs.uk/templates/page.aspx?id=3343)

a learning disability, including details of how they communicate, their health needs, medication and likes and dislikes. Tools like these need to be rolled out to every hospital setting. And all staff must be trained to use them effectively and with confidence.

## Diagnostic overshadowing

The most shocking case of diagnostic overshadowing that has come to our attention following the publication of *Death by indifference* is that of Carole Foster.



A woman in her 50s with a severe learning disability, Carole was admitted to hospital with suspected gallstones. Because she found the hospital setting distressing, she was sent home to await test results. Arrangements were made for her to return as an outpatient. However, due to the pain and distress she was in, Carole's behaviour deteriorated. Instead of taking into account her physical health needs, she was sectioned and taken to a mental health ward – on the same site as the hospital she had been in just a few days before. From this moment on, her family desperately tried to intervene, explaining that Carole was suspected to have gallstones, and that her challenging behaviour was caused by her pain, not her learning disability or any mental health problem.

Carole's family were ignored for five months. Carole missed her outpatient appointments because she was being held on a ward a short walk away from where her appointments were due to take place. Eventually, her family managed to persuade a member of staff to listen to them. Carole was found to have multiple gallstones, and her gallbladder had to be removed – it was infected and full of pus. She died a few days later.

The doctor who sectioned Carole and supervised her care said she was attention seeking. Carole's physical health needs were totally ignored because her behaviour was challenging – despite the fact that her behaviour was a direct result of the intense pain she was in. She was unable to express this verbally to those around her.

There are other examples. One parent told us how her daughter's heart condition was dismissed as indigestion for two years. Tom Wakefield languished on the ward that was meant to assess his needs, gouging marks into his head with his nails. Meanwhile, his family were desperately trying to tell staff that this was not how Tom would normally behave. The physical causes of his behaviour were never investigated properly. If taken seriously sooner, it seems likely that Tom would have survived.

The Disability Rights Commission has also highlighted diagnostic overshadowing as a barrier to equality for people with a learning disability in the health service.<sup>6</sup> Health professionals need to be aware of the risks of diagnostic overshadowing. They must be trained to recognise how people who do not communicate verbally may express pain and distress. This is where the knowledge of families and carers is vital – their awareness of the individual makes them more likely to notice changes in behaviour.

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<sup>6</sup> *Equal treatment: Closing the gap*, DRC (2006) pp.69-70

## Pain treatment

When communication breaks down between patients, family and NHS staff, and diagnoses are delayed, the likelihood of appropriate pain treatment being given is greatly lessened.

As highlighted in *Death by indifference*, there is an entirely false, but widespread belief among health professionals that people with a learning disability have a higher pain threshold than the rest of the population.<sup>7</sup>



Carole was in intense pain, but she received no pain treatment for nearly five months. Ten year-old Sophie Ham was in great pain, but the delay in diagnosing her 8cm brain tumour meant that she received nothing more than Calpol to alleviate it. Her parent's distress at losing their daughter is compounded by the knowledge that their little girl was in such pain leading up to her death – pain that a correct diagnosis would have prevented. Emma's mother had to go to the high court before doctors gave Emma pain treatment for the cancer she had been diagnosed with.

As these examples show, a range of factors contribute to patients with a learning disability being left without appropriate pain relief. Tools do exist to assist staff in assessing the pain of disabled patients who can't communicate verbally. Dr Claude Regnard has developed the DisDat tool at St Oswald's hospice,<sup>8</sup> and Great Ormond Street hospital has been trialling a similar tool, developed by the Royal College of Nursing, for disabled children.<sup>9</sup>

Such tools, used in conjunction with family carers' knowledge, and appropriate training, can be used to prevent unnecessary pain. Every member of staff whose role involves pain treatment needs to be aware of the potential difficulties in diagnosing pain in patients with a learning disability. This is especially important in cases that involve people with limited verbal communication. Staff must be trained to overcome issues around communication in order to bring about the best outcome for the patient.

## Role of parents/carers

The family of one young woman who died complained that they had to give round-the-clock nursing care to their loved one in hospital. Her father had to change her as nursing staff were neither checking nor changing her incontinence pads. This was obviously extremely uncomfortable and undignified for her father, but it was the only way for him to prevent his daughter sitting wet and uncomfortable for hours. When the complaint was raised with the hospital they responded that *'it is often the case that personal needs of patients with learning difficulties are dealt with by relatives or carers'*. This despite concerns raised by the National Patient Safety Agency that care in hospitals should not fall on the shoulders of family and carers.

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<sup>7</sup> D Kerr, C Cunningham and Wilson H, *Responding to the pain experiences of people with learning difficulty and dementia*, Joseph Rowntree Foundation, 2006

<sup>8</sup> For more information visit: [www.mencap.org.uk/html/campaigns/deathbyindifference/goodpractice.asp](http://www.mencap.org.uk/html/campaigns/deathbyindifference/goodpractice.asp)

<sup>9</sup> For more information visit [www.ppprofile.org.uk/index.htm](http://www.ppprofile.org.uk/index.htm)

In all the cases that we have been told about since launching *Death by indifference*, families and carers have told us that they have had to carry out caring duties such as cleaning, feeding and administering medication to patients with a learning disability during their time in hospital. One parent told us '*I worry for those people who don't have families or carers who are able to stay with them*'. A family came to Mencap because they had to give round-the-clock nursing care to their adult son. The hospital had decided he needed additional support through his admission, and asked his care home to provide staff. The care home refused, but the hospital didn't find a solution so the family were obliged to step in.

Hospital staff need to be reminded of their responsibilities to patients, including those with specific additional care needs. Hospitals need to have policies in place to assess patients who have additional needs. And they must have systems that meet these needs – including increasing staffing levels. The care should not fall on already distressed family members.

## Capacity and consent

*'If she had been a normal young woman we wouldn't have hesitated to treat her.'*



For Emma, the hospital's failure to understand capacity and consent cost her the opportunity to have potentially lifesaving treatment.

The law has recently been made even clearer with the introduction of the Mental Capacity Act, and its code of practice. But these messages need to be at the root of medical practice in order to prevent situations where treatment is not given, or where inappropriate treatment is given, under the guise of concern about consent. A misunderstanding of the law can never excuse depriving a young woman of a chance to survive.

Kathryn Lewis has severe epilepsy, but her learning disability means she doesn't understand why she needs to take medication. Staff looking after Kathryn failed to understand the law around capacity and consent and left Kathryn to decide whether she took her medication or not. Kathryn often did not take her drugs, and as a result her epilepsy became out of control, resulting in hospitalisation and severe deterioration in her health.

In another case, a needle phobic young man was nearly left without blood tests to track his diabetes, despite lacking the capacity to understand the consequences of in resisting the tests. Intervention from his family, with the help of Mencap, encouraged health professionals to put him through a needle de-sensitisation programme, which has happily worked in his case. But without his family to advocate for him, he would have been left with unchecked, uncontrolled, and therefore life-threatening diabetes, because of a lack of understanding around the law of capacity and consent.

# The scale of the problem

The failings of the health service towards people with a learning disability are finally being recognised. Ivan Lewis, the social care minister, has admitted to a 'systemic indifference' towards patients with a learning disability within the NHS,<sup>10</sup> but the scale of the problem is not yet fully understood.

Research on the mortality and morbidity of people with a learning disability indicates the scale of the inequality that this group face:

- People with a learning disability are 52 times more likely to die under the age of 50 than the rest of the population.<sup>11</sup>
- Overall mortality among people with a learning disability is three times that of the general population (even with external causes of death taken into consideration).<sup>12</sup>
- In people with a learning disability aged 20-29 years, mortality was nine times higher in men, and 17 times higher in women.<sup>13</sup>

But on both a national and local level, monitoring of the health and mortality of people with a learning disability is patchy and difficult to analyse. There is no consistent 'tag' or 'read code' for learning disability in use across the country, or even across strategic health authorities. This makes it impossible to measure both inequalities for this group, and the efficacy of schemes put in place to address them. Initiatives by government to increase equality of service and outcomes in public bodies are virtually impossible to implement effectively in healthcare for people with a learning disability.

Monitoring needs to be improved if the health inequalities of people with a learning disability are to be properly understood and tackled. The confidential inquiry into premature deaths among people with a learning disability, suggested by the government in 2001, would give a vital national picture of how widespread the issues are for people with a learning disability accessing the health service. The inquiry would find the necessary information and provide the impetus for action.

## Complaints procedures

Compounding the NHS' failing to meet the needs of people with a learning disability is a complaints procedure that neglects to resolve why such events happen, and does not generate the changes needed to prevent them recurring.

Families who enter the complaints system quickly feel they meet a brick wall. One family was told by a doctor to photocopy their daughter's notes after she died as he was so concerned over her treatment. But once the complaints procedure was enacted, he denied questioning the quality of treatment received. Medical notes

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<sup>10</sup> Channel 4 News at Noon, 12/03/07

<sup>11</sup> DRC, *Background evidence for the DRC's formal investigation into health inequalities*, 2006

<sup>12</sup> Tyrer F; Smith L K; McGrother C W, *Mortality in Adults with Moderate to Profound Intellectual Disability: A Population-based Survey*, *Journal of Intellectual Disability Research*, 51, 7, 520 – 527 (July 2007)

<sup>13</sup> *Ibid*

have gone missing, are incomplete or indecipherable, and there has even been a failure to identify members of staff involved in individuals' care.

After being frustrated by the local complaints procedures, families turn to the Healthcare Commission. Here they meet long and frustrating delays. Sadie complained about her brother's care, and found no answers at the local level. She turned to the Healthcare Commission, only to have them refuse to investigate part of her complaint. (The Ombudsman later returned this portion of the complaint to the Healthcare Commission, instructing them that it was indeed covered by their remit.). Three months and four case reference numbers later, Sadie has yet another case worker and no answers as to what went wrong with her brother's care. She is confused and disillusioned with the entire system.

Even after its lengthy process has ended, the Healthcare Commission often merely refers people back to the trust where the original complaint came from. Mark's family received a response three years after their son's death that picked up on 15 issues raised by the family, and simply referred them back to the trust that had already failed to provide answers.

More worrying than the delays and responses that fail to answer the fundamental questions, are the responses that show how imbedded the discrimination against people with a learning disability is in the health service. A quote from the paperwork concerning Tom's case following review highlights how a clinical advisor excuses poor treatment on account of Tom's disability:

*"The clinical advisor goes on to say that individuals like Tom are unique and that the medical needs of disabled people like Tom with a complex of physical and mental issues are rarely well met by generic services. He acknowledges that they are "one offs" and that the exact clinical service to meet their needs often does not exist."*



In a draft copy of the response to Warren's death, he was said to have 'suffered from learning disabilities'. This wording was changed after an intervention from Mencap. In Warren's final report it was claimed that due to his learning disability, the appendicitis would have been more difficult to diagnose 'than in a similar patient without a learning disability'. To use a patient's learning disability as an excuse for poor treatment in answering a complaint is discriminatory, but this discrimination is so imbedded that clinical advisors and staff at the Healthcare Commission simply accept it.

Complaints should be handled quickly and effectively at the local level. The response to a complaint should directly answer the questions posed by those making it. It should be written in jargon-free, accessible language, and should admit where failures have taken place – and show how changes will be made to prevent such incidents happening again.

Katie Green has learning disabilities and autism. The experience of going into hospital was traumatic both for her and her mother. Information about Katie's needs and challenging behaviour wasn't passed on, and adjustments, such as providing Katie with a side room to wait in, weren't made. Katie became very agitated. Her severe needle phobia wasn't taken into account, and at 21 years of age she was going to be put on a geriatric ward. Angie, Katie's Mum, complained, and was impressed with the response that came from the hospital.



They listened to her, admitted their shortcomings and invited Angie to help them set up a hospital-wide scheme to improve the treatment they provide for people with a learning disability. The hospital response included an 'All about me' document for patients with a learning disability to give staff information about their care, a discharge planning pathway and trust-wide guidelines on meeting the needs of patients with a learning disability.

Angie now feels confident that if Katie has to be admitted again she will receive better care, as will all other patients with a learning disability. She feels that her complaint was dealt with in the best possible way. This should be the norm, not an exceptional example of good practice.

## Training

Training for healthcare professionals, both before and after registration, that includes meaningful contact with people with a learning disability is the best way to challenge the assumptions and unknowing discrimination against people with a learning disability.

Feedback from a learning disability placement course within pre-registration nursing training shows the potential benefits:

*"Even though this is a short experience, students do seem to gain a lot from it. We have received a number of very positive comments from staff in adult settings about these students being good at working with those with a learning disability admitted for acute care."*

Prof. J Boore, University of Ulster, programme lead (adult nursing branch)

It is clear that when training in learning disability is offered, particularly post-registration, it has a poor take up. Such training needs to become mandatory to ensure that staff are equipped to treat their patients with a learning disability.

## Annual health checks

The government has acknowledged the need for health checks. But they have still not delivered them for people with a learning disability. This is despite evidence that they would have a major impact on addressing the health inequalities that people with a learning disability face, and would help them overcome barriers to access by giving them entry to the healthcare system.

Evidence from the annual health checks introduced in Wales reveals that 51% of those with a learning disability who received a health check had newly identified health needs. 9% had a serious health problem. Subsequent checks a year later identified further new health needs among 68% of people, and serious problems were identified in 11%. These figures highlight the need for health checks to take place at least once a year.<sup>14</sup>

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<sup>14</sup> DRC, [http://www.drc-gb.org/about\\_us/drc\\_wales/newsroom/news/investigation\\_exposes\\_healthca.aspx](http://www.drc-gb.org/about_us/drc_wales/newsroom/news/investigation_exposes_healthca.aspx) (November 2006)

If it is really serious about tackling the health inequalities of people with a learning disability, the Department of Health needs to make implementing annual health checks across England a priority.

## Learning disability liaison nurses

People with a learning disability also need ‘champions’ when accessing healthcare services. Learning disability liaison nurses, sometimes called health facilitators, assist with admissions, help to assess needs and give help and advice to ward staff on meeting the needs of patients with a learning disability. These specialists can challenge preconceived notions of learning disability, and help to ensure that the lives of these patients are valued.

### ***What is a learning disability liaison nurse?<sup>15</sup>***

The role focuses on improving access to hospital services for people with a learning disability.

The specific tasks this involves include:

- training
- developing protocols, care pathways, and guidelines for good practice
- developing and adapting systems (e.g. ‘trigger’ or flagging systems to alert pre-admissions and discharge services that someone has a learning disability)
- liaising with patient advice and liaison services (PALS) within hospitals
- developing resources (e.g. information and resources for hospital staff, traffic light systems, patient passports, accessible information for people with a learning disability)
- direct patient contact (e.g. preparation and planning before hospital admission, clinical advice, interventions, co-ordination, risk management, and promoting, modelling and producing personalised accessible information).

Too often, these posts are on short-term, part-time contracts, despite indications that it can take three years for the role to become established. The role needs to imbed a change of practice and culture among all staff – short-term posts are not likely to have this impact.

Mencap asked a group of learning disability liaison nurses what impact they felt a role such as theirs could have played in the six deaths described in *Death by indifference*. All felt that an intervention would have been possible:

*“In the cases described ... the liaison nurse would have flagged the issues earlier and would have been able to assist the acute service staff in looking at ways of accurately assessing pain and distress, managing difficult behaviour and making decisions about best interest treatment.”*

Family carers also let us know the value they placed on such posts:

*“I feel strongly that learning disability liaison nurses working within a hospital setting is a giant plus for all services. It would be invaluable for my brother to know that he is able to communicate to someone who fully understands and can correlate his care. It would not be undermining the staff, but enabling them to provide good practice.”*

<sup>15</sup> Manchester Learning Disability Partnership, ‘Access to secondary healthcare for people who are learning disabled’ (July 2007) p.18

# Conclusion

That people with a learning disability experience serious inequalities when accessing the health service has long been recognised. The actions needed to address these inequalities, many of which are highlighted above, have also been laid out clearly for many years. What has been missing is the political will to address the inequalities, and implement the necessary changes across the health service.

It has taken the deaths of Emma, Mark, Martin, Ted, Tom and Warren to bring about an inquiry into the inequalities people with a learning disability face in the NHS. The unnecessary pain and deaths of yet more people are detailed in this submission. To ensure that people with a learning disability have their health needs met, the Department of Health must take the lead on this issue. It must make sure that tackling these inequalities is a priority at every level of the health service.

All those who have contacted Mencap to tell the stories of their loved ones have done so in the hope that sharing what has happened will prevent others suffering in the same way. We hope that including these stories in this submission will lead to recommendations that, if implemented by the Department of Health, will make a real difference to the healthcare experiences of people with a learning disability.

Quite simply, there are no more excuses for inaction – people with a learning disability have a right to equal healthcare. It is time the NHS made the changes necessary to fulfil this right.