



# Treat me right!

Better healthcare for people with  
a learning disability

**MENCAP**  
*Understanding learning disability*

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This report covers England and Northern Ireland. The policy context relates to England, but the policy direction is similar in Northern Ireland.

In England the main local organisation responsible for healthcare is the Primary Care Trust. In Northern Ireland, Health and Social Services Boards have responsibility for commissioning and ensuring the provision of health and social care services for their local populations.

In Northern Ireland, there is little guidance available on how health services should meet the needs of people with a learning disability. *The Review of Mental Health and Learning Disability*, currently taking place in Northern Ireland, includes the physical health of people with a learning disability in its work programme.

In Northern Ireland, the framework for improving health – and for combating inequalities in the services provided – is outlined in *Investing for Health*. Health and Social Services Boards are required to produce health and well-being investment plans and to work in partnership with other statutory agencies, public bodies, local communities and voluntary organisations. The emerging Local Health and Social Care Groups are viewed as having a key role to play in the development of the new primary care strategy and in commissioning some health and social services.

Please note that, in the case studies in this report, the names of the people involved have been changed to protect their identity. The photos are for illustrative purposes only and use models.



# 1. Introduction

There is widespread agreement that people with a learning disability have poorer health than the rest of the population. There have been many policy reports and recommendations about how to improve this situation. So why is it that very little has actually changed?<sup>1 and 2</sup>

***Treat me right!*** seeks to engage with everyone involved in improving the health and the healthcare experiences of people with a learning disability. It summarises what is known about their health needs and looks at what is actually happening when people seek health service support.

***Treat me right!*** aims to build support for the changes that are needed, by proposing recommendations that will make a real difference.

***Treat me right!*** wants the health of people with a learning disability to be visible to public health practitioners when they assess the whole population's health and take action to improve the health of the worst off.

***Treat me right!*** argues that professionals in all healthcare sectors need to show that they can do things better and rise to the challenge of improving the health of people with a learning disability.

***Treat me right!*** is a wake up call to the NHS. Through real stories, ***Treat me right!*** confirms sobering national and international research findings about the health of people with a learning disability. It shows that urgent action is needed to improve the health of people with a learning disability.

## Max

*“Why would nobody listen to us when we told them there was something terribly wrong? At times it seemed that the doctors didn't care whether Max was suffering. Had they treated him with more care, I truly believe he would be alive today.”* Alison, Max's mother

### Max's story:

“My son Max was thirty years-old when he fell and broke his hip. A few weeks later he died in hospital. Had he received adequate care, I believe he would still be alive today.



*Max's story continued...*

Max lost a great deal of blood during the operation on his hip. He was given blood afterwards, but the nursing staff forgot to give him his epilepsy medication. His body began to convulse. Max's father and I told the doctors that we thought he was fitting due to the loss of blood and lack of replacement medication. But the doctors insisted that he was just reacting to the operation.

It was awful to see Max in so much distress. For twelve days we kept going in to the hospital to find him moaning and punching himself in the face. We had never seen him like this. He was allowed home with us, but he didn't settle. We knew something was terribly wrong. Max was readmitted to hospital.

It was three days before the pain team saw Max. In this time, I spent every day with him to make sure that he was properly cared for. The hospital staff had had trouble administering his epilepsy medication on his first morning, and so they left his tablets by his bed. Had I not noticed this, he would not have had any medication at all. Eventually Max was sent home again after being given stronger painkillers and drugs for a urinary infection.

We had Max at home for a week, but he was moaning and slapping himself all over. He didn't sleep at all. It was still clear to us that he was in acute distress. He really started to deteriorate. My husband and I had had no sleep for weeks because of the non-stop noise and moaning from Max. It was completely out of character for him, but it seemed nobody could tell us what was wrong. Then he stopped eating and lost weight rapidly. He developed a high temperature and was having fits.

A few days later I made the decision to call an ambulance and get Max back into hospital. He was taken straight to a resuscitation ward where it was found that his kidneys were failing. He was also malnourished. The next day he was taken into intensive care and put on a respirator. That morning he suffered a cardiac arrest. He stayed in the intensive therapy unit for two weeks, where they worked hard and showed genuine care and concern for his well-being. However, he had picked up septicaemia and the doctors decided that he would not be able to recover from this.

Nobody noticed that Max had developed a kidney problem, or that he was malnourished, until he got to the intensive therapy unit. That's what killed him. Surely somebody should be able to recognise trauma in a hospital? Why would nobody listen to us when we told them there was something terribly wrong? At times it seemed that the doctors didn't care whether Max was suffering. Had they treated him with more care, I truly believe he would be alive today."

Everyone would agree that Max's story is terrible and tragic. But the key question to ask is this: was this just an unfortunate, one-off situation that could have happened to anyone, regardless of the fact that he happened to have a learning disability? Or, as Mencap believes, is the catalogue of poor treatment that led up to Max's death something that happens far too often to people who have a learning disability?

*Treat me right!* will look at the reasons why Mencap believes that the latter is really the case. And it sets out what we think should be done to make sure that people with a learning disability get the treatment they need to live longer, healthier and fulfilling lives.





Outpatient		
<b>5</b> Blood Tests		
<b>4</b> <b>ENT</b> - Allergy Clinics - Oral Surgery 4B - Audiology - ENT	4B - Eye Clinics - Speech Therapy 4C - Women's Health	
<b>3</b> This Level	<b>Clinics</b> ← 3B - Medical Clinics - Paediatrics ← Appointments ← Pharmacy (consulting)	- Medical Clinics - Cardiac Invest - ECG & EEG Green Zone 4D - Children's Orange Zone
<b>2</b>	<b>Ambulance &amp; Emergency</b> CT Scanner MRI Scanner X-ray	Way In/Exit Way Out & Drop-off
<b>1</b>	<b>Clinics</b> 1A - Medical Clinics 1B - Fracture Clinic CAMDOC ES&S	GP X-ray Nuclear Med Pharmacy Ultrasound

## 2. What do we know about the health of people with a learning disability?

It is generally accepted that people with a learning disability have poorer health than the rest of the population. This section of the report will look at the reasons for this.

### a) An increased risk of early death

We know that people with a learning disability are much more likely to die before the age of 50<sup>3</sup> and that life expectancy is shortest for people who have the most support needs<sup>4</sup>. We also know that the leading causes of death differ from those of the rest of the population<sup>5</sup>. In fact, people with a learning disability:

- are three times more likely to die from respiratory disease<sup>5</sup>
- have a higher risk of coronary heart disease (the second most common cause of death)
- have higher rates of gastrointestinal cancer and stomach disorders.

These are certainly startling facts. But they do not totally explain the disproportionately high number of early deaths. We need to know much more about the causes and the reasons why people with a learning disability are at risk of becoming ill or dying from these conditions.

### b) A higher prevalence of certain medical conditions

We know that people with a learning disability experience a greater variety, complexity and range of health problems than the rest of the population. This leads to a greater risk of poorer health<sup>6</sup>. These conditions include<sup>7</sup>:

- **Epilepsy** – 22% of people with a learning disability, compared to 1% in the general population, have epilepsy.
- **Dementia** – 21.6% of people with a learning disability, compared to 5.7% of the general population, have dementia. People with Down's syndrome are also at a high risk of developing it younger.
- **Schizophrenia** – 3% of people with a learning disability, compared to 1% of the general population, have schizophrenia.
- **Thyroid problems** – people with a learning disability have a greater risk of having thyroid problems, particularly those with Down's syndrome.



- **Osteoporosis** – people with a learning disability tend to have osteoporosis younger than the general population and have more fractures.
- **Sight problems** – people with a learning disability are more likely to have sight problems.
- **Hearing problems** – 40% of people with a learning disability have hearing problems.
- **Poor dental hygiene and dental care** – 36.5% of adults and 80% of adults with Down's syndrome have unhealthy teeth and gums.
- **Underweight or overweight** – people with a learning disability are more likely than the general population to be either underweight or overweight.
- **Mental health problems** – one in three people has problems with their mental health.

### c) Being part of a disadvantaged group in society

There is plenty of evidence that people from disadvantaged groups have more illnesses and have shorter lives than those who are well off.<sup>8 and 9</sup> People with a learning disability are disadvantaged in society. Children with a learning disability often go to segregated schools, while many adults go to day services and live in segregated accommodation. People with a learning disability are generally poor – living on benefits or a low income. It is also acknowledged that people with a learning disability who are from an ethnic minority are at an even greater disadvantage<sup>10</sup>.

### d) Having unhealthy lifestyles

Much is also known about the unhealthy lifestyles of people with a learning disability. Many live in residential care homes, supported living, or with their families – where they are dependent on others to enable them to lead active lives and take part in sports and leisure activities. As a result, many people with a learning disability have a sedentary lifestyle and so are more likely to be overweight than the general population. They are also dependent on others for what they eat. Less than 10% of adults with a learning disability eat a balanced diet; while more than 80% do less physical activity than is recommended. A lot of good quality accessible material has been produced on healthy living. If you want to know more about this, please go to the Mencap healthy lifestyle factsheet on the *Treat me right!* website: [www.mencap.org.uk/treatmeright](http://www.mencap.org.uk/treatmeright)

Of course, all these factors are important in assessing why the general standard of health among people with a learning disability is so much lower than the rest of the



population. But there is a danger that they could be used as an excuse for not dealing with the fundamental issue: namely, that many people with a learning disability have a poor experience of using health services. The next section of *Treat me right!* looks at some of these experiences.





### 3. Experiences of using health services

There has been limited research into the experiences of people with a learning disability using primary (GPs, dentists etc) and secondary (hospitals) health services. A report by the British Institute of Learning Disabilities (BILD) commissioned by the Department of Health (DOH)<sup>11</sup> provided a useful analysis of current hospital provision. It identified poor communication, fear and distress, together with poor quality of care, as the key problems.

To get the views of people with a learning disability, we carried out a survey of nearly 1,000 people with a learning disability. This showed generally high levels of satisfaction with the service received. But it also threw up cases of poor experiences – some of which are detailed in this report. [The response may in part reflect the low reporting rates and unidentified health problems of people with a learning disability and their tendency not to complain.] The main contrary finding was in respect of stays in hospital, and this is mirrored by the case studies in this report. It is also the case that for the population generally, satisfaction surveys show a very positive response, even though some people do suffer from poor treatment.

This part of the report will tell the stories of some people with a learning disability who have had a poor experience of using health services. We are including these to explore the reasons why people encounter these problems.

#### **a) Specialist or mainstream: whose responsibility is it?**

Thirty years ago 60,000 people with a learning disability lived in long-stay hospitals. It was seen as the hospital's responsibility to meet their health needs. These hospitals were regarded as specialist learning disability services. As a result mainstream health services did not see (and some still do not see) people with a learning disability as being their responsibility. In some areas Community Learning Disability Teams (CLDTs) have tried to take on this role and provide, in effect, a parallel service to mainstream services.

This approach has isolated people with a learning disability from the help they need from mainstream health services. It has also resulted in many healthcare professionals having little understanding of learning disability.

Sarah's story on the next page illustrates this unfortunate turn of events.



## SARAH

*“I didn’t understand why Sarah couldn’t be seen by her GP like everybody else...She doesn’t understand why she was treated this way.”*

Mandy, Sarah’s carer

Sarah’s story:

“Sarah went to see her GP three times with an incontinence problem. Twice she was given antibiotics and told that it was probably a urinary infection. Finally, on her third visit, she was examined. A urine sample showed that there was no infection after all.

I asked on Sarah’s behalf whether she could be seen by a continence nurse within the doctor’s surgery. I was told that there was no continence nurse in our area, and that because Sarah had a learning disability, she would have to be seen by someone from the learning disability team. This seemed unusual. I didn’t understand why Sarah couldn’t be seen by her GP like everybody else.

The learning disability team assured me that Sarah should of course be seen by her GP. So I was shocked when the surgery didn’t seem prepared to treat Sarah, and referred her back to the learning disability team. They said that Sarah would then have a named nurse who would be trained to communicate with people with a learning disability. When I explained this to the learning disability team, they said that the surgery was passing the buck. Meanwhile, Sarah was still suffering. It seemed nobody wanted to help her.

I went back to the GP surgery and told them that I didn’t think Sarah’s needs were being met. I insisted that she should have the same access to good health care as everybody else and that there was no need for her to be treated separately.

Finally, after quite a fight, Sarah has received an appointment to see a continence nurse, having been told all those weeks ago that there was no such service in the area. She doesn’t understand why she was treated this way.”

## **b) Access to GPs and other primary health practitioners**

The evidence suggests that a GP with a list of 2,000 patients will have about 40 with a learning disability. Of these 40 about eight will have severe learning disabilities and the remainder will have milder disabilities<sup>12</sup>. Given that nine out of 10 contacts that people have with the health services are with primary care – such as the GP – it is very important that these services are able to meet the needs of people with a learning disability.

Mencap commissioned research<sup>13</sup>, which found that of 215 GPs:

- **75% had received no training to help them treat people with a learning disability**
- **90% felt that a patient's learning disability had made it more difficult for them to give a diagnosis.**

These findings are backed by those of the NHS Executive (1999)<sup>14</sup>, which stated that primary care teams reported feeling poorly equipped to work with patients with a learning disability. There is a wealth of evidence to suggest that the impact of this has – unsurprisingly – resulted in people with a learning disability having poor access to primary healthcare services<sup>15</sup>. There is also a low reporting of illnesses and symptoms among people with a learning disability. This places them at risk of misdiagnosis and of getting inappropriate treatment or no treatment at all<sup>16</sup>. It is also known that health screening of adults with a learning disability registered with GPs reveals high levels of unmet physical and mental health needs.

## **c) Assumptions and attitudes**

Many families of people with a learning disability report that some doctors look at their son or daughter and – consciously or unconsciously – believe their health problem is as a result of the learning disability and that not much can be done about it. This is a dangerous assumption to make: it can lead to undiagnosed or misdiagnosed conditions. This has been well documented by the Down's Syndrome Association<sup>17</sup> and also by the National Patient Safety Agency (NPSA)<sup>18</sup>. It is sometimes called 'diagnostic overshadowing' and is described as "dismissing changes in behaviour, personality or ability that would be taken very seriously in a person without a learning disability."<sup>19</sup>

Simon's and Laura's stories on the next page illustrate this point well.



## SIMON

*“His GP told us: ‘That’s just the way they are sometimes. Just take him home.’”* Stephanie, Simon’s mother

### Simon’s story

“We knew there was something wrong with Simon. He was scratching his face and screaming and seemed extremely distressed. So we took him to see his GP, who couldn’t find anything the matter. We kept saying that we thought he must be in pain. But he just wouldn’t listen. He told us: ‘That’s just the way they are sometimes. Just take him home.’ Luckily, the dentist took more time to examine Simon and found that he had an abscess. I hate to think how much pain he must have been in.”

## LAURA

*“I asked one of the nurses why Laura wasn’t speaking. She looked surprised and said: ‘Can she speak?’”* Sally, Laura’s support worker

### Laura’s story:

“Laura was a very active, independent woman when I first knew her. That all changed when she went into hospital last year for an emergency operation.

When I went in to visit Laura after her operation, I wasn’t surprised at first that she wasn’t talking at all. She’d been through a major operation and I thought she must be still in recovery. I expected the old Laura to be back before long. But over the following two days I got more and more worried because she wasn’t improving at all. And she didn’t say a word, no matter how much I chatted to her.

On the third day I asked one of the nurses if she knew why Laura wasn’t speaking. She looked surprised and said: ‘Can she speak?’ I told her that Laura could speak as well as anybody else. There was no reason for anybody to assume otherwise.

I went back in to see Laura and I offered her a pen and paper, thinking that she might be able to communicate with me that way. Laura couldn’t even hold the pen. When I saw the pen roll on to the floor, I suddenly thought, oh my god, she’s had a stroke. Two days later, the doctors confirmed that Laura had suffered a stroke during her operation.”



## d) Training and skills

Some of the medical conditions known to be associated with having a learning disability can be prevented. Most of these conditions can be successfully treated. But this depends on health services being vigilant in diagnosing them. It is also vital that health services know about the nature and characteristics of these conditions.

### CATHY

*“Cathy has been wearing a hearing aid ever since she went along for a hearing test. There was nothing wrong with her before she went.”* Lorraine, Cathy’s carer

#### Cathy’s story:

“Cathy went along for a hearing test because she had been experiencing a little discomfort. It should have been a routine procedure, but the audiologist didn’t know that people with Down’s syndrome have short, straight ear canals. He pushed the otoscope too far into her ear and perforated her eardrum. The perforation was irreparable and she’s been wearing a hearing aid ever since.”

The NPSA report also drew attention to the lack of awareness among health and social care staff of the symptoms of aspiration pneumonia and the risk of death caused by swallowing difficulties. Problems with eating and drinking can be life-threatening. They can lead to respiratory tract infection, which is a leading cause of death for people with a learning disability.

Effective communication skills are also a vital part of diagnosis and treatment.

### JAMES

*“We had to go to the optometrist four times before we were finally taken seriously. James has now been registered blind.”* Mary, James’ mum



### **James' story:**

“James kept telling me that he could see a ‘funny black thing’. I took him along to see the optometrist, but he didn’t seem to take us seriously. I knew that there was something wrong, so I kept taking him back. On our fourth visit, James said: ‘Black blob bigger’. This finally prompted the optometrist to have a look at the back of James’ eyes. He found two detached retinas, which it has so far not been possible to repair. James has now been registered blind.”

James’ story shows us how crucial it is that health professionals understand about the different ways that people with a learning disability may communicate. They need to understand that people with a learning disability may find it hard to communicate their symptoms and to understand what they are being told. Sometimes this can result in people with a learning disability not complaining of a health problem at all, or being unable to describe their symptoms accurately. It is known that there is a low reporting of illnesses and symptoms among people with a learning disability and that they are at greater risk of misdiagnosis or inappropriate treatment<sup>20</sup>. For some this may mean putting up with a lot of pain and discomfort before they get the help they need. For others it may be far more serious, as Cathy’s and James’ stories illustrate. In some cases, lives are put at risk – for example, when cancers go undetected until a late stage.

### **e) Poor quality of care**

There are problems with treatment in hospital because nurses and doctors often do not understand the needs of people with a learning disability. There have been cases of people with a learning disability being neglected because they are unable to tell staff they are in pain or something is going wrong with an intravenous drip.

## **ANTHONY**

*“We had to stay with Anthony from 10am to 10pm because no one was feeding him.”* Diane, Anthony’s mum

### **Anthony’s story:**

“I still find it very upsetting to recall the way Anthony was treated in hospital. The nurses had no idea how to meet his needs, and had I not stayed with him I think he may have died.



Anthony was admitted as an emergency patient but they kept him in for a month. We were extremely worried about him. He was very ill and could barely move. When we arrived in the mornings to visit him, we would find that his breakfast and morning drink had been left out of his reach. It was really important that he took in lots of fluids, but if we weren't there to feed him, his food was taken away untouched.

We kept on stressing the kind of care Anthony needed. But it soon became clear that if we left him, nobody would take over. Anthony's younger sister, who is also disabled, had to come along to the hospital with us because there was no one at home to care for her. We had to stay with Anthony from 10am until 10pm. We were all exhausted.

Eventually the hospital found somebody to come in and help with Anthony. But by then we were furious at the way Anthony's needs had been disregarded.”

The BILD report found a lot of evidence to suggest that Anthony and his family are not alone in this experience<sup>21</sup>. They found that there were particular problems around feeding, resulting in some patients not getting food or drink. Ward staff had low expectations for patients with a learning disability and were unresponsive to their needs. As a result, they failed to manage bedsores, or to ensure that they were getting enough food and water. There were examples of a lack of attention to epilepsy and a failure to prescribe appropriate medicine. The lack of adapted facilities resulted in one patient with profound and multiple learning disabilities going six weeks without a bath.

In addition, there is the fundamental problem that most hospitals expect parents or care home staff to provide basic care in hospital. Parents (and care home staff) often feel they have no choice but to provide this care, because otherwise their son or daughter might starve or come to harm. In fact, hospitals have a 'duty of care' to all patients while they are in their care. The NPSA report<sup>22</sup> has identified this as a major patient safety issue.

These are extremely serious issues. In the worst cases, the consequences are fatal – as Katherine's story on the next page shows.



## KATHERINE

*“Katherine was only 30. I feel angry that she died so needlessly.”*

Patricia, Katherine’s friend

### Katherine’s story

“Katherine was only 30 when she went into hospital for the last time. She was suffering from chest problems and needed to be admitted for a number of weeks. The hospital was aware that she had severe epilepsy and that she needed medication to control her fits.

After a few weeks, Katherine was put on an intravenous drip. Tragically, the hospital staff forgot to include Katherine’s epilepsy medication in the drip feed, which led to Katherine having a violent and prolonged fit. She died needlessly as a result.”

## f) Discrimination

It is hard to know the extent of the discrimination faced by people with a learning disability when they are trying to access health services. It is also difficult to determine to what extent such experiences can be explained by a lack of understanding and training among healthcare professionals. But there is a body of opinion that it could be due to discrimination involving value judgements by healthcare staff about the worth of people with a learning disability.

The following story is a good example of the kind of discrimination some people face.

## VICTORIA

*“I overheard the doctor say, ‘that’s not coming in my room.’”*

Jean, Victoria’s mum

### Victoria’s story:

“I was appalled at the lack of respect my daughter was shown by the doctor who was to carry out her kidney scan. We were waiting in the corridor and we overheard him say: ‘That’s not coming in my room. It will destroy the equipment.’ I asked him directly if he was



referring to Victoria and of course he denied it. I told him that I felt that this was discrimination and that I would complain to the chief executive. The ward sister came to tell us the scan would go ahead, but they all made it quite obvious that we were not welcome.”

A report by the Down’s Syndrome Association (DSA)<sup>23</sup> listed a catalogue of discriminatory behaviour and actions against people with a learning disability. About half of those with Down’s syndrome have a congenital heart problem and many could have their life prolonged by treatment at an early age. In the DSA report a mother of a 17 year-old says: *“We were told that our son’s heart condition was inoperable. We now know this to be untrue”*. Another parent of an eight year-old was told that *“it would cost at least £10,000 for heart surgery”* and that they would *“rather spend that sort of money on a ‘normal’ child”*.

In 2001, a report was published into allegations made against the Royal Brompton and Harefield Hospitals that children were refused heart surgery because they had Down’s syndrome. The inquiry, chaired by Ruth Evans, former Director of the National Consumer Council, found that some doctors had failed to take a ‘balanced’ view. As a result, the report claimed, some children with Down’s syndrome were less favoured. The Department of Health said that even if discrimination had not been deliberate, that was the effect of the doctors’ attitudes.

## VICTORIA

*“He didn’t know our lovely 33 year-old daughter and all the quality of her young life.”* Jean, Victoria’s mum

### Victoria’s story:

“Victoria was rushed into A&E after a series of seizures. She wasn’t responding to medication and needed to be put on a ventilator. The doctor came up and spoke to us. It took me a moment to realise that he was questioning whether we should go ahead with treating Victoria. He was suggesting that it wasn’t worth trying to save her. He didn’t know our lovely 33 year-old daughter and all the quality of her young life. I sometimes wonder what might have happened if I hadn’t told him how good her life was when she was well, about her social life and the people who love her.”

Victoria’s story is not an isolated one. There have been repeated allegations of denial of treatment to people with a learning disability.



## SAM

“We think they tried to kill Sam.” George, Sam’s dad

### Sam’s story:

“Sam was rushed into hospital after visiting his GP with an enlarged testicle. Further tests soon confirmed that he had testicular cancer. He suffered a massive haemorrhage after his first operation and had to be rushed back in to surgery the following day.

We were amazed when the doctor started to suggest to us that it might be time we started to consider our own quality of life. He queried whether it was in our best interests to allow the surgery to go ahead.

We now wonder if he was trying to justify all that happened after that. You could explain their treatment of Sam as incompetent or neglectful, but that is not how we see it. He was on a drip, but we didn’t know that all he was receiving was basic salts. During the three weeks he was in hospital our six foot-tall lad went down to seven stone. He lost so much of his body weight that he nearly starved to death. We think they tried to kill Sam.”

### g) ‘Do not resuscitate’ notices

The most extreme form of denying treatment can be in the form of ‘do not resuscitate’ notices (DNRs) or the failure to make life saving interventions. There is evidence of doctors making value judgements about the quality of life of people with profound and multiple learning disabilities, and assuming that it would be in their best interests to die.

## NASRIN

*“They told me that my baby daughter had Edward’s Syndrome. At the same time they discussed putting a ‘do not resuscitate’ order in her notes.”* Sosan, Nasrin’s mum

### **Nasrin's story:**

“As soon as Nasrin was diagnosed with Edward's Syndrome, when she was five weeks old, I felt that the medical profession lost interest in saving her life. She had been born very small and up until that point they had been weighing her every morning. This stopped straight away. They told me that Edward's syndrome was ‘incompatible with life.’ It was a devastating way to be told that your baby will die.

At the same time as they gave me the diagnosis, they discussed putting a ‘do not resuscitate’ order in Nasrin's notes. I was still in shock. I didn't want my baby to suffer unnecessary medical treatment just to prolong her life for a short while. But I also believed that Nasrin's life was not being valued enough. I felt bullied into giving my consent while I was still coming to terms with what I'd been told.

Shortly afterwards, Nasrin contracted a respiratory virus. I could see that she was in a great deal of pain and the consultant asked for an immediate x-ray to determine the cause of the swelling in her tummy. But this didn't happen. I can't find out why they didn't think it necessary to x-ray my little girl. She was left with peritonitis.

Nasrin went into surgery later that night and afterwards into an intensive care ward, where she seemed to do well. However, the hospital was short of beds in intensive care and wanted Nasrin's bed for someone else, so moved her to a high dependency unit. She should never have been moved. Her condition was dangerous in a small child and she needed to be in intensive care. She died the next day.

I think the medical profession should question whether it is ever right to put a ‘do not resuscitate’ order in a baby's notes. It makes an assumption about the quality of a disabled baby's life. Nasrin's life may have been different. How can we judge the quality of another's life and the joy they bring to those around them? It should also be understood that it is inappropriate to discuss a ‘do not resuscitate’ order with a mother while she is so distraught by the news that her baby has not long to live.

I believe that Nasrin was the victim of a series of neglectful acts. If she'd stayed in intensive care, none of this would have happened. If she'd been a child without her level of disability, she would have received serious care. I can't help feeling that they gave this other person Nasrin's bed because she was disabled and would die young anyway – so why waste time? Nasrin deserved better than that.”





## 4. What should be done?

Much of what needs to be done to improve the health and the healthcare experiences of people with a learning disability has already been clearly set out within existing policy documents and guidance.

The National Health Service was created to provide comprehensive health support for all people. It has always had responsibility for people with a learning disability. Furthermore, the specific policy aim of enabling people with a learning disability to use mainstream health services is not new. This policy aim has been clearly stated since 1992<sup>24</sup> and subsequently laid down for the NHS in numerous documents, such as *Signposts for Success*, *Once a Day, All Means All*, and *Valuing People*. For further detailed information about this, visit the *Treat me right!* website: [www.mencap.org.uk/treatmeright](http://www.mencap.org.uk/treatmeright)

Despite this, many people with a learning disability still have poor health – due in no small part to unequal access to healthcare services. In some tragic cases, the result is premature death.

In Northern Ireland, there is limited reference within wider health policies to how the needs of people with a learning disability should be met. *The Review of Mental Health and Learning Disability*, currently taking place in Northern Ireland, has included the physical health of people with a learning disability within its work programme. The government's framework for improving health and for tackling health inequalities is outlined in *Investing for Health*.

The argument made in these policies has also been reinforced by the need to comply with the Disability Discrimination Act (DDA). This requires organisations to make 'reasonable adjustments' to ensure that people with a disability are not excluded from services and do not get worse services than people without a disability.

Mencap supports these policies and believes that there are some key actions that can be taken to develop good practice and ensure the delivery of good healthcare for people with a learning disability.

### a) Better training in learning disability for all healthcare staff

Many of the disturbing experiences described in this report happened because of the lack of training and skills among healthcare staff in dealing with people with a learning disability. Staff should receive general disability awareness training so that they have the opportunity to examine their attitudes and values toward people with a learning disability.



Karen's story below shows how important it is that staff have this training.

## KAREN

### Karen's story:

"The hospital which admitted Karen had drawn up its own guidance detailing how to care for people with a learning disability in hospital. But none of this was followed. We talked through Karen's needs and routines with the admissions nurse, but this information wasn't passed from one nurse to another as they changed shifts. In the end we had to stay at the hospital to make sure Karen would survive."

Bill, Karen's father

**Mencap's survey confirmed the need for more training: 80% of GPs surveyed thought the Department of Health should provide medical students and practitioners with more training.**

**Two thirds of GPs surveyed thought the most useful type of training would be practical training involving people with a learning disability.**

It is only with good support and training that discriminatory attitudes and behaviour can begin to change. Good communication skills are absolutely essential for two reasons: firstly, so that staff can use a broader range of communication methods with people with a learning disability; and secondly, so that they can understand the importance of listening to people's families and carers (who know them best). This report has also set out information about the medical conditions that people with a learning disability may be vulnerable to. Healthcare staff need to understand these conditions and be able to identify them.

### **b) Longer and more flexible appointments**

Many people with a learning disability and their families say that longer appointments would help them a great deal.



## IBRAHIM

### Ibrahim's story:

“My GP is always in a rush. I'd like him to take more time when he sees me. I feel rushed because I don't have enough time to explain what's wrong and I don't always understand what he says to me. He doesn't ever ask me if I have any questions, nothing like that. It's just rush, rush, rush.”

For those with severe or profound learning disabilities, a long delay is particularly stressful. Some surgeries have tried – with success – to schedule first or last appointments. They have also been able to be flexible in a way that has transformed the health experiences of the people they see.

### c) Accessible information to be provided in all healthcare settings

People with a learning disability would benefit greatly from a range of communication aids and patient information provided in an accessible, easy-to-read format. Mencap's commissioned survey showed that 70% of GPs did not have accessible information in their surgeries. The NPSA has also highlighted a particular concern about a lack of accessible information on medication.

There have been some very successful projects and publications on the subject of producing information in an accessible format. These practices should be developed more widely in healthcare services. For more information go to the *Treat me right!* website: [www.mencap.org.uk/treatmeright](http://www.mencap.org.uk/treatmeright)

With regard to people with profound and multiple learning disabilities, health professionals may need to take advice about the best way to communicate information. To do this, it is absolutely vital to listen to parents and carers and to respect their knowledge and experience.



## EDWARD

### Edward's story:

“When Edward came to the clinic we were aware that he had diabetes. He seemed to understand what was being said as he nodded and said ‘yes’ all the time. No-one double checked this, so he left the clinic being expected to inject himself with insulin.” Sandra, learning disability practice nurse consultant

### **d) All screening programmes to ensure that people with a learning disability have the same access rate as others**

Women with a learning disability are about four times less likely to undergo cervical smear tests than the general population<sup>25</sup>. They are also less likely to have breast cancer examinations or be invited to attend for a mammogram. This situation must change. There are many ways to support people with a learning disability through these procedures. For example, they should be well prepared as to what will happen. There is more information about this on the *Treat me right!* website: [www.mencap.org.uk/treatmeright](http://www.mencap.org.uk/treatmeright)

## MELANIE

### Melanie's story

“I found it strange that Melanie wasn't called for breast screening like her older sister. Why is she treated any differently?” Jane, Melanie's mum

### **e) Identification on health records that someone has a learning disability**

It is not always obvious that someone has a learning disability. This can result in overestimating their ability to understand and co-operate in health settings. So it is vital that medical records identify that someone has a learning disability. One way of doing this is by using an appropriate code, in this instance ‘read code E3 (learning disability)’<sup>26</sup>.

This is a very useful way of ensuring that this essential information is picked up. It would help GPs and hospitals plan ahead so they put in place appropriate levels of care.

**f) Tackle health inequalities by ensuring the Health Equity Audit addresses how well people with a learning disability are accessing mainstream services and proposes action to reduce the gap in life expectancy**

*Tackling Health Inequalities – A Programme for Action* (DOH 2003) identified the Health Equity Audit as a key tool to drive this forward in the health service. Primary Care Trusts (PCTs) are the local bodies that have responsibility for this, while the NHS Planning and Policies Framework for the period 2003-2006 includes the requirement for services to be informed by a Health Equity Audit and a public health report. The NHS guidance on Health Equity Audit for PCTs makes it clear that they should address health inequalities by aiming to narrow the gap in health outcomes between:

- social classes
- geographical areas
- men and women
- black and ethnic minority groups
- age groups, particularly infants and children, and the over 50s
- vulnerable groups and those with special needs.

Of this last group, the guidance says that they “might include: rough sleepers and homeless people, including homeless families with children in temporary accommodation; prisoners and their families; refugees and asylum seekers; looked-after children and care leavers; vulnerable people with mental health problems, chronic conditions, physical or learning disabilities.”

## **IBRAHIM**

“Sometimes I have to wait a week to see my GP, and even then he doesn’t take the time to treat me properly. He just asks what’s wrong and then writes a prescription.”

The Government’s programme for tackling inequalities must be used as a lever for bringing about real improvement in the health of people with a learning disability. *Tackling Health Inequalities – a Programme for Action* states under delivering change: “work to implement the recommendations of the *Valuing People* White Paper to tackle the health inequalities for people with a learning disability”. The lead agency at a local



level is the PCT, and they now need to rise to the challenge of tackling the disadvantages faced by people with a learning disability.

In Northern Ireland the Government's framework for tackling health inequalities is outlined in *Investing for Health*. Health and Social Services Boards are required to produce health and well-being investment plans and to work in partnership with other statutory agencies, public bodies, local communities and voluntary organisations. The emerging Local Health and Social Care Groups are viewed as having a key role to play in the development of a new primary care strategy and in commissioning some health and social services.

### **g) Annual health checks should be offered to all people with a learning disability**

Many of the examples given in this report have been about how signs and symptoms that something was not right were missed. Health checks are one way of reducing the chance of this happening. They are also an example of something that has been clearly set out in policy, but very poorly implemented. For example, under the Care Standards Regulations, there is a requirement for all those in residential care homes to be offered health checks. But there is evidence that this is not currently being enforced.

## **SAM**

### **Sam's story**

"If Sam had had a regular health check, his cancer could have been caught in the early stages." George, Sam's dad

Also, given the greater health needs of people with a learning disability, the above average death rate of younger people, inadequate diagnosis and treatment, and hidden health problems, it is important to consider whether an annual health check should be offered to all people with a learning disability.

*The Action Guide – Valuing Health for All* (Institute for Applied Health and Social Policy 2003) recommended the introduction of health checks as a foundation for health action planning. The Government, in their response to the consultation exercise *Building on the Best Choice, Responsiveness and Equity in the NHS* (2003), stated they would look into the possibility of introducing annual health checks for people with a learning disability. The



DOH stated in *Signposts to Success* that: “there is emerging evidence that routine health checks can lead to the identification of previously unrecognised health problems in people with a learning disability. Early identification can prevent the development of more serious problems and produce long-term benefits.”

In one GP practice, annual doctor-led health checks were carried out across a five-year period:

The health checks identified an average of one and a half interventions per patient. The most frequent interventions were blood tests for thyroid problems or anaemia, earwax syringing, changes of treatment, screening, referrals for eating and diet, referrals to orthopaedic surgeons, and urine checks for bacteriology.

Mencap strongly supports all people with a learning disability being offered an annual health check. These checks will not happen, however, unless the Government makes funds available for GPs to carry them out.

A number of short-term innovative health projects aimed specifically at improving the health of people with a learning disability have taken place in Northern Ireland, such as Healthcheck 2000, Challenge 2000 and Footsteps to Health.

## **h) Hospitals to fulfil their legal duty of care and provide appropriate levels of support to patients with a learning disability**

This report has highlighted the very poor care offered to people with a learning disability when they are staying in hospital. Hospitals have a legal responsibility to provide the level of care that is needed. For some people this might mean one-to-one support. Many hospitals either do not recognise this need or fail to plan to meet it. On a busy ward with only a few staff it is impossible to meet the needs of a person with a severe or profound learning disability who may need one-to-one support. Care should not be dependent on parents or care home staff – and hospitals must face up to their legal responsibilities.

### **ANITA**

#### **Anita's story:**

“They shut Anita in a side ward and left her there. They didn't bring her food or drink. We had to bring her food in. I think it's because she couldn't understand that she was being neglected, so she couldn't make a complaint.” Margaret, Anita's mum



## i) An inquiry into premature deaths should be conducted

We do know some of the reasons why people with a learning disability die young. However, we do not know all the reasons.

Max's story below (described in full on pages 3 and 4) illustrates this point:

### MAX

*“His whole body had gone into trauma. Nobody noticed that he had developed a kidney problem, or that he was malnourished, until he got to the intensive therapy unit. That’s what killed him. Surely somebody should be able to recognise trauma in a hospital?”* Alison, Max’s mother

*Valuing People* (England) stated that: “there is an above average death rate among younger people with a learning disability”. Under ‘Key Actions – Health’ the first ‘key action’ is “action to reduce health inequalities: explore feasibility of establishing a confidential inquiry into mortality among people with a learning disability”. It later states: “Evidence of available illness and premature death amongst people with a learning disability is a major cause of concern for the Government. We will explore the feasibility of establishing a confidential inquiry into mortality among people with a learning disability. This will help us take steps to reduce the number of avoidable deaths”.

We believe an inquiry would not only identify the causes of death, but also be a powerful lever for improvement in the delivery of health services. Mencap therefore strongly supports a confidential inquiry into the premature death of people with a learning disability.

## 5. Recommendations and conclusions

*Treat me right!* confirms that the NHS has a poor track record in dealing effectively with people with a learning disability. As a result, people with a learning disability have poorer health, greater health needs and shorter lives. There is a real concern that negative, discriminatory attitudes and poor communication skills amongst healthcare staff contribute to this unfortunate state of affairs.

For many years it has been NHS policy that people with a learning disability should have equal access to mainstream services. Despite good intentions on the part of the Government and healthcare services – as demonstrated by good policy and practice guidance, ministerial and prime ministerial commitment – people with a learning disability still get a poor deal.

Mencap recognises that some GPs and hospitals have tried hard to improve their practices. There are examples of good practice in various areas. We want to see these shared and developed in all areas. See the *Treat me right!* website, [www.mencap.org.uk/treatmeright](http://www.mencap.org.uk/treatmeright), for good practice examples.

Mencap wants to see action taken to ensure a better deal for people with a learning disability: people whose health is made worse – and lives shortened – by avoidable and unacceptable disadvantages.

### ***Treat me right!* recommendations:**

The following list is a summary of the recommendations detailed in section 4 of this report (*What should be done?*).

- Health professionals should be properly supported and trained to provide healthcare that does not discriminate against people with a learning disability. This training should involve people with a learning disability.
- All NHS organisations must fully comply with the Disability Discrimination Act (DDA) so that they fulfil their legal responsibility to provide equal access to healthcare. This should include:
  - longer and more accessible appointments
  - accessible information
  - identification of 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 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.

Some of our recommendations – particularly the annual health check – will require more money. But most do not. Rather they depend on changing attitudes and developing a better understanding of learning disability. To do this, there needs to be a clear understanding and acceptance among all healthcare staff that people with a learning disability have the same rights as everybody else. It is vital that people with a learning disability are treated with the same respect and value as other members of society. They should be seen as people first. But at the same time it must be recognised that their particular needs and communication difficulties have to be addressed.

Mencap is pleased that the Government acknowledges the barriers facing people with a learning disability in accessing an array of effective health services. It is unacceptable, however, that people with a learning disability have to put up with poor health and a poor service from the NHS. Mencap urges the Government to accept these recommendations and ensure that they are implemented throughout the health service to ensure that people with a learning disability have good healthcare and much-improved life expectancy.

## JENNY AND MARCUS

*“Attitudes within the NHS ranged from patronising ignorance to excellent and appropriate. But everywhere, in all hospitals and on all wards, professionals admitted to a need for appropriate staff training and better staffing resources.”* Siobhan, Jenny and Marcus’ mum

### **Jenny and Marcus' story:**

“Marcus and Jenny were both advised to have botox injections in their salivary glands to reduce dribbling which, as they have become adults, many people find difficult. As their parents, we wanted what was best for them. We were assured that the botox treatment would be entirely safe, despite the fact that Marcus and Jenny had not yet had the results of full diagnostic tests.

Within days of the botox treatment, my husband and I had to rush to the hospital where Marcus and Jenny had been admitted as emergencies, to provide them with 24-hour care. There were not enough staff available to nurse them, let alone deal with their high dependency needs. As their Mum, I ended up with hardly any support over a period of four days and three nights. I have never been so exhausted in my life!

Both Marcus and Jenny had suffered an allergic reaction to the botox, which left them sick and unable to swallow. They became severely dehydrated and very poorly. In a later appointment with the consultant who recommended the botox treatment, he admitted that had he known Jenny and Marcus had a mitochondrial condition, then they would not have administered the botox. He said, when told of how sick they had become: “Well, at least they're not dribbling.” It also transpired that a test could have been carried out to see whether their swallow would cope with the botox injections. This test had not been offered.

Following her first admission to hospital Jenny had to be readmitted to a different hospital for a further two weeks. Again, my husband and I had to provide most of her care. Whilst Jenny was recuperating with us, Marcus was readmitted to a hospital in another city. Again I had to provide 24-hour care to Marcus in hospital, while my husband stayed at home to care for Jenny.

We tried to have Marcus transferred to a hospital closer to our home, where a bed had been found for him, but the consultant in charge refused to sanction or co-operate with the request for Marcus' transfer. We have never been offered any reason for this decision. The consultant displayed an arrogance and ignorance of disability issues that was totally unacceptable and distressing. He refused to listen or even try to comprehend our predicament.

What happens when we as parents are too old, too ill or too dead to provide support?”



# Glossary

The following is a list of terms that are used throughout this report – together with others that appear frequently in literature about healthcare for people with a learning disability.

**A Health Action Plan** – This is a personal plan about what a person with a learning disability can do to be healthy.

**Community Learning Disability Team** – This is a group of professionals who work together to support people with a learning disability in the community. They usually have different skills, and usually come from the NHS and social services.

**Health facilitation** – This is about helping people get full access to all the services they need from the NHS.

**Health inequalities** – This is when some people do not have the same chance for good health as other people.

**Patient Advocacy Liaison Services (PALS)** – This provides on-the-spot help and information about health services.

**Patient forums** – This is a group of local people who have a say in how health services are run in a NHS Trust or Primary Care Trust.

**Primary Care Trust** – This is the place where you can see your doctor and other members of the Primary Health Care Team (see below).

**Primary Health Care team** – These are the people who you see first when you need healthcare. They include the doctors and nurses at the health centre as well as people like dentists and chiropractors.

# References

1. *NHS for all*, Mencap (1998)
2. *Prescription for change*, Mencap (1997)
3. *Journal of Intellectual Disability Research* 39, pages 527-531, McCuigan et al (1995)
4. *Journal of Gerontology Series A: Biological Sciences and Medical Sciences* 57, M470-472, Bittles et al (2002)
5. *Key Highlights of Research Evidence on the Health of People with Learning Disabilities*, Institute for Health Research at Lancaster University
6. Welsh Planning Forum (1992), NHS Scotland (2004)
7. *Key Highlights of Research Evidence on the Health of People with Learning Disabilities*, Institute for Health Research at Lancaster University
8. *Independent Enquiry into Inequalities in Health*, Sir Donald Acheson (1998)
9. *Tackling Health Inequalities – A Program for Action*, Department of Health (2003)
10. *Learning Difficulties and Ethnicity: a Framework for Action*, Department of Health (2004)
11. Cumela and Martin – British Institute of Learning Disabilities, commissioned by Department of Health (2000)
12. *Once a Day*, NHS Executive (1999)
13. *Health Care Omnimed Survey*, Taylor Nelson Sofres (2004)
14. *Once a Day*, NHS Executive (1999)
15. *Developing Better Access to Primary Health Care Services for Adults with a Learning Disability*, Janet Cobb NWTDT
16. *Journal of Intellectual Disability Research* 24, 4, pages 283-297, Beange et al (1999)
17. *He'll Never Join The Army*, Down's Syndrome Association (1999)
18. *Understanding The Patient Safety Issues for People with Learning Disabilities*, National Patient Safety Agency (2004)
19. *British Journal of Psychiatry* 176, pages 26-31, Holland AJ (2000)
20. *Journal of Intellectual Disability Research* 24, 4, pages 283-297, Beange et al (1999)
21. Cumela and Martin – British Institute of Learning Disabilities, commissioned by Department of Health (2000)
22. *Understanding The Patient Safety Issues for People with Learning Disabilities*, National Patient Safety Agency (2004)
23. *He'll Never Join The Army*, Down's Syndrome Association (1999)
24. *Health Services for People with Learning Disabilities HSG (92) 42*, Department of Health (1992)
25. *Key Highlights of Research Evidence on the Health of People with Learning Disabilities*, Institute for Health Research at Lancaster University; and *Health for all*, Mencap
26. *Valuing Health for All*, Institute for Applied Health and Social Policy (2003)



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**Mencap**

123 Golden Lane  
London EC1Y 0RT

Telephone: 020 7454 0454

Fax: 020 7696 5540

Email: [information@mencap.org.uk](mailto:information@mencap.org.uk)

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

Learning Disability Helpline 0808 808 1111

**Mencap in Northern Ireland**

Segal House  
4 Annadale Avenue  
Belfast BT7 3JH

Telephone: 02890 691351

Fax: 02890 640121

Email: [mencapni@mencap.org.uk](mailto:mencapni@mencap.org.uk)

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

Mencap's Information Service 0845 7636 227

**Mencap Cymru**

31 Lambourne Crescent  
Cardiff Business Park  
Llanishen, Cardiff CF14 5GF

Telephone: 02920 747588

Fax: 02920 747550

Email: [information.wales@mencap.org.uk](mailto:information.wales@mencap.org.uk)

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

Learning Disability Helpline 0808 8000 300

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