

Summary Report: is healthcare “Getting Better” for people with a learning disability?

Report produced by:



In association with:



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Executive Summary

BILD, Mencap and the Department of Health worked together to consult with people with a learning disability and their families to gain an understanding of their views and experiences of healthcare. We wanted to know if they thought that healthcare for people with a learning disability had improved since the Department of Health's last Six Lives progress report in 2010 and what things still needed to change. We gathered people's opinions via a survey¹ and a listening event. Both allowed people with a learning disability and their families and carers to share their views and experiences with us. Looking through the responses, we were able to identify key themes about what people felt had gone well for healthcare, what had not gone well and what needs to change to improve healthcare for people with a learning disability. We used these to identify indicators of healthcare going well and not going well, as well as the top 5 things that were identified as needing to change. These are listed below:

Top 5 signs of things going well in healthcare

1. Reasonable adjustments being made across the board
2. Staff having a positive attitude towards people with a learning disability
3. Involvement of people with a learning disability and their families/carers
4. Employment of learning disability nurses
5. Following the Mental Capacity Act

Top 5 signs of things not going well in healthcare

1. Delays in diagnosis, care and treatment
2. Poor quality health checks
3. Inaccessible or lack of communication and information
4. Failure to recognise or treat pain
5. Not involving people in decisions about their care

Top 5 things that need to change

1. Better complaints system
2. People with a learning disability and their families being treated with respect and as experts in their care
3. Improved attitudes and communication
4. More training for NHS staff
5. Greater availability of advocacy support

We hope everyone will listen to and take notice of the information gathered, which will shape the future of healthcare for people with a learning disability. We are confident that if everyone from national Government to local commissioners and providers and organisations like Mencap and BILD listen to the views of people with a learning disability and their families we will be able to create a healthcare system that better meets their needs and sees people with a learning disability receiving the high quality healthcare they deserve.

¹ The full survey report can be found here: <http://www.mencap.org.uk/campaigns/take-action/death-indifference/six-lives-report>

Background

In 2007, Mencap published *Death by indifference* which exposed the unequal healthcare that people with learning disabilities often received within the NHS and the devastating consequences this had for six people with a learning disability who died in NHS care.



Death by indifference cases

Emma died of cancer in 2004, aged just 26. The hospital delayed treating her because they said she would not co-operate with treatment and therefore could not consent to it.

Warren was 30 years old when he died. He died of aspiration pneumonia, paralytic ileus and peritonitis, following perforation of the appendix. His mother and father had repeatedly asked whether Warren had appendicitis or a blocked bowel when doctors visited Warren. They were told that Warren had a virus.

Ted died in May 2004. The death certificate stated that this was due to a heart attack, but this was changed after the inquest to 'aspiration'. He was 61 years old. He had been admitted to hospital a few weeks earlier due to problems with urine retention. He was discharged three weeks later, despite the fact that his care staff raised concerns about his health. The following day he collapsed and died.

Mark had been admitted to hospital with a broken leg. After an operation in which he lost a lot of blood, Mark was discharged and readmitted twice in two months, finally dying in intensive care eight and a half weeks after the operation.

Tom died after a very delayed diagnosis of an ulcerated oesophagus. Tom's parents found that the concerns they raised over Tom's expressions of pain weren't listened to. He was 20 years old.

Martin was admitted to hospital with a stroke when he was 43 years old. Whilst in hospital, Martin wasn't given the nutrition he needed. He went for 26 days without food before he died.

Death by indifference triggered an independent inquiry called *Healthcare for All* led by Sir Jonathan Michael (Michael, 2008). In addition, the Parliamentary and Health Service Ombudsman conducted an investigation of the six cases; *Six Lives* (2009). The report looked at the services given to Emma, Warren, Ted, Mark, Tom and Martin. The Ombudsman found evidence of significant and distressing failures in services across health and social care and recommended that the NHS urgently address existing inequalities to improve the care provided for people with a learning disability and to protect them against discrimination.

Within the Six Lives Report, the Ombudsman called on the Department of Health to address the problems identified by promoting and supporting the implementation of the Ombudsman's recommendations around improving healthcare for people with a learning disability. As part of this, the Ombudsman requested that the Department of Health actively monitor its progress in relation to the recommendations and publically report on their progress within 18 months of the publication of the Six Lives Report.

Accordingly, the Department of Health published the Six Lives Progress Report in 2010. The report described some of the progress that had been made since the Ombudsman's report, including improvements around annual health checks, reasonable adjustments and employment of acute liaison nurses and health facilitators. However, the report also acknowledged that there was still room for further progress. In particular, the Department of Health recognised that more needed to be done to: increase awareness and understanding of laws around capacity and consent, improve the complaints system and address the understanding of staff, particularly in relation to communication.

The latest progress report from the Department of Health updates on the progress that has been made since 2010². What follows is a summary of the information collated through engagement with people with a learning disability, their families and carers, ensuring their voices, views and experiences were included within the report.

How we listened to people with a learning disability and their families

BILD, Mencap and the Department of Health worked together to consult with people with a learning disability and their families to gain an understanding of their views and experiences. We wanted to know if they thought that healthcare for people with a learning disability had improved since the last report in 2010 and what things still needed to change. We did this in two main ways:

- 1. We asked people with a learning disability and family members to take part in a survey. They were asked to think about their experiences of healthcare over the last 12 months. There were 75 responses from people with a learning disability and 191 responses from family members.**
- 2. We invited people with a learning disability and family carers to a listening event on 9th April 2013. In total, 52 people took part in the event. During the day we had a number of workshops where we invited people to share their experiences of what had gone well, what hadn't gone well and what needs to change in relation to healthcare. People's feedback was recorded in each group and was also collected via a graphic facilitator, video recordings throughout the day and a story box. Some people who could not come to the event sent us information in letters and emails as well.**

What we found out

'Some good people, some good practices, some proactive families but we must have cultural change'

'I have never received care like that before-they understood my son and they cared'

'They understood she was special'

Overall there were many examples of improvement identified. Participants commented on positive experiences they had had in the services they had used. Several hospitals and GP practices were identified as having significantly improved their care and treatment of people with a learning disability

² The latest 6 Lives progress report (2013) can be read in full on the Department of Health's website: [https://www.gov.uk/government/publications?departments\[\]=department-of-health](https://www.gov.uk/government/publications?departments[]=department-of-health)

in recent years. Many comments reflected that there were clearly some strong champions for change, with the actions of some individual health professionals given high praise.

There was also strong praise for the role of learning disability liaison nurses and evidence that many more health professionals had received learning disability awareness training. There were also many examples of the NHS making reasonable adjustments in the way it delivered healthcare to people with a learning disability.

However, the good stories were balanced with some very concerning ones, including a moving account submitted to the 'story box' on the death of someone's daughter. There was a general concern that good practice was still too reliant on a handful of outstanding individuals rather than indicative of an overall culture change within the health service. Indeed, many areas identified as having gone well in some instances were identified as not having gone well in others. We have tried to highlight these differences throughout the report.

There were also many concerns raised about the way people were communicated with, the negative attitudes of some health professionals and the lack of involvement in decision making.

Throughout this report, we have used the words of people with a learning disability and their families and carers to highlight the themes and issues that were raised during the survey and listening event. What follows is intended as a summary of their views, experiences and opinions.



What has gone well?

In this section, we will outline some of the areas identified by people with a learning disability and their family/carers as having gone well in relation to the healthcare they had received.

Reasonable adjustments

'Accessible information has improved'

'NHS funding was used to pay for people with a learning disability to put together easy read information for local chemists/pharmacists'

At the listening event, participants gave many examples of reasonable adjustments being made across primary and acute care settings. This indicated an improved understanding of reasonable adjustments across the NHS. Examples of the range of reasonable adjustments that had been found helpful included:

- easy read information
- accessible signage
- allowing family members to stay with the person in hospital
- being first on the surgery list
- the way information was explained to people
- providing a treatment at home instead of at the surgery
- the development of resources and ward packs to help NHS staff treat patients with a learning disability.

The provision of health passports was described as important, especially when written with the involvement of the person with a learning disability and their family.

Specific comments were also made about the good service provided by particular health services:

GP's

'I have had a good experience with my new GP who is honest that he has not worked with people with a learning disability before so I am teaching him'

'They gave me a Dictaphone so I could listen back and check what they said'

'I get sent easy read letters'

Hospitals

'The nurse supported me and helped me to stay at the hospital'

'The learning disability nurse came to meet me'

'My family were allowed to stay with me'

Other NHS services

'The palliative care team have ensured that all health professionals are talking to each other to coordinate care'

'The optician explained everything and took their time and reassured me'

'The specialist dentist is very special and she explains what is happening to me every step of the way'

Involving people with a learning disability in improving services

'The learning disability nurse runs a focus group for people with a learning disability and their families'

The importance of involving and engaging with people with a learning disability and their families and carers was strongly felt. There were several examples of services working collaboratively with people with a learning disability and family carers in driving change. A number of forums had been set up to feedback on services. For example, one local GP practice had set up a patient forum that included people with a learning disability. Also, some partnership boards and advocacy groups had been involved in training health staff and auditing services.

Staff attitudes and respect

'They treated him like any other child'

'They have always been fantastic with my daughter'

'I was treated with dignity'

What the survey said

62% of respondents with a learning disability felt that healthcare staff treat them with respect all the time, **32%** said this happens sometimes and only **1%** said this never happens.

50% of respondents in the family survey stated that healthcare staff sometimes treat the person with a learning disability they care for with respect compared to **48%** feeling healthcare staff treat them (family members and family carers) with respect. Overall families felt that healthcare staff treat the person with a learning disability they care for with more respect than health staff treat them (family members and family carers).

On the whole, the evidence supported an improvement in attitudes towards people with a learning disability and their families with more survey respondents stating that they felt that they had been treated with respect. However, there was still evidence of things not going well in terms of staff attitudes and respect, with some negative experiences recorded. These points will be covered in the later section around what things had not gone well.

Compliance with the Mental Capacity Act

What the survey said

The majority of people with a learning disability had not been asked to sign a form about their treatment without it being explained to them (61%) although this had happened to 20% of respondents in the last 12 months.

Of the respondents in the family survey who said that the person they care for had gone into hospital in the last 12 months, the majority reported they had not been inappropriately asked to sign a form on behalf of the person with a learning disability (81% combined response rate for 'No this hadn't happened' and 'No the person I care for is/was unable to do so themselves'). However, 19% of family member and family carer respondents reported this had in fact happened.

Although the survey found some evidence of compliance with the Mental Capacity Act improving this seemed confined to the technical aspects of consent such as who should sign the consent form, rather than to proper involvement in medical decision making. There was clearly scope for further improvement in relation to professionals understanding of and compliance with the Mental Capacity Act. These issues are touched on further in later section on "decision making".

Learning disability liaison nurses

'The consultant learning disability post has made an enormous difference- cuts red tape and makes things happen'

'The learning disability liaison nurse runs a focus group for people with a learning disability and their families'

'Learning disability nurses in acute hospitals work well-but only if you know about them'

As we would expect, there was strong praise for learning disability liaison nurses where and when they were available. However, worryingly, the survey results showed that most people had not had access to one during their hospital stay.

What the survey said

The majority of respondents (73%) in the family members and family carers survey said they had not been offered the support of a learning disability liaison nurse in hospital for the person with a learning disability.

Information

'Sending letters to people who can't read is very frightening. They think you are telling them they are ill'

'There was no easy read information to help you get to the different hospital departments'

Despite the good examples of reasonable adjustments given by event participants there was still some concerning feedback from the listening event and the survey results that indicated that whilst there appears to be an increased understanding in some services about how to provide accessible information to people with a learning disability this is far from common place.

What the survey said

70% of respondents with a learning disability and **84%** of respondents in the family survey stated that healthcare staff never ask the person with a learning disability how they like their information. **46%** people with a learning disability found the information they get about their health hard to understand. While **34%** found the information OK to understand. Only **20%** found it easy to understand.

Taking pain seriously

'My son needed stitches and was not allowed pain relief'

We were extremely concerned to learn that management of pain remains a significant issue. Tools exist to assist staff in assessing the pain of disabled patients who have trouble communicating making this finding particularly disturbing as there have been considerable efforts taken to raise awareness around the issue of recognising pain.

What the survey said

49% of respondents with a learning disability stated that healthcare staff help them all the time if they are in pain, **40%** said this happens sometimes and **4%** said this never happens. This means **44%** of respondents reported that health staff do not *always* help them if they tell them they are in pain.

39% of respondents in the family survey stated that healthcare staff sometimes help the person with a learning disability they care for if they are in pain, **29%** said this happens all the time and **11%** said this never happens. This means **50%** of respondents in the family survey reported that healthcare staff do not *always* help the person with a learning disability if they tell them they are in pain.

Care and treatment

'It was so inadequate, he died'

'Ward care is non-existent; dignity suffers!'

'A member of (advocacy group) was left in hospital with little support; no support from hospital staff to eat meals, drink and get out of bed-she has complex needs'

Duty of care is a legal requirement due to all patients, but for people with a learning disability it is often overlooked. Listening event participants gave many examples of poor care they had experienced. These included getting pressure sores, general neglect and staff being rough with patients. There was a feeling that quality of care depended greatly on how much previous experience the nurses might have had in caring for people with a learning disability.

What the survey said

46% of respondents with a learning disability felt that healthcare staff are very caring towards them compared to **14%** of respondents in the family survey who felt healthcare staff are very caring towards them (family members and family carers). Families felt that healthcare staff are more caring towards the person with a learning disability they care for than to family members.

Furthermore, the majority of respondents in the family survey (**61%**) had been required to carry out personal care themselves for the person with a learning disability they care while they were in hospital.

Diagnosis

'The GP failed to diagnose that my ankle was broken and I had to go to hospital'

'People have to go to hospital because their GP has got it wrong and does not understand'

'They missed the diagnosis of a bladder stone'

Failures and delays in diagnosis result in delays in beginning appropriate treatment. Worryingly, many examples of problems associated with making a diagnosis and the assumptions made because someone had a learning disability were given by event participants. These included missing important symptoms, delayed diagnosis and a lack of understanding about how displays of behaviour that challenges could be a means of communicating that something was wrong.

What the survey said

36% of family members and family carers found the length of time between meeting healthcare staff and receiving a diagnosis moderately acceptable. A significant proportion felt that the length of time was not very acceptable or not acceptable (**19% and 24% respectively**). This means that **43%** collectively appeared unsatisfied the length of time a person with a learning disability has to wait for a diagnosis.

Decision making

'Why should we think that education and health law is not as important as the laws on driving and killing?'

'Capacity is not respected at all'

'The MCA (Mental Capacity Act) is used to over protect people'

The most serious example given at the event was that a Do Not Attempt Resuscitation notice had been put on the records without consulting the family. Other examples reflected a lack of understanding about how to properly involve individuals and their families in making decisions about care and treatment. These views were reflected in the survey findings.

What the survey said

46% of respondents with a learning disability said that healthcare staff include them in decisions about their care all the time. While a significant proportion reported this only happened sometimes (**36%**), very few said this never happened (**4%**). However, when combined this means that **40%** of respondents felt that healthcare staff do not *always* include them in decisions.

When family carers were asked if they were included in decisions made about the care of the person with a learning disability they cared for, where this had been necessary, **44%** of respondents said that they were sometimes included. **40%** said they were included all the time, and only a small proportion said they were never included (**8%**). However this means that **over half (52%)** felt they were not *always* included in decisions where this was necessary.

Annual health checks

'My GP gets paid for these. My son never gets out of his wheelchair or has any kind of body check. They just ask. No blood pressure, nothing. It's money for old rope!'

'My annual health check was done on the phone'

Annual health checks, when done well, can help detect symptoms or problems early on allowing for earlier treatment. Event participants raised a number of concerns about the quality of annual health checks. Some people had not had one at all whilst some who had questioned their quality and thoroughness. One person even gave the example of having been offered their annual health check over the phone! There was a feeling that annual health checks should be made available to all people with a learning disability although there were concerns that annual health checks were not being conducted correctly everywhere, reducing their value.

Complaints

'Families do not have a clue how to complain and are scared that they will be punished'

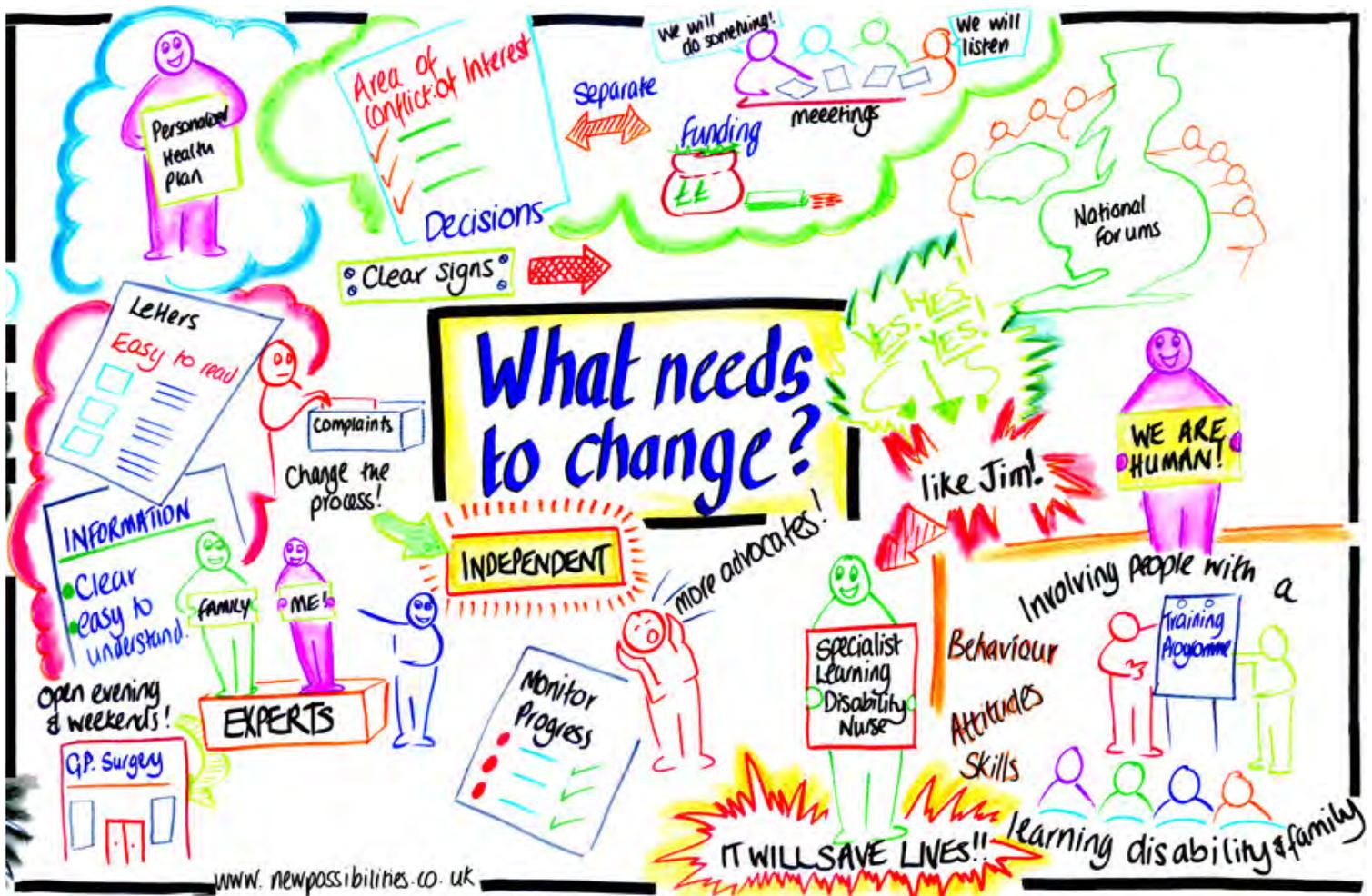
'They just try to pull apart who said what and why'

'I am still waiting for the local hospital to reply'

There was a clear message from the listening event that the complaints system was not working well. Event participants made strong points about the difficulties that they had had when they needed to complain about their health experiences. One family reported having to make 18 complaints and are now seeking judicial review. Others were reluctant to complain because of the fear of a negative impact on the person receiving treatment.

What the survey said

The majority of family members and family carers who had made an official complaint about the care of the person with a learning disability they care for found the complaints process very difficult (**39%**) or difficult (**38%**). This amounts to **77%** when the figures are combined.



What needs to change?

At the listening event, we asked people with a learning disability and their families and carers for their ideas on what things need to be changed to improve healthcare for people with a learning disability. There were a lot of ideas but 9 key messages emerged.

1. Change attitudes

'We are human!'

'You can't teach compassion- recruit the right people'

'Look at the symptoms not the disability'

'Use your common sense!'

Although there was some evidence of positive attitudes reported, there was also a strong feeling that more needed to be done to improve the attitudes of health professionals across the board. Emphasis was placed on the need for compassion and empathy amongst health professionals, making sure people treat people with a learning disability equally and do not make any judgements about their quality of life.

2. Make advocacy more available

'It reduces stress'

'Needs to be more available'

'Located on hospital sites'

'Better funded'

There was a strong feeling that advocacy support should be available for all those who need it. This is particularly important for those people with a learning disability who do not have family, carers or friends to advocate on their behalf. The provision of effective advocacy can be life-saving for such individuals, particularly given the evidence of poor adherence to the Mental Capacity Act.

3. Improve communication

'Listen!'

'Communicate in the best way for the individual'

'A greater focus on people from BME backgrounds'

'Use a range of different communication methods'

'Lots more accessible information'

It is disturbing to hear that some hospital staff are still ignoring advice and information that could improve treatment and save lives. Listening to and including people with a learning disability, their families and carers should be common practice. Many of the listening event participants reported difficulties they had faced in getting health professionals to take crucial information when accessing healthcare. Healthcare professionals should see attempts to share such knowledge as a means of helping them successfully meet the needs of their patients.

There are now excellent tools to assist in passing over essential information to hospital staff, such as hospital passports, grab sheets and communication books, so there is little excuse for poor communication. In addition, it is crucial that healthcare professionals communicate well with each other, particularly when handing over the duty of care. All staff working with an individual should have the same level of understanding of that person's needs.

4. Train all NHS staff

'A national programme of training delivered to all NHS staff that involves families and people with a learning disability'

'Training at all staff levels and at all career stages'

'Include how people with learning disability are treated in staff appraisals'

'Keep refreshing the training'

'More training on capacity and consent'

There was a strong feeling that healthcare professionals should receive training and education to help them better meet the needs of people with a learning disability. There should be mandatory training for all healthcare professionals around learning disability, ideally with the involvement of people with learning disabilities and their carers in the provision of the training.

5. Make complaining easier

'Complaints departments need to be independent'

'It should be easier to make one'

'They need to be open and transparent'

There was an agreement that the complaints process is currently not meeting peoples needs and that steps need to be taken to make the system easier. Families should feel that their concerns are taken seriously and are dealt with thoroughly and this is currently not the case. In addition, the current complaints system is hindering learning across the NHS and preventing professionals from improving their practice in response to people's complaints. Responses to complaints should be quick and comprehensive, addressing all the concerns raised. In addition, it is important that those individuals investigating the complaint have an adequate understanding of learning disability and the risks people face in the NHS as well as a detailed knowledge of the Equality Act and Mental Capacity Act.

6. Make sure everyone has a hospital passport

'Everyone should have one'

'They should be online'

'Always involve the person and their family'

Many hospitals now use hospital passports which, together with the crucial advice that families or paid support staff can provide, give much of the information needed to provide good quality care. People with a learning disability and their families want everyone with a learning disability to have a hospital passport as it was felt these were invaluable tools for communicating crucial information about an individual.

7. Get more involvement of people with a learning disability and their families

'See the family carer as experts and don't forget Dads!'

'Listen to, believe and work with the family carers and people with a learning disability'

'All hospitals should have a learning disability panel to advise them'

There was a strong feeling that people with learning disability and their families should be involved in decisions about their care and treated as experts by experience. Involving people with a learning disability and their families will help improve the quality of care that the individual receives.

8. Make more reasonable adjustments

'Learning disability volunteers in hospitals'

'Change the visual information in hospitals like they do in children's hospitals to make it easier to get around'

'Provide quiet areas in hospitals'

'Think of the small stuff too'

Although there was evidence of an improved understanding and implementation of reasonable adjustments for people with a learning disability it was still felt that more was needed to increase understanding amongst healthcare professionals and make sure that reasonable adjustments are put into practice as routine. Reasonable adjustments are often simple changes, but they make a huge difference to the experience of people with a learning disability.

9. Give more help to understand the new NHS

'Explain the new structures

'Tell us how we can take part in Healthwatch

'Involve us in training people in clinical commissioning groups (CCGs)'

'Tell us how to hold NHS England to account'

The Health and Social Care Act (2012) introduced a series of complex reforms which have changed the way the NHS works. It was felt that more needed to be done to help people with a learning disability and their families understand the new NHS structures and their responsibilities.

Summary

To summarise the findings, we have identified what we felt were the top 5 themes that came out within each session around what has gone well, what hasn't gone well and what needs to change.

Top 5 signs of things going well in healthcare

1. Reasonable adjustments being made across the board
2. Staff having a positive attitude towards people with a learning disability
3. Involvement of people with a learning disability and their families/carers
4. Employment of learning disability nurses
5. Following the Mental Capacity Act

Top 5 signs of things not going well in healthcare

1. Delays in diagnosis, care and treatment
2. Poor quality health checks
3. Inaccessible or lack of communication and information
4. Failure to recognise or treat pain
5. Not involving people in decisions about their care

Top 5 things that need to change

1. Better complaints system
2. People with a learning disability and their families being treated with respect and as experts in their care
3. Improved attitudes and communication
4. More training for NHS staff
5. Greater availability of advocacy support

We would advise healthcare professionals to take note of all these factors to understand what good and bad healthcare looks like for people with a learning disability. Also, we believe that if healthcare professionals listen to the recommendations from people with a learning disability and family carers about what needs to change they will be better equipped to meet the needs of people with a learning disability.

Our recommendations

On the basis of the findings from the listening event and survey we have pulled together the following key questions that we think people with a learning disability and their family carers should ask when accessing healthcare and a list of key questions that healthcare professionals should ask when treating someone with a learning disability. We believe that if these questions are asked, it will help to improve good practice in the treatment of people with a learning disability and result in more good practice.

Top 5 things health professionals should ask when treating someone with a learning disability

- 1. Ask how you should communicate**
- 2. Ask if there are any reasonable adjustments you can make**
- 3. Ask if the individual would like additional support such as advocacy support**
- 4. Ask if they have a health action plan and/or hospital passport**
- 5. Ask if they understand what you have told them**

Top 5 things people with a learning disability and family carers should ask

- 1. Ask for an annual health check**
- 2. Ask for a learning disability nurse and/or advocate**
- 3. Ask for a hospital passport**
- 4. Ask for a longer appointment time**
- 5. Ask for information in easy read**

We hope that everyone from national Government to local commissioners and providers, as well as organisations like Mencap and BILD will take note of what was said by participants at the listening event and via the survey, to seek to improve healthcare for people with a learning disability. By getting healthcare right for people with a learning disability, we strongly believe we will get it right for many other people too.

The last word

We would like to end this report with the experience of one of the families who told their story to us by email which we felt captures much of the sentiments expressed via the survey and during the listening event.



'We were very involved in our local partnership board during the work of 'Death by indifference' and the Sir Michael reports. However my daughter lost her life to 'poor care' at the hands of the NHS on her birthday in 2011. The people who were charged to deliver her care in hospital neither listened to us as her carers nor to her. She subsequently lost her life and there followed an investigation and inquest which identified many failings. How can this still happen? What do I need to do to stop this horrendous treatment of our vulnerable loved ones? I can and more importantly will not let my daughter's death go in vain'

References

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st century.* London: Department of Health

Mencap (2004) *Treat me Right!* London: Mencap

Mencap (2007) *Death by Indifference.* London: Mencap

Michael, J. (2008) *Healthcare for all: Report of the Independent Inquiry into access to healthcare for people with learning disabilities.* London: Aldrick Press

Parliamentary and Health Service Ombudsman and Local Government Ombudsman (2009) *Six lives: the provision of public services to people with learning disabilities.* London: The Stationary Office

Department of Health (2009) *Valuing People Now.* London: Department of Health

Department of Health (2010) *Six Lives: Progress Report.* London: Department of Health

Mencap (2010) *Getting it right.* London: Mencap

Mencap (2012) *Death by indifference: 74 deaths and counting.* London: Mencap

Heslop, P. et al (2013) *Confidential Inquiry into premature deaths of people with learning disabilities.* Bristol: Norah Fry Research Centre

Appendix

About learning disability

A learning disability is a reduced intellectual ability and difficulty with everyday activities - for example household tasks, socialising or managing money - which affects someone for their whole life.

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complex information and interact with other people.

The level of support someone needs depends on individual factors, including the severity of their learning disability. For example, someone with a mild learning disability may only need support with things like getting a job. However, someone with a severe or profound learning disability may need full-time care and support with every aspect of their life - they may also have physical disabilities.

People with certain specific conditions can have a learning disability too. For example, people with Down's syndrome and some people with autism have a learning disability.

Learning disability is often confused with dyslexia and mental health problems. Mencap describes dyslexia as a "learning difficulty" because, unlike learning disability, it does not affect intellect. Mental health problems can affect anyone at any time and may be overcome with treatment, which is not true of learning disability.

It's important to remember that with the right support, most people with a learning disability in the UK can lead independent lives.

About BILD

BILD is the British Institute of Learning Disabilities. We want people with learning disabilities to be valued equally, participate fully in their communities and be treated with dignity and respect.

Our services help develop the organisations who provide services, and the people who give support.

That way we play a part in making sure people are supported with dignity and respect and can make choices and decisions about their lives.

We have around a thousand members who we make sure get the latest news in learning disabilities.

As part of the Learning Disability Coalition - now part of the Voluntary Organisations Disability Group - we campaign for proper funding for support for people with learning disabilities and their family carers.

About Mencap

Mencap is the UK's leading charity working with people with a learning disability, and their families and carers. Together, we are fighting for a fair deal for everyone with a learning disability and the people who support them.

We campaign for change at every level of government – locally and nationally. And we support people with a learning disability to get involved in their communities, speak up for themselves and fight for the changes they want.

We also provide a wide range of services for people of all ages – like housing, education, employment and leisure – that give people the chance to lead fulfilling, active lives with as much independence as possible.

About the Department of Health

The Department of Health's purpose is to help people live better for longer. It will lead, shape and fund health and care in England, making sure people have the support, care and treatment they need, with the compassion, respect and dignity they deserve. The new and changing health and care organisations work together with the Department to achieve this common purpose.

The Department of Health will enable health and social care bodies to deliver services according to national priorities and work with other parts of government to achieve this. It will set objectives and budgets and hold the system to account on behalf of the Secretary of State.

The Secretary of State for Health has ultimate responsibility for ensuring the whole system works together to meet the needs of patients and the public and reflect their experiences.