Understanding the patient safety issues for people with learning disabilities
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Introduction

The National Patient Safety Agency (NPSA) is the first patient safety organisation in the world to look at the specific patient safety risks for people with learning disabilities using healthcare services.

Due to complex needs, many people with learning disabilities need additional support and services throughout their lives. This means they may have a longer and more intense involvement with the NHS than the vast majority of people.

Studies suggest that there are 3-4 people with a severe learning disability for every 1000 people in the UK. Those with a mild learning disability are estimated at 6 in every 1000 people in the population, suggesting a total figure of about 1.2 million (British Institute for Learning Disabilities website www.bild.org.uk).

This report outlines the work that the NPSA has done to find out what the patient safety priorities are for people with learning disabilities.

The report may be of interest to learning disability and general health and social care staff, people with learning disabilities and family carers. It details how the NPSA established the priorities and explains what the NPSA will be going next.

The NPSA uses the term ‘learning disability’ in this report but acknowledges that many people prefer the term ‘learning difficulty’.
About the National Patient Safety Agency

The National Patient Safety Agency (NPSA) looks for ways to improve the safety and quality of care for patients in the NHS.

There are many ways that the NPSA is working to improve patient safety. NHS staff and patients can tell the NPSA about patient safety where they work or receive healthcare services.

This information shows the NPSA things in the NHS that staff and patients think need to be made safer.

The NPSA works with NHS staff, other health care organisations, patients and the public to reduce the risk of errors.

It also learns how other organisations have improved their safety standards.

The NPSA tells the government, patients and the public what it is doing and lets other organisations know of ways to make patients safer.
People with learning disabilities are at risk

It is well known that people with learning disabilities have far greater healthcare needs than the general population.

They are more likely to have mental illness, long-term health problems, epilepsy and physical and sensory disabilities.¹

Despite more health concerns, people with learning disabilities have problems accessing health services; finding out what is wrong with their health; and are sometimes treated differently to those without a learning disability.²

All of these things could be causing suffering, harm and reducing the quality or length of life for people with learning disabilities.³

The NPSA wanted to find out how these things affect the safety of people with learning disabilities using healthcare services.
What the NPSA did

Three separate pieces of work have helped us to understand the patient safety issues:

1. Professor Hilary Brown, Consultant in Social Care and Adult Protection at Salomons, Canterbury Christ Church University, did a literature review.

2. Speaking Up! a self-advocacy charity spoke to people with learning disabilities and family carers about their views on patient safety.

3. The NPSA met with frontline health and social care staff to hear about the types of patient safety incidents that people with learning disabilities are involved in.

Academics, people with learning disabilities, family carers and NHS and social care staff were all included in the project.

An independent consultant, Jackie Downer, a person with a learning disability, and her enabler worked closely with the NPSA, advising throughout the project.

1. Literature review

We asked Professor Hilary Brown, Consultant in Social Care and Adult Protection at Salomons, Canterbury Christ Church University to put together a report on everything that has been written about patient safety and people with learning disabilities. The report has details of references, key papers, searches, websites and a detailed bibliography.

A full summary of the literature has been produced and is on the NPSA website.
2. People with learning disabilities and family carer workshops and interviews

Speaking Up! met with 46 people with learning disabilities and 12 family carers. Workshops and one-to-one interviews were held to hear views and experiences.

Groups consulted included:

- Newcastle Skills for People
- Lewisham Partnership Forum
- Sandwell People First
- Cardiff People First
- Merseyside Partners (family carers’ group)

To make sure that views were heard from diverse groups, Speaking Up! met with people:

- from black and minority ethnic groups
- with mental health problems
- with a sensory impairment
- with high support needs
- who live in residential homes
- who live independently or in supported accommodation
- who live with their families
Speaking Up! has produced a detailed accessible report on the main safety priorities and this is on the NPSA website www.npsa.nhs.uk. It is also available as a hard copy from the NPSA. You can telephone 020 7927 9500 for a copy.

Copies of Speaking Up!’s accessible report will be sent to self-advocacy groups in England and Wales. This report can also be made available in alternative formats, on request.

3. Focus groups with health and social care staff

The NPSA held focus groups in England and Wales and met with approximately 150 frontline health and social care staff. The majority of staff worked directly with people with learning disabilities. General healthcare staff that took part included GPs, theatre nurses, adult psychiatrists, practice nurses, district nurses and audiologists. All have a particular interest in improving the quality of services for people with learning disabilities and act as local or national champions.

The purpose of the focus groups was to gather information about patient safety incidents involving people with learning disabilities.

Participants shared examples of patient safety incidents that they had been involved in and examples of things that had improved patient safety in their area.
The patient safety priorities

The literature review, Speaking Up! workshops and staff focus groups have confirmed that people with learning disabilities are more at risk of being involved in a patient safety incident than the general population. The breadth of information received has suggested that the diverse needs of people with learning disabilities, the range of different agencies involved in care and the long term nature of the relationship with the NHS may make them more vulnerable.

We had to decide which of the wide range of issues brought to our attention were priorities for further work. To do this we used the NPSA’s prioritisation framework and got advice from independent consultants.

The following areas have been highlighted as priorities:

1. Inappropriate use of physical intervention (control and restraint)

Patient safety issue: People with learning disabilities may be receiving injuries and being harmed when physical restraint is used inappropriately.

The British Institute of Learning Disabilities (BILD) describes physical intervention as: ‘A method of responding to the challenging behaviour of people with learning disabilities and/or autism which involves some degree of direct physical force which limits or restricts the movement or mobility of the person concerned.’

BILD suggests that 50 percent of people with learning disabilities and challenging behaviour will have physical interventions used on them at some point in their life (British Institute for Learning Disabilities website www.bild.org.uk).
Professionals working with vulnerable people have a duty of care to ensure that they act in the best interest of a person, whilst avoiding actions that may cause harm. Physical intervention should only be used when other less intrusive approaches have been tried and found to be ineffective.

One person told Speaking Up!:

“They used to restrain me for nothing, for the slightest thing...wham me on the floor straight away. I think restraining should be banned.”

Another man with a learning disability said that he was “restrained in a horrible way” with pressure on his arms. He was left with bruises from being restrained and often couldn’t breathe as a result.

Other concerns raised through the focus groups with staff were:

- People being restrained without having a clear understanding of the potential harm this could cause.
- Confusion about recommended ways of using safe restrictive physical intervention.
- Lack of involvement or consultation with people with learning disabilities when planning for physical interventions.
- Conflicting policies between the agencies providing care leading to different approaches being used.
- Physical intervention being the first response rather than the last resort.
- Problems recruiting and retaining staff to work in services supporting people who are challenging.
A learning disabilities nurse working in an in-patient assessment and treatment service, described the inconsistencies in using physical intervention as “an accident waiting to happen”. This view was echoed by many staff in the workshops.

The literature review points to physical intervention needing to be closely monitored by effective policies, otherwise it can be an abusive experience for the person being restrained. While some people will require time on their own to assure their own safety and that of others, the literature points to situations where this is used as an alternative to active support. Sometimes physical intervention can be seen as punishment.

Particular concerns were voiced by both those with learning disabilities and staff about the use of physical interventions in acute mental health wards sometimes not being in line with good practice guidance. The view was that people with learning disabilities may generally be at risk in an acute mental health in-patient service.

The British Institute for Learning Disabilities (BILD) is recognised as taking a lead in developing policies and good practice documents for physical interventions. In July 2002, the Department of Health and Department for Education and Skills issued *How to provide safe services for people with Learning Disability and Autistic Spectrum Disorder*. This guidance aims to “ensure that restrictive physical interventions [which employ force] are used as infrequently as possible... and ensure that everything possible is done to prevent injury and maintain the person’s sense of dignity.”
We will be looking into ways of reducing the risk of harm when people with learning disabilities are physically restrained. We will start by exploring why and how patient safety incidents involving physical intervention happen.

Team working, communication and empowering people with learning disabilities will be looked at when developing practical solutions.

2. Vulnerability of people with learning disability in general hospitals

Patient Safety Issue: People with learning disabilities may be more at risk of things going wrong than the general population, leading to varying degrees of harm being caused whilst in general hospitals.

An estimated 26 percent of people with learning disability are admitted to general hospitals every year, compared to 14 percent of the general population.7

Staff raised concerns about the general NHS’s ability to ensure people with learning disabilities are as safe as possible. Learning disabilities and general healthcare professionals suggested general healthcare staff may lack the appropriate skills to meet the specific needs of people with learning disabilities. They said individual needs are often overlooked when people with learning disabilities are admitted to general hospitals.

People with higher support needs were highlighted as the most vulnerable group of patients. Family carers interviewed as part of the study told Speaking Up! that they felt:

“A need to take responsibility when their family member was in hospital.”
They feared their relative would come to harm if they were not at the hospital at all times.

One carer had observed many patient safety incidents involving her son; her and her husband have to constantly advocate on his behalf. Her concerns about the risk of harm are so great, that she said:

“It makes me hope that he dies before we do.”

Particular concerns were:

- Communication difficulties makes it harder for people with learning disabilities to ask for help when they are feeling ill, in pain or need to describe symptoms.

- Lack of training in specific health concerns suggests that general health staff may overlook the seriousness of symptoms of illness and disease.

- Additional health conditions, such as epilepsy, are often not recognised in general hospitals.

- Learning disabilities staff and carers are often assumed by general healthcare staff to be capable of providing full nursing care.

- The person’s learning disability is likely to affect their ability to understand their illness and treatment.

- Consent being sought from a carer rather than taking the time to gain consent from the person with the learning disability.

The government says general healthcare has been slow to develop the skills to meet the needs of people with learning disabilities. This has led to community learning disability teams providing an all-encompassing service. As a result, the wider NHS has failed to consider the needs of people with learning disabilities. Several national initiatives are underway to address this. These include health
facilitators, health action plans and new roles for specialist learning disability teams to support mainstream health services.

From the staff focus groups, it was clear that there are several examples of good practice being used to improve the safety of people with learning disabilities in general hospitals. These included a ‘handy hints card’ for general healthcare staff, health communication passports and learning disability nurse liaison roles in wards and departments.

The good practice examples we heard about will contribute to our development of national solutions. We will invite ideas from local or national good practice to inform the development of national solutions.

3. Swallowing difficulties (dysphagia)

Patient Safety Issue: Swallowing difficulties are more common in people with learning disabilities. If not managed safely they can lead to respiratory tract infections, a leading cause of early death for people with learning disability.

Problems associated with eating and drinking can be life threatening for people with learning disabilities. They can lead to poor nutritional status, dehydration and aspiration that can lead to chest infections, a leading cause of death among people with learning disabilities.\(^8\)

One study suggested that respiratory disease was a leading cause of death in 52 percent of adults with learning disability, compared to 15 percent of males and 17 percent of females in the general population.\(^9\)

In the focus groups, staff raised the following issues:

- Increased swallowing difficulties for those with high support needs.
- Differences between the health and social care model of care causes confusion when caring for someone with swallowing difficulties.
• Guidelines for a safe swallow not being adopted in the social care setting.

• Lack of awareness of the symptoms of aspiration pneumonia and the risk of death caused by swallowing difficulties.

At one focus group, a team of speech and language therapists, dieticians and community nurses shared examples of how they were improving the safety of adults with learning disabilities and swallowing difficulties. They had designed a range of local solutions including: mealtime mats, training for social care staff and dysphagia checklists for carers. Although not yet recognised nationally, the team had been approached by others interested in adopting these good ideas.

4. Lack of accessible information

Patient Safety Issue: Harm may result if a person with a learning disability is unable to understand information relating to illnesses, treatment or interventions.

Staff said a lack of accessible information created a barrier to accessing healthcare and appropriate treatment. This ranged from information about services through to illnesses and disease. Often specialist learning disability staff, paid carers and family carers act as supporters and translate general information so that it is understood by the person.

Lack of information about medication that people with learning disabilities have been prescribed was highlighted as an area of concern.
One person said:

“If I could change health services, I would make bigger labels on medicine bottles, especially for people with learning disabilities who can’t read them properly. Instructions for taking tablets need to be explained to people who cannot read.”

Several people with learning disabilities said that they did not understand patient information produced to raise awareness of health problems.

“The information at the surgery...they use too many big words, not enough pictures. What’s the use of having a leaflet that is full of writing for someone that can’t understand it? I’ve got a booklet on asthma at home, but it’s not very accessible. My carers have to sit down and explain the leaflets to me.”
Particular concerns were:

- Lack of information in alternative formats such as visual and audio.
- Healthcare professionals not having the resources to explain treatment or care in accessible ways.
- People with learning disabilities being asked to sign consent forms, when they are unable to give informed consent based on the information given.

A learning disabilities community team, who took part in the focus groups, talked about a local solution that had improved accessibility of information. They had developed a menu card of pictures of health-related issues. These included pictures that indicated symptoms of illness, pain, safety and emotions. The picture menu has been adopted by the district general hospital for use with stroke patients and the results have been positive.

‘Change’ is a national organisation run by disabled people. ‘Change’ has produced a picture bank which has 500 pictures aimed at giving people with learning disabilities better access to information. ‘Change’ has expressed an interest in developing a set of new pictures for patient safety. For people who use pictures and symbols to communicate needs, as well as those supporting them, this would enhance the opportunity for them to communicate about patient safety.

5. Illness or disease being mis or un-diagnosed

Patient Safety Issue: Access to treatment is often delayed because symptoms are not diagnosed early enough. This could lead to undetected serious health conditions and avoidable deaths.

Symptoms are often overlooked on the assumption that they are part of the person’s learning disability. This is sometimes called ‘diagnostic overshadowing’.
Diagnostic overshadowing is:

“dismissing changes in behaviour, personality or ability that would be taken very seriously in a person without a learning disability.”

It is estimated that 2 percent of the patients on a GP’s register are likely to have a learning disability. A GP with a list of 2000 patients will have about 40 patients with a learning disabilities. The report by Speaking Up! suggests that people with learning disabilities rarely feel they have enough time to communicate their needs to their GP.

It is well known that people with learning disabilities access their GP less than the general population. Some studies suggest that 70 percent of people with learning disabilities see their GP less than 4 times a year. This is less than the average 5 visits per year for the general population. The suggestion of double appointments was made and there was evidence that this is happening in some local areas. Lack of communication, pressure on time and not understanding the additional health conditions associated with learning disabilities may lead to a missed or wrong diagnosis.

Particular concerns raised were:

• The length of time between early symptoms being recognised and obtaining an accurate diagnosis.

• Symptoms being linked to a person’s learning disability and not their illness.

• Difficulties people with learning disabilities have communicating when they are feeling ill or are in pain.

• Carers missing signs related to poor health.
Access to treatment is often delayed because symptoms are not diagnosed early enough or in some cases, at all. One nurse told us about a man she had cared for; he had been frequently referred to the hospital for investigations into bladder and bowel problems but she felt that he hadn’t been listened to because of his disability. The cause of these symptoms were never diagnosed and as a result the man died of kidney and heart failure. The nurse said:

“This could have been prevented if a clear diagnosis had been made earlier to allow for prompt treatment. Instead, this man suffered. He shouldn’t have died.”

Another member of staff told us about a woman she had cared for who had been diagnosed with a psychiatric condition because her behaviour had changed and she was refusing to open her eyes. The member of staff insisted on taking her for an eye appointment. She was diagnosed with glaucoma and had a successful operation. The member of staff said:

“If she hadn’t gone to the ophthamologist on that day, she would have lost her eye sight.”

Mis-diagnosis cuts across all care settings in the NHS and further work is needed to identify particular problem areas and then solutions.
Next steps

Through looking at literature, and meeting with people with learning disabilities, family carers and health and social care staff, the NPSA now has a clearer understanding about the main patient safety issues for people with learning disabilities.

The NPSA will now work to look in more detail at each priority area and start to develop solutions that address the problems. This will be achieved through:

• Gathering more information about the exact size and nature of the problem.
• Building on existing information about local and national solutions gathered from the staff focus groups and considering how these may inform the work of the NPSA.
• Consider the role the NPSA can have in influencing any national initiatives already underway to address patient safety.
• Learn from local, national and international solutions and look at their relevance to improving patient safety for people with learning disabilities.
• Undertaking further research.

We will continue to work closely with people with learning disabilities, family carers and other key stakeholders as we continue our work.

Local learning disabilities partnership boards may like to discuss this report and start to consider how the five priority areas could be addressed locally.

The NPSA is interested to hear of any local solutions that have been developed to improve patient safety in the identified priority areas.

If you would like to share any ideas or find out more about the information in this report and our ongoing work, please email: vicky.stobbart@npsa.nhs.uk
References

This publication can also be made available in alternative formats on request. Please contact The NPSA on 0207 927 9500, or visit the NPSA’s website www.npsa.nhs.uk

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and

Pictures from People FIRST
020 7485 6660

A Welsh/English version of this report will be available from March 2004

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