Dignity in health care for people with learning disabilities
RCN guidance (third edition)
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This publication is due for review in December 2019. To provide feedback on its contents or on your experience of using the publication, please email publications.feedback@rcn.org.uk

Publication
This is an RCN practice guidance. Practice guidance are evidence-based consensus documents, used to guide decisions about appropriate care of an individual, family or population in a specific context.

Description
There are an increasing number of people with criminal justice setting who have multiple and complex health care needs. From time-to-time these people require attention in NHS settings outside of prison/police custody. This guidance is aimed at nursing staff working in NHS settings and gives further support and advice to provide optimum care to this group of patients.

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Evaluation
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# Contents

## Contents

1. Introduction 4

2. What is dignity? 5
   - What does dignity mean to people with learning disabilities? 5

3. Dignity, health care and people with learning disabilities 6
   - Understanding my health 7
   - Respect me 10
   - Get to know me 11
   - Having choices and making my own decisions 13
   - Feeling safe 15
   - Communicating with me 17

4. The health needs of people with learning disabilities 19

5. Appendix 1 - Bill of Rights 21

6. Resources 22

7. References and key publications 24

8. Contributors to the first edition 25
Introduction

This guidance, developed by the Royal College of Nursing Learning Disability Nursing Forum, aims to improve dignity in health care for people with learning disabilities. While designed primarily to support the nursing workforce working in all health care settings, other health care and social care staff may also find this publication a useful resource.

A small proactive group of individuals with learning disabilities who use health care services in South East London agreed to contribute to the development of this guide. Referred to as the expert panel, they shared their thoughts, feelings and experiences at three focus group meetings. During these events, which were facilitated by a learning disability nurse, group members were encouraged and supported to discuss their thoughts in relation to three key questions:

• what does dignity mean?
• what were their experiences of health services?
• what could nurses do to make dignity better?

The core themes defined by the expert group have shaped the structure of this document and each section presents the reader with:

• the experiences of people with learning disabilities using health care services
• positive experiences
• lareas for improvement in relation to dignity
• what’s needed to improve dignity
• getting it right for people with learning disabilities
• practical ideas on what nurses can do to improve dignity
• signposting
• sources of further information and support.

The guidance concludes with information relating to the particular health needs that people with learning disabilities may have, and provides ideas on working in collaboration with other service providers.

The RCN Learning Disability Forum would like to thank everyone involved in the development of this publication for their time and expertise.

All health professionals have a role in promoting the health of people with learning disabilities. The skills, knowledge and experience of Learning Disability Nurses are vital in this area, whether it be providing discreet assessment and intervention or supporting colleagues in general services. The RCN and the government of the four UK countries recognise this unique contribution and the continued development of the profession (RCN, 2011; Scottish Government, 2012).
What is dignity?

Dignity can be difficult to define, as it is a multi-faceted concept and can be interpreted in many different ways. In our Dignity at the heart of everything we do campaign, the RCN offered the following definition:

‘Dignity is concerned with how people feel, think and behave in relation to the worth of value of themselves and others. To treat someone with dignity is to treat them as a being of worth, in a way that is respectful of them as valued individuals.’ (RCN, 2008)

In care situations dignity may be promoted or diminished by a number of factors including the physical environment, organisational culture, the attitudes and behaviours of the nursing team and others, and the manner in which care activities are carried out.

When dignity is present people feel in control, valued, confident, comfortable and able to make decisions for themselves. When dignity is absent people feel devalued and lacking in control or comfort. They may lack confidence and be unable to make decisions for themselves. They may feel humiliated, embarrassed or ashamed.

Dignity applies equally to those who have capacity and those who lack it. Everyone has equal worth as a human being and must be treated as if they are able to feel, think and behave in relation to their own worth or value.

The nursing team should therefore treat all people in all settings and of any health status with dignity, and dignified care should continue after death (RCN, 2008).

What does dignity mean to people with learning disabilities?

The expert panel had lengthy discussions when it came to defining the term ‘dignity’ in relation to health care. From these discussions they agreed:

“Dignity is being treated as a human being. It is about being treated as an individual and with respect.”
Dignity has been a pertinent issue in relation to services for people with learning disabilities for many years. In the past a significant number of individuals were placed in long stay institutions which were often situated outside of towns and cities. These were generally characterised by a lack of dignity, examples of which include:

**Place**
- offered little or no privacy
- barren environments, with little or nothing to do
- institutions/hospitals often situated miles away from the person’s community, family and friends
- little or no access to the outside world; everything that was considered to be needed was within the institution

**People**
- personal identity was not promoted (wards had shared clothing and toiletries for all residents)
- little in terms of personal possessions
- language was often stigmatising and undignified

**Process**
- inflexible regimes (for example, refreshments at set times)
- lack of choice
- family having to apply in writing to take their relative out of the grounds.

During the late 1980s hospital closure Emphasis was placed on delivering person-centred services which support individuals to take control of their lives.

At the turn of the millennium the four UK countries developed national policies with regards to people with learning disabilities, all of which enshrined the importance of health care and fair access to services for this group. Each country policy highlighted the specific health needs of people with learning disabilities and stipulated that people should be able to use the same health services as any other citizen, whilst noting that general services needed support and training to facilitate this.

Despite the plethora of policy relating to people with learning disabilities, there have been a number of damning inditements of individuals’ actual experiences of using health services. Reports have described poor practice, have been highly critical of the way people with learning disabilities have been treated, and have reflected on the inexcusable deaths of some of society’s most vulnerable individuals in places where one would expect them to be safe (DRC, 2006; Mencap, 2007; Michael, 2008; DH, 2012). Some of the commonly reported issues are:

- discrimination
- assumptions being made about individuals with no assessment
- lack of communication with the individual and their carers
- difficulty in accessing services
- staff with a lack of knowledge and skills in learning disabilities
- abuse and neglect.

All of these factors have a shared outcome for the individual – an undignified experience of health care. This guidance explores what nurses can do to improve dignity in the health care they provide, highlighting practical ways of improving dignity for the patient with learning disabilities. As one member of the expert panel said:

“It’s only a few nurses that give others a bad name. We need to remember all the good things nurses do for people with learning disabilities.”

**Signposting**

Dignity: at the heart of everything we do – Royal College of Nursing, [www.rcn.org.uk](http://www.rcn.org.uk)

Dignity in care campaign – Care Services Improvement Partnership, [www.dignityincare.org.uk](http://www.dignityincare.org.uk)

Healthcare for all: independent inquiry into access to healthcare for people with learning disabilities 2008, [www.iahpld.org.uk](http://www.iahpld.org.uk)

Death by indifference – a report by MENCAP describing the tragic deaths of six people with learning disabilities who died in NHS care, [www.mencap.org.uk](http://www.mencap.org.uk)
Understanding my health

**Experiences of people with learning disabilities**

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<tr>
<th>Positive experiences</th>
<th>Areas for improvement in relation to dignity</th>
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<tr>
<td>Having a hospital passport is really important and its help people understand your health. I had a really good experience in hospital, the nurses and doctors listened to me. Coming to the Community Learning Disability Team is good. I see the psychiatrist there, he understands my mental health. I learn about the medication and the appointment letters are really easy to understand. I had a personal care plan, the community nurse helped write it. They use picture and its help me understand my health.</td>
<td>All GP surgeries should use people with learning disabilities to become health checkers. Making sure everything is right. They should check everyone has drinking water, should use a tannoy system to call out names. Receptionists should ask people if they need help reading appointment letters. Every GP surgery should use butterfly needles for people who don’t like blood tests. Also teaching people coping strategies if they have a fear of needles is important, like thinking of something positive.</td>
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**Getting it right for people with learning disabilities**

Dignity for people with learning disabilities often involves what other people may take for granted — asking the person what they want, what support they need and including the individual at all stages of the care planning process. This may involve taking more time to prepare and using alternative or additional methods of communication, such as the use of pictures and symbols.

Allow sufficient time when you meet with the person. Book a double appointment if you think it will be necessary. This will help enable a dignified experience for the individual, giving them sufficient time to adapt to the situation, absorb and process information and express their points of view.

Before meeting with the person, think about the environment you will be seeing them in. Does it promote dignity? Pay particular attention to the following:

- privacy
- physical accessibility
- information, such as signs on doors and toilets (are they accessible?)
- is it clean and tidy?

• how does the person know when it is time to see the clinician? Some people may have difficulties with electronic signs. Perhaps clinics could develop a method of identifying those that require additional support.

Health care can be an anxiety provoking experience for anyone. Having learning disabilities may increase this anxiety, as the individual may not understand why they are there or what to expect. Try to make the situation as predictable as possible for the person, always letting them know what is happening:

- every time something new is introduced, explain what is happening and why
- who everyone is, what they do and why they are there – in ward round situations, minimise the amount of staff present and ensure everyone is introduced to the person
- what’s going to happen afterwards
- who gets to see the relevant information.

If an individual does become anxious, react to the situation in a dignified manner. Offer reassurance and use a non-judgemental tone. As part of your preparation find out any techniques the person uses or you could use to reduce anxieties (for example, what they like to talk about, hobbies, music, relaxation techniques).
Examples of good practice

Staff at the Sussex Partnership NHS Trust developed a half-day training workshop for staff working in local acute hospitals and mental health services. The main aims of the training were:

- to have an understanding of the key issues of learning disabilities
- to explore the communication difficulties that people with a learning disability can have, and how to make the best of them
- to explore the issues of challenging behaviour that people with learning disabilities may have and how to overcome these
- to explore the issues of capacity and consent with respect to people with learning disabilities and how best to work with these issues
- to explore what resources are available to support staff and managers in a general hospital working with people with learning disabilities.

At East Sussex Hospitals NHS Trust each ward has a learning disability link nurse who receives training and advice with staff from the learning disability service. Each ward is given a resource pack, which offers practical advice, support and links to further information. A sensory suitcase is also available via the equipment library, which can be used by staff to develop a calming atmosphere in their ward. An alert system has been developed on the A&E IT system; if the name of someone previously identified as having challenging needs comes in, the staff are advised that there are some special needs to take into account, and what action they can take to support the individual.

Jane, a 16 year old girl who has an autistic spectrum condition, attended the day surgery unit at Crosshouse General Hospital in Kilmarnock, Scotland for dental treatment under general anaesthetic. A previous admission for a similar procedure that had not gone well and in response to concerns expressed by Jane’s family, a meeting was set up involving Jane’s parents, the anaesthetist, the community dentist and the nurses involved in Jane’s care. Topics discussed were communication, environment, fear factors, pre-medications, personal items, and music and distraction therapies. Alternative care plans were agreed upon for varying scenarios that could occur on the day. The actions put into place included:

- communication – supported by Jane’s parents
- environment – the admission area was cleared and available only to Jane and her family. A room was set up to resemble Jane’s bedroom at home, her own bedding, toys and music were brought in before her arrival and the multi-disciplinary team all wore their own clothes. Staff were led by the parents throughout this, enabling them to maintain Jane’s dignity without compromising her care
- pre-medication – a dose was given to Jane before arrival in a juice of her liking. After admission a further dose was administered with much support from Jane’s parents. This allowed the anaesthetist to successfully site a venflon and administer an anaesthetic drug without any distress to Jane or her parents
- distraction therapies – a snoezeling (specialist sensory equipment) mattress was used, along with personalised bedding and toys. Her favourite music and films were played throughout the pre-operative time.

Jane was safely supported onto a theatre trolley whilst still aware, and was able to follow prompts from her mum without any stress being experienced. Surgery went ahead as planned and an uneventful recovery followed. Jane’s parents stayed in the unit throughout and were fully involved in her pre-operative and post-operative care and decisions.

The Basic Personal Care MOT was developed in Nottingham, with the collaboration of the Nottingham Carers Forum, in response to parents and carers of adults with a learning disability becoming increasingly concerned about the personal care their sons and daughters were receiving from services.
The MOT provides advice and guidance to those assisting people with learning disabilities in regards to meeting aspects of personal care with confidence and dignity. It contains a summary checklist highlighting the minimum frequency that tasks should be carried out, and signals the need for further assessment and specialist support if a person is having difficulty with aspects of personal care. The summary checklist provided within the tool acts as the MOT certificate and ensures seven key areas are considered when planning and delivering an individuals’ care:

- Personal hygiene
- Oral hygiene
- Fingernail and hand care
- Toe nail and foot care
- Shaving
- Hair care
- Clothing

The MOT tool was launched at a multi-stakeholder event that included carers and health and social care staff, and has had great success improving dignity for people with learning disabilities. It is now included in the contract monitoring of supported living provision across the county, and has been highlighted as an example of good practice by the valuing people support team.

Signposting

Getting it Right!

A project developed by several health professional bodies to help improve healthcare for people with learning disabilities. See www.mencap.org.uk/gettingitright

Easy Health

Provides a wide range of accessible information on health issues for people with learning disabilities. See www.easyhealth.org.uk

Intellectual Disability Health Information

Provides a wealth of information on the health needs of people with learning disabilities. See www.intellectualdisability.info

The Elfrida Society

Researches better ways of supporting people with learning disabilities and provides a wide range of accessible information on health issues. See www.elfrida.com

Epilepsy Action

A nationwide organisation that aims to improve the quality of life and promote the interests of people living with epilepsy. See www.epilepsy.org.uk

Equal Access?

A practical guide for the NHS: Creating a single equality scheme that includes improving access for people with learning disabilities. See www.dh.gov.uk

Estia Centre

Specialises in the mental health needs of people with learning disabilities. See www.slam.nhs.uk/about-us/clinical-academic-groups/behavioural-and-developmental/estia

Improving health and lives: Learning disability observatory

Gathers and provides information on the health of people with learning disabilities in England. See www.improvinghealthandlives.org.uk

Meeting the health needs of people with learning disabilities – guidance produced by the RCN. Available at www.rcn.org.uk

Mental health nursing of adults with learning disabilities – guidance produced by the RCN. Available at www.rcn.org.uk

Promoting access to healthcare for people with a learning disability – a guide for frontline NHS staff – guidance produced by NHS Quality Improvement Scotland. Available at www.nhsquality.org
Respect me

Experiences of people with learning disabilities

Positive experiences

Making allowances for people with learning disabilities shows you respect me. Good practice in hospitals should be to get to know the person, ask how they would like to be called, i.e. by their first name or last name. When I went to A & E they had a Liaison Nurse for people with learning disabilities. She respected me, listened to me. Every hospital should have a nurse like this.

Areas for improvement in relation to dignity

Should always speak to the person first not the carer. When I went to A & E the doctor asked my brother what was wrong. I spoke up for myself, told the doctor that I am the patient. Making sure that everyone receives the care they need and that nurses need a pay rise! Some staff turn the radio on at night and talking loudly, it’s not right in hospitals. Staff should be more caring.

What’s needed?

- Services should realise that people with learning disabilities are all different. We should be treated as individuals.
- If you are an adult, you should be treated as an adult.
- Having a learning disability doesn’t mean you are stupid, it just means you might need more support.
- It doesn’t matter what you can do or can’t do, doctors, nurses and care staff need to respect everyone.

Getting it right for people with learning disabilities

Ask the individual how they prefer to be addressed and use this term consistently (for example, Mr, Miss or by their first name/nickname).

When talking to the person always talk to them directly and do not ask their carer questions first. With the person’s consent, you may ask the carer questions.

People with learning disabilities have the right to privacy like everyone else, but they may need support in putting this into practice (like being shown how to lock the bathroom door, or needing support in closing curtains).

Before entering a room always knock first, even if you know the person is unable to answer you.

Do not use terms that are out of date and will cause offence, such as mental handicap, mental retardation, mental subnormality.

Remember everyone you work with is a ‘person first’.

Some individuals may prefer the term ‘learning difficulties’ instead of ‘learning disabilities’; find out what term the person uses.
Experiences of people with learning disabilities

SHIELD (Sexual Health Innovation Education for Learning Disabilities) is a programme developed on the Isle of Wight to give people with learning disabilities access to sexual health information and support.

The SHIELD Team worked with a large number of stakeholders to establish a wide-ranging service which offers people with learning disabilities the information they need to lead sexual lives, while respecting their dignity and human rights.

The SHIELD service includes a range of initiatives. The SHIELD clinic, in partnership with the local sexual health service, gives people the time to express their needs in a way which suits them and information is in a format they can understand.

The clinic is supported by a network of more than 60 SHIELD ‘links’ – professionals working in organisations which deal with people with learning disabilities, such as residential care homes, who have undergone a specially created SHIELD training course that includes a section on sexually inappropriate behaviour.

Service users have access to chlamydia screening, condoms and information on the learning disability section on the sexual health website, as well as peer training – a two day sexual health course delivered by people with learning disabilities.

Signposting

People First is an organisation run by and for people with learning difficulties to raise awareness of, and campaign for the rights of, people with learning difficulties, and to support self-advocacy groups across the country. See www.peoplefirstltd.com

Getting it right for people with learning disabilities

People with learning disabilities are a diverse group. Promote dignity by recognising each person as an individual with a unique personality, history and range of abilities.

Do not make assumptions about the person. You need to take time to establish what their abilities are and what they need support for. Ask the person what they can do for themselves, what support they need and how they prefer the support to be given.

It is important that people with learning disabilities do not feel disempowered. It may be frustrating for the clinician to watch an individual seemingly struggle with a task and it may seem easier to do it for them. It may take the person longer to complete certain tasks but giving them the opportunity to work through it themselves will enhance feelings of self-worth and achievement, thus promoting their dignity.

In the past there have been low expectations of people with learning disabilities which had led to increased dependency that leads to low levels of achievement and self-esteem. Conversely, it is important that clinicians and carers have realistic expectations of individuals, thereby avoiding unnecessary feelings of failure and low self-esteem.

Many people with learning disabilities will have some kind of document, often referred to as a passport or personal profile, detailing their abilities and their health and support needs; find out if the person has one.

Experiences of people with learning disabilities

Positive experiences

I broke my arm and needed an operation. My keyworker took my personal file into the ward. It helped the nurses get to know me.

Areas for improvement in relation to dignity

Just because I have a learning disability, they thought I couldn’t do anything. They didn’t even ask what I could do.

What’s needed?

- Nurses should find out what people can do for themselves and not do it for them.
Examples of good practice

Anne, a 48-year old woman with Down’s syndrome and who has dementia, was admitted as an inpatient on a ward at St. George’s Hospital in London suffering from pneumonia. Her friend Gwen was worried that the nursing and other staff may not be able to support Anne. The staff, with the help of a community learning disability nurse, found out when filling in a hospital passport (containing important information about the person such as their likes and dislikes, health difficulties and any medication they may be on) with Anne that she is frightened of the dark, so ensured that she had a bedside light by her bed at night. They also discovered that she likes Elvis Presley so prior to any procedures, for example blood pressure monitoring, they would talk to her about Elvis. By making small personalised changes at no financial cost Anne’s quality of care and dignity was greatly improved.

A nursing student was on placement in an acute mental health setting and a patient was admitted who had a dual diagnosis of learning disability and schizophrenia. The patient was very distressed at the time of admission. The student made a point of spending time with the patient on every shift, and would try to have conversations in a quiet room. The patient seemed to appreciate this. In her interventions with him the student did not really do anything differently to how she would treat any patient. However, the only difference was that it took longer. The patient, in his distress, would often stutter over words, and repeat himself, requiring careful and active listening. The student tried to make it clear that she was listening to him, and valued what he had to say. Over the course of a few days working with the patient, the patient opened up more, while his levels of distress were visibly less. Though the student does not claim any part in the patient’s gradual recovery, she felt that, by taking extra time to listen to him and his concerns, she helped to create an environment where he could express himself.

Support for Living in West London has been running a project called Treat Me Right, which has collaborated with people using services, carers, advocacy groups and hospital staff. The project is designed to improve patient care for people with learning disabilities at Ealing Hospital. One of the crucial messages to come out of the discussions was that every individual with a learning disability is very different, and a way was needed to communicate this to all the hospital staff encountered by the patient while they were in hospital. To deal with this issue they have developed About Me Plans, which have been hugely successful in improving people’s hospital experience and have promoted dignity. The plans are short – just a few pages of A4 – and they go everywhere with the patient. The plans contain all sorts of information which will help staff communicate more effectively and should help the individual feel more comfortable. This might be anything from how someone is able to move or speak to what makes them stressed or the kind of food and drink they prefer.

Some people with learning disabilities may engage in behaviour that is considered challenging. This is often associated with environmental issues like noise levels, or boredom and communication difficulties such as other people not understanding the individual. Preparation is the key to promoting dignity in these situations. Ask the person or their carers if there are any triggers for ‘challenging behaviour’ and try to avoid these or minimise their effects. Respond to any ‘challenging’ situation in a dignified manner. Ensure you adopt a non-judgemental attitude, stay calm, do not to raise your voice and never reprimand the individual for their behaviour. It is crucial that you try to understand the reasons behind their behaviour.

With the person’s consent, it may be very helpful to seek the advice and opinions of carers but it is important to remember that their views may be very different to that of the individual.

Discovering a person’s likes and dislikes is fundamental to successful interventions and will enhance the individual’s experience of health care services. Useful information will include food and drink preferences, an understanding of key relationships and detail of specific personal
routines. Some individuals have very particular needs or rituals which may not appear as significant to other people but are crucial to the person’s functioning and wellbeing. For example, the person may like their belongings placed in a certain position and become agitated if they are moved. Taking time to get to know someone and facilitate their likes and dislikes as much as is possible will be mutually beneficial to both the individual and the service, as it will reduce any anxieties about future interventions.

### Experiences of people with learning disabilities

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<tr>
<td>Some nurses ask what you can do for yourself. It makes me feel good about myself. The nurse always asks service if they need to have an easy read care plan. It’s our choice! Having an advocate really helps me, they speak up for me.</td>
<td>Staff should always check if a person wants an operation. They should help by giving them information about the operation like why I should the operation and what might go wrong. Giving the patients information helps them make their own decisions. We should a better choice of foods in hospital. I know they prepare a healthy menu in hospital but why do that when you have hospital shops that sell unhealthy foods.</td>
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**What’s needed?**

- We have the right to say yes or no to treatment.
- Doctors and nurses should give us information to help us make decisions, which is easy to understand.

**Getting it right for people with learning disabilities**

The choices we make define who we are. People with learning disabilities have often been denied a diverse range of choices, from small day-to-day to significant health care decisions. Empowering people contributes to an enhanced dignified experience of health care.

Some people may have high support needs, and may not communicate verbally. In these situations it will be necessary to use alternative methods of communication, such as signs and symbols. The clinician should also pay particular attention to the individual’s reactions to different experiences; this will be beneficial when ascertaining people’s choices or what is in their best interests if they are unable to make the decision themselves.

Over the last few years personal health budgets have been introduced allowing individuals with continuing health care needs and disabilities to take greater control over their lives, health and wellbeing. Once health needs have been identified, an individual with their local health team will develop a care plan and a budget will be allocated to the individual to implement their care plan. It can be used for a range of interventions such as therapy, exercise, equipment and personal care. Personal health budgets have been welcomed by people with learning disabilities, carers and services, especially in light of their increased health needs and the continuing drive for individuals to have autonomy over their lives.
Examples of good practice

At Cardiff and Vale NHS Trust a project was developed to enable people with learning disabilities to participate in decision-making in relation to chronic kidney disease (CKD) care. An educational package was specifically developed for people with learning disabilities. An accessible information group advised on presentation and accessibility. The package covered four key areas:

- functions of the kidney
- symptoms related to CKD
- treatments available
- symptoms and treatment of renal anaemia.

The project has supported people with learning disabilities to understand treatment options, ensuring that individuals can make informed choices.

Pacesetters is a partnership between local communities that experience health inequalities, the NHS and the Department of Health. The programme involves work with six strategic health authorities in England and aims to promote equality with regards to age, disability, ethnicity, gender, religion and sexual orientation. As part of the programme East Kent Hospitals University NHS Foundation Trust has developed an ‘easy read menu’ for people with learning disabilities who are staying in hospital. The project provides specifically designed menus, ensuring that people with learning disabilities have the same range of choices as other patients.

Information is presented in simple language, uses accompanying photographs/pictures and offers signposts to further help. The project involved a collaboration between a wide range of stakeholders including people with learning disabilities, the voluntary sector, local university and the health care staff.

In North Wales NHS Trust a Health Liaison Service for adults with learning disabilities co-developed a DVD for service users about accessing GP surgeries. It also highlighted the importance of annual health checks. The DVD was jointly developed with service users, as the nursing team wanted local people to own it and it has proved to be a great success since its launch in August 2008.

The team also produced hand held ‘health action plans’ for adults with learning disabilities to enable them to gain control and own their health needs and plan how to meet these needs.

Signposting

Best interests: guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves – available at www.estiacentre.org

Office of the Public Guardian – supports and promotes decision-making for those who lack capacity or would like to plan for their future within the framework of the Mental Capacity Act 2005 – see www.justice.gov.uk/about/ogp
Feeling safe

Experiences of people with learning disabilities

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<tr>
<td>Staff make sure I have the right medicine and then they double check it.</td>
<td>I feel safe with my mobile phone, especially if I’m in hospital for more one day I need to charge it.</td>
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<tr>
<td>When I was in hospital I got really anxious. A nurse sat with me until I was calm and feel safe.</td>
<td>Find out if I have any coping strategies that help me feel safe.</td>
</tr>
<tr>
<td>The most important person in hospital is the receptionist. They are the first person you meet. They can make you feel safe, being kind and respecting you.</td>
<td>A&amp;E can be scary places. You have to wait a long time. All sorts of people are there, some are drunk, some are grumpy, some are in lots of pain. There might also be police there. Other patients can make you feel unsafe and some patients are rude to the staff. That’s wrong.</td>
</tr>
</tbody>
</table>

What’s needed?

- Tell us what the routine is. Tell us what is happening, like when you turn the lights out.
- If it’s really noisy, ask if the person would like to go somewhere quiet.
- If you need to restrain someone don’t do it in front of other people.

Getting it right for people with learning disabilities

Accessing health care services can be an anxiety provoking experience and this may be further exacerbated for people with learning disabilities, as their understanding of the situation may be limited. This can result in the person feeling ill at ease and unsafe. Individual care plans should address issues of safety in collaboration with the person, thereby promoting a dignified experience of health care.

All health care staff should be up-to-date and familiar with local policies and procedures for the safeguarding of vulnerable adults and children.

The safety of the person should always be assessed (especially with regards to hospital admissions). There may be a variety of risk issues that need to be considered, such as vulnerability, harm to self or others (deliberate or accidental) and medication management. Clinicians should devise proactive plans that aim to minimise risk and promote the person’s safety. Balancing risk management against the person’s independence is fundamental to proving a safe and dignified experience.

As well as managing risk, emphasis should be placed on developing a sense of safety and security for the person. Factors that may contribute to people with learning disabilities feeling safe and secure will be individual and may vary to those of the wider population. Clinicians should consider the following with this group:

- routine and predictability
- orientation to the environment (frequent reminders may be needed), such as toilets, where to get a drink
- somewhere quiet to go if it’s noisy or chaotic
- opportunity to contact family, friends and carers and support to do this if required
- regular access to a named professional.

In some circumstances frequent observation of the person may be required. If this is necessary consideration should still be given to the person’s dignity, including privacy and avoiding disruption of activities.

When finding out about an individual’s support needs, especially with regards to their personal care, clinicians should consider what makes the person feel safe and comfortable, for example, the gender of the care provider.

If individuals witness a disturbing incident (including the use of restraint) staff should provide opportunities for people with learning disabilities to be de-briefed.
Examples of good practice

Sheffield Care Trust and Sheffield City Council developed a benchmarking tool to promote the safety of people with learning disabilities in acute mental health and general hospital settings. The factors included were:

- supporting people prior to admission
- orientation to the health environment
- assessment of risk of individuals with mental health needs
- balancing observations and privacy in a safe environment
- meeting the individual’s safety needs
- a positive culture to learn from complaints and adverse incidents related to harm and abuse.

The tool provides general indicators of best practice and additional indicators for the individual’s care plan, based around the activities of daily living, and concludes with an action plan for the service to complete.

The Metropolitan Police Service has developed an easy guide to staying safe for people with learning disabilities which, while not directly aimed at health care, provides valuable information that nurses can use as part of care plans and discharge plans, especially for those who are particularly vulnerable (Metropolitan Police, 2001). The guide covers staying safe:

- at home
- when you go out
- travelling on buses and trains
- using taxis and minicabs
- what to do if there is real trouble.

Signposting

Ann Craft Trust – works with staff in the statutory, independent and voluntary sectors to protect people with learning disabilities who may be at risk from abuse. See [www.anncrafttrust.org](http://www.anncrafttrust.org)

National Patient Safety Agency – the NPSA leads and contributes to improved, safe patient care by informing, supporting and influencing the health sector. See [www.npsa.nhs.uk](http://www.npsa.nhs.uk)

Respond – provides a range of service to victims and perpetrators of sexual abuse who have learning disabilities. See [www.respond.org.uk](http://www.respond.org.uk)

Voice UK – a national charity supporting people with learning disabilities who have been victims of abuse or crime. See [www.voiceuk.org.uk](http://www.voiceuk.org.uk)
What’s needed?

• Find out how we communicate.
• Talk to us like adults.
• Don’t talk to us like we are stupid.
• Nurses need to change the way they communicate, we don’t have to change.
• Use everyday words, not jargon.

Communicating with me

<table>
<thead>
<tr>
<th>Positive experiences</th>
<th>Areas for improvement in relation to dignity</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the person can't speak or use signs it’s good that some staff listen to sounds the person makes and watch out for facial expressions.</td>
<td>Signage can be much better in hospitals.</td>
</tr>
<tr>
<td>GP surgeries and hospitals should look at the personal health profile to learn about how the person communicates. We call these ‘black books’ where I live.</td>
<td>Use easy language when writing signs.</td>
</tr>
<tr>
<td>Remember that communication is the key to health. If you understand the person and they understand you, you’re half way there.</td>
<td></td>
</tr>
<tr>
<td>Having photos of the staff on shift today is really helpful and badges that say ‘hello my name is…’</td>
<td></td>
</tr>
</tbody>
</table>

Getting it right for people with learning disabilities

Effective health care provision is dependent on good communication between all stakeholders, and leads to an inclusive and dignified experience. Many people with learning disabilities will have significant communication needs. It is essential that clinicians adapt their service delivery to accommodate this. This includes implementing larger organisational changes, such as providing a range of accessible information, to preparing appropriately for one-on-one interactions.

Improving communication with people with learning disabilities should always be considered on an individual basis and carers can provide support with this. A number of general points that clinicians’ should consider, include:

• use simple everyday language
• before meeting the person try to think of easier ways of saying a word, for example using ‘sad’ instead of ‘depressed’
• when introducing fresh information to someone use no more than two new information-carrying words in a sentence and provide an explanation, perhaps using alternative methods, to support this
• consider the use of photographs, pictures and symbols to support communication
• check if the person has had a speech and language therapy assessment, and if there are any recommendations that have arisen from it
• avoid abstract words or concepts and use concrete terms where ever possible.
Examples of good practice

In collaboration with service user groups and with advice from speech and language therapy, South London and Maudsley NHS Foundation Trust developed 29 different leaflets on mental health and associated issues for people with learning disabilities. The leaflets covers areas such as:

• what is mental health and mental health problems?
• the common mental health problems
• mental health assessment
• the care programme approach (CAP)
• the role of various mental health professionals and services
• Mental Health Act.

Local service users developed a DVD explaining what mental health means to them, the support they need, and what they expect from health and social care staff. DVDs were also developed highlighting what happens when a person sees a doctor, nurse or psychologist.

Signposting

Easy Info provides a wide range of advice on making information accessible to people with learning disabilities. See www.easyinfo.org.uk

Makaton is a signing vocabulary often used with people who have learning disabilities. Learning some common signs would be very helpful. See www.makaton.org

Change provides a picture bank, commonly used for people with learning disabilities, which includes a specific bank on health issues. See www.changepeople.co.uk

South London and Maudsley NHS Foundation Trust developed a series of easy read leaflets on mental health. See www.slam.nhs.uk
The health needs of people with learning disabilities

People with learning disabilities have increased health needs compared to the wider population. Although mortality rates have improved over recent decades, they are still likely to die younger than other people. Preliminary findings from a recent study found that the median age of death for people with learning disabilities was 67 years, with this significantly decreasing as the level of learning disability increases. They found that over half of all deaths were cardio-respiratory related and 49.5 per cent of the deaths were unexpected. Below are some of the health problems that they may be more vulnerable to.

- **Cancer** – people with learning disabilities are at greater risk of developing gastrointestinal cancers, specifically oesophageal, stomach and gall bladder.

- **Coronary heart disease** – individuals with learning disabilities are more likely to develop hypertension, obesity and not partake in exercise, all of which increase the risk of ischaemic heart disease. People with Down’s syndrome are at greater risk of congenital heart problems.

- **Dental issues** – poor diet and poor dental hygiene have often been reported in people with learning disabilities, which may explain increased rates of tooth decay, gum disease and tooth extraction. Dental interventions cause anxiety for many people, but for people with learning disabilities who may not fully understand what is happening or what is required of them, it maybe even more so, and may lead to changes in behaviour. Dental practitioners need to work in partnership with the patient and their carers to reduce any barriers to treatment.

- **Diabetes** – people with learning disabilities are at higher risk of developing diabetes than the wider population.

- **Epilepsy** – approximately one-third of people with learning disabilities have epilepsy, and the rate increases in people with higher support needs. They are more likely to have more than one type of seizures, have complex seizure patterns and be difficult to manage. Status epilepticus is also more common and carers/staff need to be fully aware of the individual’s treatment plan should this situation arise.

- **Gastro-intestinal problems** – people with learning disabilities, especially those who live or have lived in large communal settings, are at risk of contracting helicobacter pylori which may cause peptic ulcers and is a predisposing factor to gastric carcinoma.

- **Mental health problems** – due to a range of biological, psychological and social factors, people with learning disabilities are vulnerable to developing mental health problems. The full range of mental health problems can occur; in particular schizophrenia has three times the average prevalence.

- **Weight problems** – levels of obesity are higher, especially in women and those with milder learning disabilities. Some genetic conditions are linked to obesity, especially Down’s syndrome and Prader-Willi syndrome. Some people with higher support needs or those with metabolic disorders such as phenylketonuria are at risk of being underweight. Some individuals may be on medication where an increase in appetite is a side effect.

- **Respiratory disease** – this is the main cause of death in people with learning disabilities. They may be at risk of respiratory track infections caused by aspiration or reflux if they have swallowing difficulties. People with Down’s syndrome are at particular risk, as are people with tuberous sclerosis.

- **Sensory problems** – both sight and hearing problems are far more common in people with learning disabilities and they need support to access regular examinations.

- **Swallowing and eating problems** – problems with swallowing are common, especially among those with high support needs. Swallowing problems can lead to choking, secondary infections and weight loss. Some people may have a percutaneous endoscopic gastrostomy (PEG) to ensure adequate nutrition.

- **Thyroid disease** – hypothyroidism is more common among people with learning disabilities and is particularly associated with Turner’s syndrome and Down’s syndrome. (Adapted from Hardy et al., 2006)
The following practical ideas will help you improve your knowledge, skills and health care delivery to people with learning disabilities.

- Most areas will have a self-advocacy group for people with learning disabilities. Ask them to give your team a teaching session or if they have produced any learning materials. Social services will know of any local groups.

- Contact your local school of nursing; ask them if they cover health needs of people with learning disabilities on their courses and if not, why not!

- Most areas have a community team for people with learning disabilities (CTPLD) which employs a range of specialists, including learning disability nurses. Find out if they have any information to offer your service or could perhaps run a teaching session. Contact your local primary care trust or social services to locate your local CTPLD.

- Ensure there is information about people with learning disabilities included in every local induction.

- Contact your organisation’s training department; ask if people with learning disabilities are included in the corporate induction programme, if not, ask why not!

- Identify a nurse in your team to be the formal link to the local CTPLD and ask for a reciprocal arrangement with a learning disability nurse.

- Many areas have introduced the post of Acute Liaison Nurse for people with learning disabilities. The acute liaison nurse will work in acute hospitals and in collaboration with hospital staff to support easy access and develop a better understanding of the needs of people with learning disabilities.
Appendix 1 - Bill of Rights

Bill of Rights
for people with Learning Disabilities
inspired by the ‘Can you understand it?’ team,
Bexley Mencap, Bexley Advocacy for All and ResearchNet

- Respect me and respect each other
- Speak slowly, clearly and politely
- Speak to me in a way I understand
- Please check I have understood what you are saying
- Speak to me first, then my carer
- Find out how I communicate
- Find out if I need a family member or advocate to speak for me
- Help me to make my own choices
- Ask me if I have a black book or hospital passport
- Make signs easy to understand in hospitals
Resources

**National policies on learning disabilities Northern Ireland**

*Equal lives: review of policy and services for people with a learning disability in Northern Ireland (2005)*, see [www.rmhldni.gov.uk](http://www.rmhldni.gov.uk)

**Wales**

*Fulfilling the promises: what future services will look like for people with learning disabilities in Wales (2001)*, see [www.wales.gov.uk](http://www.wales.gov.uk)

**Scotland**

*The same as you? A review of services for people with learning disabilities (2000)*, see [www.scotland.gov.uk](http://www.scotland.gov.uk)

**England**


**Law on consent to treatment**

Northern Ireland: *Guidance on consent to treatment (2003)*, see [www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

Scotland: *Adults with Incapacity (Scotland) Act 2000*, see [www.scotland.gov.uk](http://www.scotland.gov.uk)

England and Wales: *Mental Capacity Act 2005*, see [www.justice.gov.uk/about/opg](http://www.justice.gov.uk/about/opg)

**Networks**

**A2A Access to Acute Network**

Formed in 1998, the A2A network has expanded to become a national network for people who support people with a learning disability when they are in a general hospital as an outpatient or on admission (emergency or elected). Membership is open to anyone who has an interest in this area of work and facilitation for people with learning difficulties and on any issues related to the identification and training of health facilitators and health action planning. Contact: mark.bradley@oxleas.nhs.uk

**Useful national organisations**

**British Institute of Learning Disabilities (BILD)** [www.bild.org.uk](http://www.bild.org.uk)

BILD provides research and training on a wide range of issues affecting people with learning disabilities and has a range of free leaflets to download and publications/training materials to purchase.

**Foundation for People with Learning Disabilities**

[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

Promotes the rights, quality of life and opportunities for people with learning disabilities through research, development and influencing policy. Free resources are available for download from the Foundation’s website.

**Improving Health and Lives: Learning Disability Observatory**

[www.improvinghealthandlives.org.uk](http://www.improvinghealthandlives.org.uk)

Provides a range of information and statistics on the health of people with learning disabilities.

**Mencap**

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

A national organisation that fights for equal rights and greater opportunities for people with learning disabilities.

**National Autistic Society**

[www.autism.org.uk](http://www.autism.org.uk)

A national organisation that fights for the rights and interests of all people with autism, to ensure that they and their families receive quality services appropriate to their needs. It produces a number of free leaflets and publications/training materials for purchase.

**National Development Team for Inclusion**

[www.ndti.org.uk](http://www.ndti.org.uk)

Promotes the rights and inclusion of vulnerable people and has produced a range of information on services making reasonable adjustments for people with learning disabilities.
Royal National Institute for the Blind (RNIB)  
www.rnib.org.uk
The RNIB offers information, support and advice to over two million people with sight problems.

Royal National Institute for the Deaf (RNID)  
www.rnid.org.uk
The RNID offers information, support and advice to over two million people with hearing problems.

Other useful websites

Challenging and/or offending behaviour

Care and Treatment of Offenders with Learning Disabilities
Provides information on people with learning disabilities who have, or are at risk of committing offences. See www.lodoffenders.co.uk

Challenging Behaviour Foundation
Provides guidance and information on supporting people with challenging behaviour, including downloaded fact sheets. See www.thecbf.org.uk

Genetic syndromes

Assert (Angelman’s Syndrome)
Offers advice and support for those caring for or supporting people with Angelman’s Syndrome. See www.angelmanuk.org

Down’s Syndrome Association
This organisation helps people with Down’s syndrome to live full and rewarding lives. It provides a range of downloadable information. See www.dsa-uk.com

Down’s Syndrome: health issues
Offers advice on the specific health needs of people with Down’s syndrome. See www.ds-health.com

Down’s Syndrome Scotland
Provides information about the condition, with advice and guidance for individuals affected, their families and carers. See www.dsscotland.org.uk

Fragile X Society
Provides advice and information about the needs of people with Fragile X syndrome. See www.fragilex.org.uk

Prader-Willi Association (UK)
Offers advice, support and information on Prader-Willi syndrome. See www.pwsa.co.uk

Tuberous Sclerosis Association
Supports sufferers, promotes awareness, and seeks the causes and best possible management of tuberous sclerosis. See www.tuberous-sclerosis.org

Turner Syndrome UK
Support and information to both girls and adult women with Turner syndrome, their families and friends. See www.tss.org.uk
References and key publications


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Royal College of Nursing (2008) *Dignity: at the heart of everything we do*. www.rcn.org.uk


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