Dignity
At the heart of everything we do

Royal College of Nursing

Dignity in health care for people with learning disabilities

RCN guidance

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ROYAL COLLEGE OF NURSING

Dignity in health care for people with learning disabilities

Guidance for nurses

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Dignity
At the heart of everything we do

1

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
  - areas 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.

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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."*

They went on to deconstruct the term into several key themes:

- understanding my health
- respect me
- get to know me
- having choices and making decisions
- feeling safe.

This guidance has contains material in each of these categories to reflect the views of those using health care services.

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Dignity, health care and people with learning disabilities

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 programmes resulted in people being moved into the community, living independently or in small supported housing. 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 mainstream 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). 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**
Dignity in care campaign – Care Services Improvement Partnership, **www.dignityincare.org.uk**
Healthcare for all: independent inquiry into access to healthcare for people with learning disabilities 2008, **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**

Understanding my health

Experiences of people with learning disabilities	
Positive experiences	**Areas for improvement in relation to dignity**
The nurse at the surgery gives me information about good foods and bad foods. We made a plan of what I should eat. I have lost some weight. I get anxious at the clinic. They always give me the first appointment. It helps keep me calm.	I hear people with learning disabilities get a bad deal from hospitals; I saw it on the news. They need to take better care of us. It's like getting health care from a third world country. We are treated like second class citizens.

What's needed?

- All nurses and support staff should have training about people with learning disabilities.
- We should have regular health checks.
- CTPLDs (Community Teams for People with Learning Disabilities) should give other nurses information and support.
- We should be given information and help about how to stay well, like having a good diet or doing exercise.
- If you want to give us medication you should tell us:
  - what it is for
  - why we should take it
  - how it will help
  - about the side effects
  - information in a format that is easy to understand
  - how to take the medication.

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**

Estia Centre
Specialises in the mental health needs of people with learning disabilities. See **www.estiacentre.org**

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	**Areas for improvement in relation to dignity**
The district nurse always speaks to me first. She talks to my mum if I cannot answer her questions.	The doctor always speaks to my mum. He doesn't really look at me. He never asks me what is wrong.
When I was in hospital the nurses always helped me close the curtains when I got dressed.	They sent an appointment letter to my mum instead of me. I can read and I have my own diary. They treat me like a child.
The nurses were very caring. They took time to speak to me. They helped me get better.	I was in hospital. The doctor came to see me. She had lots of students with her. She didn't ask me if I minded. I was very embarrassed.
They treated me the same as everyone else.	They stood by my bed and talked about me. No one asked me what I thought.
Nurses need respect as well.	I made a complaint about a nurse. She was horrible to me. She said I was lying. The other nurses said they didn't hear anything, but they were there. They stick together. They didn't respect me.

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.

EXAMPLES OF GOOD PRACTICE

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**

Values into Action provides research, training, consultancy, outreach and accessible information. See **www.viauk.org**

Get to know me

Experiences of people with learning disabilities	
Positive experiences	**Areas for improvement in relation to dignity**
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.	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.

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

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.

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.

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.

Having choices and making my own decisions

Experiences of people with learning disabilities	
Positive experiences	**Areas for improvement in relation to dignity**
My nurse gave me a leaflet about the medication. The leaflet was easy to read. It used words that I knew. It also had pictures that helped. We read through it together and she answered my questions. I told the doctor that I would take the medication.	I was at the doctors and he started to write a prescription. He hadn't told me what the prescription was for. He didn't ask if I wanted the tablets.

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 had 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.

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**

Making Decisions Alliance – an alliance of national and local disability and older person services that campaign for legislation in regards of mental capacity. See **www.makingdecisions.org.uk**

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.publicguardian.co.uk**

Feeling safe

Experiences of people with learning disabilities	
Positive experiences	**Areas for improvement in relation to dignity**
I was beaten up and I went to A&E. The nurses made me feel safe. They treated me with respect. They talked to me nicely and calmed me down. They said I could have my own room, because it so was noisy there.	I was in a ward and a patient was screaming. Nobody did anything, I was scared.
I don't like the dark. The nurses let me have the bedside light on at night.	The nurses restrained a patient in front of me. They shouldn't do this in the lounge. It was frightening.
I was at A&E late at night. They said I could go home, but I didn't feel safe. The hospital paid for a taxi.	My boyfriend was sectioned. It wasn't safe in the hospital, he was so frightened. They did nothing to help him. They left him alone.

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 its 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**

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**

Respond – provides a range of service to victims and perpetrators of sexual abuse who have learning disabilities. See **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**

Communicating with me

Experiences of people with learning disabilities	
Positive experiences	**Areas for improvement in relation to dignity**
My key worker gave the nurses a list of how I communicate. It really helped them talk to me.	I was in the waiting room. I sat there for ages waiting for my turn. No-one told me that the sign says when it's your turn. I'm no good with words.
I was in hospital and they gave me a leaflet about PALS. It was for people with learning disabilities. It was very good.	They use words that I don't understand. Not everybody is a nurse or doctor.

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.

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**

4

The health needs of people with learning disabilities

People with learning disabilities may develop the same health problems as any other person. There are some 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 maybe 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.

5

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**

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

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

England
Valuing people now: a new three-year strategy for people with learning disabilities (2009), see **www.dh.gov.uk** and the valuing people website at **www.valuingpeople.gov.uk**

Law on consent to treatment

Northern Ireland: Guidance on consent to treatment (2003), see **www.dhsspsni.gov.uk**
Scotland: Adults with Incapacity (Scotland) Act 2000, see **www.scotland.gov.uk**
England and Wales: Mental Capacity Act 2005, see **www.publicguardian.gov.uk**

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 can be accessed through **www.nnld.org.uk/a2a**

Health Facilitation Network (Learning Disabilities)
A network created to share information, resources and good practice in order to improve the process of health 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**

Mental Health in Learning Disabilities Network (MHiLDN)
A free-to-join email network for anyone interested in the mental health needs of people with learning disabilities. Details of the network can be accessed at **www.estiacentre.org**

UK Health and Learning Disabilities Network
A free-to-join email network for anyone with an interest in the health needs of people with learning disabilities. To subscribe, visit **www.ldhealthnetwork.org.uk**

Useful national organisations

British Institute of Learning Disabilities (BILD)
Campion House, Green Street, Kidderminster, Worcestershire, DY10 1JL
Tel: 01562 723010
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
9th Floor, Sea Containers House, 20 Upper Ground, London SE1 9QB
Tel: 020 7803 1100
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.

Mencap
123 Golden Lane, London, EC1Y 0RT
Tel: 020 7454 0454
www.mencap.org.uk
A national organisation that fights for equal rights and greater opportunities for people with learning disabilities.

National Autistic Society
393 City Road, London, EC1V 1NG
Tel: 020 7833 2299
www.nas.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.

Royal National Institute for the Blind (RNIB)
105 Judd Street, London, WC1H 9NE
Tel: 020 7388 1266
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)
19-23 Featherstone Street, London, EC1Y 8SL
Tel: 0808 808 0123
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.ldoffenders.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**

6

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