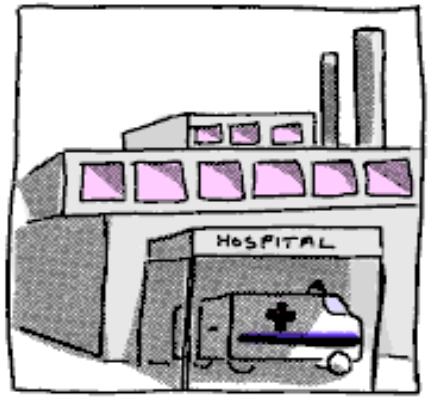
Brighton and Sussex University Hospitals NHS Trust

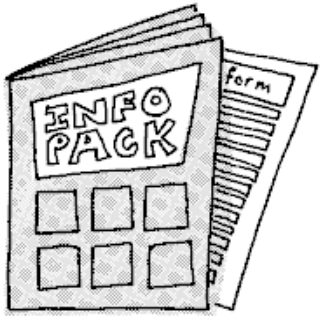
Sussex Partnership NHS Foundation Trust

The Learning Disability Liaison Team

RESOURCE PACK

IMPROVING HEALTHCARE FOR PEOPLE WITH LEARNING DISABILITIES





Sussex Partnership NHS Foundation Trust

The Learning Disability Liaison Team

Do you have a patient with a learning disability on your ward?

Please call the Learning Disability Liaison Nursing Team at BSUH on :
01273 696955 ext 4975 / bleep 8514
Or
Direct Line 01273 664975

We are available Monday to Friday, 8.30-4.30, to support you and your patient, their carers or family during admission or attendance at our hospitals.

The Learning Disabilities Liaison Team aims to provide active support, education and advice for professionals, acute hospital staff, the patient and their family and carers.

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What is a Learning Disability?

According to the Department of Health (1998), a diagnosis of learning disability is given when an individual meets three important criteria, in that they have

1. A significant impairment of intelligence, as well as
2. A significant impairment of social functioning, and that
3. Both of these impairments were acquired before adulthood.

Level of Intelligence

A person's level of intelligence is determined by a psychometric assessment (usually administered by a clinical psychologist). This gives a numerical measure of intelligence (an IQ score). A significant impairment is indicated by an IQ score of below 70 (the aveage for the population is 100).
The lower the IQ, the higher the level of the person's learning disability.

Social Functioning

'Social functioning' means the individuals ability to cope on a day to day basis with their own lives. This includes skills in communication, self care, home living, social relationships, using community resources (eg bus, shops etc), work, leisure, health and safety.
Having a significant impairment in social functioning suggests that the individual needs significant help to ensure they survive and/or adapt to daily living.

Acquired before adulthood

This means that the impairment was acquired before the age of 18. In practice, most learning disabilities are present at birth or have early onset in childhood. The causes of learning disability are split into three categories:

1. Those before the child is born (Prenatal causes, eg: Downs Syndrome, Fragile X Syndrome, drugs or alcohol during pregnancy)
2. Those occurring during birth (Perinatal causes, eg: infection in the womb, asyphyxia, premature birth)
3. Those occurring after birth (Postnatal causes, eg: head injury, Meningitis, Retts Syndrome)

Description of Learning Disabilities

(World Health Organisation, 1992)

Category of Learning Disability	IQ	Typical Abilities (Based on ICD-10)
Mild	**50-70**	Hold conversation, Full independence in self-care. Practical domestic skills. Basic reading/writing. Many adults will be able to maintain good social relationships and employment
Moderate	**35-50**	Limited language. Need help with self-care. Simple practical work (with supervision) Usually fully mobile. Most adults will achieve a degree of independence and will require varying levels of support.
Severe	**20-35**	Use of words/gestures for basic needs. Activities need to be supervised. Work only in very structured situations. Ongoing support/supervision required in all aspects of self-care.
Profound	**Below 20**	Unable to understand requests, very limited communication. Little or no self-care skills. Usually incontinent with severe impairment to mobility. Will require support to fulfil all daily living skills.

Diagnostic Overshadowing

The term ‘diagnostic overshadowing’ refers to the tendency for physical health conditions to remain undetected in people with a learning disability. Due to the person’s behaviours, level of learning disability and presentation, assumptions may be made about their health status and tests routinely offered to the general public may not be offered to learning disabled clients.

Research has shown that people with learning disabilities are more prone to certain physical health conditions than the rest of the population, but are less likely to have the relevant tests or treatment.

Clinicians need to be flexible in their approach to people with a learning disability, and to develop skills or techniques to facilitate the person receiving a treatment or test.

The observations of the carer or parent may assist with diagnosis, as they can separate the persons normal behaviour from the abnormal. They can also give examples of episodes of potential ill health and the effects upon the person which may not be within the usual range of signs and symptoms for a specific condition.

Barriers to Accessing Healthcare

It is suggested that people with learning disabilities experience difficulty in using and gaining access to assessment and treatment within mainstream health services. Some of these difficulties may be due to:

- People with learning disabilities experiencing communication difficulties in making appointments, eg: being unable to read, make appointments verbally or tell the time
- Reliance upon carers to explain the persons health needs – a person with a learning disability may find it extremely difficult to describe or indicate their symptoms which could lead to a wring diagnosis or illness going undetected
- Physical barriers experienced when examination is required, eg: lying on an examination couch, sitting still for an x-ray
- Limited development of information leaflets and documentation about illnesses or procedures for people with learning disabilties
- Communication – there may be a need for health workers to explain ‘what they need to know, what they need to do, what the equipment does, how it will be used and how it may feel’, in an appropriate way, to support the person with a learning disability to understand

Health Conditions

- People with a learning disability are three times more likely to die of a respiratory disease.
- They have a higher rate of coronary disease.
- They have higher rates of gastro-intestinal cancers and stomach disorders.
- Epilepsy – 22% of people with a learning disability have epilepsy, compared with 1% of the general population
- Dementia – 21.6% of people with a learning disability have dementia, compared with 5-7% of the general population. People with Downs Syndrome are at high risk of developing it younger than other people.
- Thyroid Problem – There is a greater risk of having a thyroid problem in people with a learning disability, particularly those with Downs Syndrome.
- Osteoporosis – People with a learning disability tend to have osteoporosis younger than the general population, and have more fractures.
- Hearing Problems – 40% of people with a learning disability have hearing problems.
- Sight Problems – People with learning disabilities are more likely to have sight problems.
- Poor dental hygiene and dental care – 36.5% of adults with a learning disability and 80% of adults with Downs Syndrome have unhealthy teeth and gums.
- Underweight / Overweight – People with a learning disability are more likely to be under / over weight.

(Taken from "Treat me right, better healthcare for people with a Learning Disability" Mencap 2003)

Communication Hints and Tips

Ways to help a person understand you:

- Gain the person's attention. Make sure they are looking at you, and reduce distractions as far as possible.
- Speak in clear, simple sentences, eg: "Can you sit up in bed please?" (pause) " Now please can you have a drink?"
- Use the signs from your ward's Hospital Communication Book – remember the most important thing is to talk normally and sign the key word, eg: Here's something to eat (eat being the key word)
- Break longer instructions into small parts
- Avoid using abstract, complex language, eg: talking about things in either the past or future, or using complex words. The 'here and now' is much easier to understand
- Avoid medical terminology!
- Use pictures, or objects, alongside talking normally, to help explain what you mean
- Some people with a learning disability may have a short attention span – limit sessions where appropriate

Some people with learning disabilities will need extra time, because communication can take longer and require care. Plain Language is best supported by visual information whenever possible. It is a good idea to ask questions or change the question. Understanding can also be checked by asking the person to explain the issue in their own words.

How an Individual with a Learning Disability may communicate

Verbal

- Individuals who have a learning disability may be able to comprehend (understand) more then they can articulate.
- They may be repetitive
- If they are anxious or upset their speech may become quicker or louder.
- Some individuals may have developed their own words to express themselves.

Non-Verbal

- The individual may avoid or overuse eye contact,
- They may not understand the social boundaries relating to personal space or touch.
- They may use different sounds or gestures to convey their needs.
- They may use signs, but may have their own way of signing.
- Individuals may use pointing as an indication of their needs.
- It is important to consider the environment, many factors can impair communication e.g. noise, distractions
- Waiting is often difficult when a person is anxious about something, fear may build up causing uncooperative or difficult to manage behaviour.

Body Language

- You should be aware of your body, a relaxed, confident manner will be more reassuring to an individual
- Facial expression should be used to back up verbal communication, e.g. smiling to reassure the individual
- People with a learning disability may have little concept of another person's space and may come very close, however this does not mean that they have no concept of their own, so verbal communication is necessary when approaching an individual
- Ensure that a rapport has been established before there is any physical contact.
- Give explanations as to what is happening.
- Observe for signs of anxiety or distress, if you feel unable to deal with this request assistance from other members of staff.
- Be aware of the way that the individual communicates. If they use signing or symbols ensure that someone who has these communication skills is available to support you.
- You may need to use gestures to emphasise verbal language – use your ward's Hospital Communication Book for ideas!

Mealtimes and Medicines

Many people with learning disabilities experience difficulty with eating, drinking and taking medicines due to a poor swallow, or other complications.

The Learning Disability Liaison Team are encouraging all carers to complete a **Traffic Light Assessment** with people they care for who have a learning disability, specifically so that staff at the hospital are able to establish this information at the earliest stage.

However, where a traffic light assessment does not exist, it is extremely important health workers clarify a person with a learning disability's eating and drinking ability as soon as possible, and also the exact way they take their medicines.

It may be that special equipment is used at home to aid eating and drinking, and arrangements need to be made for this to be brought into hospital.

Some people with learning disabilities take much longer to eat and drink, and this needs to also be taken into consideration.

It is also very important to find out whether the person needs assistance to eat and drink, and to find out the best way of providing this.

Medicines….

Many people with learning disabilities have needle phobias, often due to negative previous experiences.

Some people feel much more relaxed when a procedure is well explained and support and reassurance is offered throughout, however for some this is really not adequate.

It is therefore quite possible that preparations, such as Emla cream, may need to be considered, or even sedation in more extreme cases.

People with learning disabilities can often have medicines in alternative forms ie: syrup, solutab, capsule.

It is very important to consider the person's level of understanding at all times, and explain what medicines are for.

An Introduction to Learning Disability and Challenging Behaviour

The FUNCTION of Challenging Behaviour

- Challenging behaviour occurs for a reason and is legitimate. It occurs to get the individuals needs met.
- In order to aid an individual to better control his / her environment and to increase quality of life and reduce challenging behaviour, we need to know why the behaviour is shown and what purpose it serves for the individual.
- Challenging behaviour does not occur in a vacuum but for a reason, and within a context.
- Challenging behaviours are learnt over time and are effective for the individual.

There are four categories into which all challenging behaviour falls. Some challenging behaviour can occur for more than one reason:

- Access to social attention – the person engages in challenging behaviour to get people to spend time with them. Attention can be verbal, social, physical or related to proximity. Remember that sometimes negative attention can be as rewarding (reinforcing) as positive attention
- Demand avoidance / Escape from aversive situations – challenging behaviour can occur to avoid demands, requests or interaction as well as to escape social contact and participation in activities
- Access to tangibles (access to "stuff" – the person engages in challenging behaviour to get access to preferred objects or activities eg: to get a drink
- Sensory / Self Stimulation – the aim of the challenging behaviour is to get sensory feedback or intrinsic stimulation. So behaviour looks, sounds, feels, smells or tastes good.

As an example, a person who repeatedly hit their head with their fist may do this to gain attention, avoid interaction, and get access to preferred items or for sensory reasons. To find out the function we must look closer at the Antecedents (what happens before the behaviour), and Consequences (what happens after the behaviour, what does the person get). This Antecedent-Behaviour-Consequence (ABC) relationship is central to assessing the function(s) of challenging behaviours.

- Approximately 7-15% of people with a learning disability display challenging behaviour
- As the severity of learning disability increases, so (in general) does the level of challenging behaviour displayed
- People living in unstimulating environments are more likely to show challenging behaviour
- The challenging behaviour can be syndrome related (ie biological in origin) eg: Rett Syndrome – hand ringing / self injurious behaviour; Prader Willi – increased level of eating disorder behaviours
- Disturbed sleep patterns often equal increased challenging behaviours

Mental Health and Challenging Behaviour

- There is no proven link to say that psychiatric causes will always cause challenging behaviour.
- People with a learning disability are more likely to have mental health issues compared to the general population (Lund, 1985).
- Prevalance of depression is 10% higher for people with a low IQ, and higher for people with Downs Syndrome.
- People with a learning disability are prone to side effects of anti-depressants
- The diagnosis of psychiatric disorders such as schizophrenia are very difficult to diagnose in people with a learning disability and communication difficulties.

Forms of Challenging Behaviour

- Self Injury
- Destructiveness
- Eating in-edibles
- Severe non-compliance (more than just being strong willed, which is a good thing)
- Stereotyped behaviours (repetitive self-stimulatory behaviours – rocking, flapping, etc)
- Verbal aggression / violence

Challenging behaviour is likely to rise in hospital as they can be scary places for a person with a learning disability. It always happens for good reason and not just to annoy you! Reasons may include:

- Pain
- To get out of a difficult situation
- To avoid people
- To access preferred items, objects or activities

Remember if the behaviour hadn't a purpose it wouldn't happen. If you had limited skills and communication you might learn to use a challenging behaviour to get your point across, eg: a slap may well get someone to stand back if your frightened noises had been ignored.

Take time to find out what constitutes a bad time for this person, and what you can do so as not to exacerbate the situation. Remember everyone is unique – what reassures one person may well not for another.

6 Steps to Calming

1. IDENTIFY what the problem is
2. REFLECT - " I can see this is difficult "
3. EMPATHISE – " I would find this hard too "
4. REASSURE – " It won't last long, you're doing brilliantly "
5. REDIRECT – " Let's do this fun thing instead "
6. PRAISE – " You calmed brilliantly " (even if this is not the case, it's useful to thank the person for calming)

- Keep it simple – be nice and build a rapport so you are worth being around
- Be non-judgemental, optimistic and do not take behaviours personally
- Respond to all positive attempts at communication, so the person doesn't have to resort to challenging behaviour to get their needs met
- Ask the person what they need or don't want – Show Me – and take notice!
- Respond in a calm way to the behaviours. Be excited when the person is behaving in a positive way.
- Let rocking / flapping behaviours happen. They are a predictable element in an unpredictable world.
- Remove unnecessary triggers and requests – come back later to try again.
- Keep communication simple and clear but friendly at all times.
- Redirect the person to something fun or interesting (favourite subject, change of scene, "look at that!", etc)
- Use the environment, eg: get behind the bed, give more space, back off
- Never ignore the person, even if you are trying not to comment on the behaviour itself

CAPACITY AND CONSENT TO TREATMENT
Summary of the Mental Capacity Act 2005

What Consent is and what it isn't

"Consent" is a patient's agreement for a health professional to provide care.
Patients may indicate consent non-verbally (for example by presenting their arm for their pulse to be taken), orally, or in writing. For the consent to be valid, the patient must:

- Be competent to take the particular decision
- Have received sufficient information to take it
- Be able to weigh up and communicate a decision
- And not be acting under duress

Where an adult patient lacks the mental capacity (either temporarily or permanently) to give or withhold consent for themselves no one else can currently give consent on their behalf. From October 1st 2007, under the Mental Capacity Act 2005, a decision may be made on behalf of a person who lacks capacity once a **Lasting Power of Attorney (LPA)** has been registered by the person identified in the LPA document to act on their behalf in such matters. Any such decision and associated treatment can be given if it is in the best interests. If there is no Lasting Power of Attorney, treatment can be given if it is in the patients best interests, as long as it has not been refused in advance in a valid and applicable **Advance Decision.**

Any assessment of capacity must bear in mind the key principles of the Mental Capacity Act:

- **A presumption of Capacity:** Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.

- **Individuals being Supported to make their own Decisions:** A person must be given all practicable help (e.g. use of simple language, photo's, drawings, sign language, interpreters) before anyone treats them as not being able to make their own decisions

- **An individual may choose to make what might seem an unwise decision:** Just because they make a decision that others may think is unwise, it should not be assumed that they lack capacity.

- **Any act done or decision made under the act for or on behalf of a person who lacks capacity must be done in their best interests.**

- **Anything done for or on behalf of a person who lacks capacity must be that which is the least restrictive of their rights and freedoms.**

- **An apparent lack of capacity to give or withhold consent may in fact be the result of communication difficulties.** Rather than genuine incapacity. Appropriate colleagues should be involved in making such decisions regarding capacity, such as Specialist Learning Disability Teams, and Speech and Language Therapists, Carers and Families

Vulnerable Patients
Capacity to consent to treatment

The Mental Capacity Act 2005 says that no adult can give consent on behalf of another adult. It also says that people should be given every possible chance to make their own decisions and that you can't judge their ability to do this on the basis of a diagnosis or condition alone.

This means that you have to ask yourself some questions when treating a person who might be mentally vulnerable.

Capacity to Consent

- Is your patient mentally vulnerable through old age, a brain disorder, communication problems, learning disability?

- Do you have doubts about their capacity to consent?

- Are you assuming someone has capacity because they agree with everything you say?

- Are you taking someone else's word that they agree with treatment – a partner, carer, relative?

- Have you spoken to your patient alone and given them the information they need to make a decision?

- Did you do this in a way you know is best for them?

- Do you know who to contact for help with this?

Best Interests

The Mental Capacity Act allows health care and other professionals to act in the person's best interest if they lack capacity

- How did you agree on best interests for this person?
- Who did you talk to – family, carers, professionals?
- Do you know what the Act says about Advance Decisions?

The Hospital consent form relating to incapacity requires the treating consultant to sign on behalf of the patient who lacks the capacity but obliges them to say how they reached the decision about capacity and with whom they consulted to do this.

Treatment in an emergency is not affected by the Mental Capacity Act. Nor is treatment under section of the Mental Health Act or any treatment covered by other legislation

If at any stage you are unclear regarding the Mental Capacity Act in relation to a patient who has learning disabilities, please contact the Learning Disability Liaison Team on 4975

Questions to ask

Before you leave your appointment make sure you know the following:

What might be wrong? You could ask the following questions:

- Can I check that I've understood what you said? What you're saying is...
- Can you explain it again? I still don't understand.
- Can I have a copy of any letters written about me?

What about any further tests, such as blood tests, scans and so on?

- What are the tests for?
- How and when will I get the results?
- Who do I contact if I don't get the results?

About what treatment, if any, is best for you

- Are there other ways to treat my condition?
- What do you recommend?
- Are there any side effects or risks?
- How long will I need treatment for?
- How will I know if the treatment is working?
- How effective is this treatment?
- What will happen if I don't have any treatment?
- Is there anything I should stop or avoid doing?
- Is there anything else I can do to help myself?

What happens next and who to contact

- What happens next? Do I come back and see you?
- Who do I contact if things get worse?
- Do you have any written information?
- Where can I go for more information, a support group or more help?

1097 Crystal Mark
Clarity approved by Plain English Campaign

Top tips

Before your appointment

- Write down your two or three most important questions.
- List or bring all your medicines and pills – including vitamins and supplements.
- Write down details of your symptoms, including when they started and what makes them better or worse.
- Ask your hospital or surgery for an interpreter or communication support if needed.
- Ask a friend or family member to come with you, if you like.

During your appointment

- Don't be afraid to ask if you don't understand. For example, 'Can you say that again? I still don't understand.'
- If you don't understand any words, ask for them to be written down and explained.
- Write things down, or ask a family member or friend to take notes.

Before you leave your appointment

- **Check that:**
  - you've covered everything on your list
  - you understand, for example 'Can I just check I understood what you said?'
  - you know what should happen next – and when. Write it down.
- **Ask:**
  - who to contact if you have any more problems or questions
  - about support groups and where to go for reliable information, and
  - for copies of letters written about you – you are entitled to see these.

After your appointment, don't forget the following

- Write down what you discussed and what happens next. Keep your notes.
- Book any tests that you can and put the dates in your diary.
- **Ask:**
  - 'what's happening if I'm not sent my appointment details,' and
  - 'can I have the results of any tests?' (If you don't get the results when you expect – ask for them.) Ask what the results mean.

THE A – Z OF HEALTH ISSUES AFFECTING PEOPLE WITH LEARNING DISABILITIES *(DoH, 15.10.07*

COMMUNICATION - 50 – 90% of people with learning disabilities have communication difficulties. Communicating ill health can often be difficult for people with learning disabilities and may present in different ways i.e. through changes in behaviour, abilities or personality, social withdrawal, aggression or self harm.

CONSENT - It must be assumed that everyone has the capacity to give consent until proven otherwise. Acting in someone's 'best interest' must be a multidisciplinary decision and documented accordingly, (DOH consent form 4). Nobody should be signing consent forms on behalf of another adult.

A	**ACCESS** 2% of the population will have a learning disability. This suggests that a GP with a list of 2000 will have about 40 patients with a learning disability. Each health practice and department should ensure that their physical and cognitive environment is accessible to people with learning disabilities.	**ACCESSIBLE INFORMATION** Accessible information should be made available to all people with learning disabilities to maximise their capacity to understand and consent to treatments.	**ANNUAL HEALTH CHECKS** Regular health checks (1-3 yearly) to people with learning disabilities often leads to the early detection of previously unmet health needs.	**APPOINTMENTS** Waiting for appointments can cause great anxiety for some people with learning disabilities. GP practices and departments could be more flexible by offering double appointments, first or last appointments or separate waiting areas for challenging patients. Keeping patients informed of waiting times could also help to reduce anxiety levels.	**ATTITUDES** People with learning disabilities are people first – each health problem presented should be isolated from the learning disability and treated separately. Attitudes and assumptions that people with learning disabilities cannot make decisions, understand treatments or make their own choices are discriminatory and inappropriate.
B	**BARRETT'S CANCER** Intestinal metaplasia 15 – 26% of population are at risk due to reflux often present inn older people in the general population but seen in pwld at an earlier age.	**BARRIERS** The barriers to receiving appropriate healthcare are numerous and include inaccessible services, communication problems, complex information, fear and lack of confidence.	**BEHAVIOUR** Physical illness should always be considered as a cause of behaviour changes. Much behaviour can be attributed to environmental stress, ill health, lack of occupation or poor communication skills. Challenging behaviour could also be the result of an underlying psychiatric illness.	**BETTER METRICS** The better metrics project links in with the NHS Plan and NSF targets and includes 12 clinical performance measures relating to people with learning disabilities. These include up to date LD registers in GP practices and annual health checks.	
C	**CANCER** A growth or tumour caused by abnormal or uncontrolled cell division in general death caused by cancer is lower in pwld than the general population but we are seeing an increase in the numbers of people with gastro intestinal cancers.	**CATARACTS** An opacity of the lens of the eye can be hereditary – caused by injury or as a consequence of diabetes	**CONSTIPATION** People with learning disabilities are more prone to constipation due to immobility, poor fluid intake, medications and limited food choices. Reliance on laxatives should be replaced with fibre rich foods, exercise, more fluids and a healthy diet.	**CORONARY HEART DISEASE** This is the second most common cause of death amongst people with learning disabilities (14%-20%). Between 40 and 50% of people with Downs syndrome are affected by congenital heart defects.	**CARDIOVASCULAR** Other Cardiovascular issues for people with learning disabilities include; ➢ Mitral Valve prolapse, associated with Down Syndrome ➢ Aortic dilation ➢ Poor peripheral circulation

D	**DEMENTIA** People with learning disabilities are more likely to develop early dementia (21% vs. 5.7%). Around 40 – 50% of people with Downs Syndrome will show symptoms of dementia by the age of 50.	**DIABETES** People with learning disabilities are more prone to diabetes due to sedentary lifestyles and obesity. The condition is often undiagnosed and needs to be monitored and managed effectively.	**DIAGNOSTIC OVERSHADOWING** This occurs when the learning disability 'trumps' the physical or mental health need. Health professionals need to look past the learning disability and treat the symptoms presented.	**DOWNS SYNDROME** People with Downs Syndrome have many associated health problems which need regular monitoring. These include; heart defects, poor vision, hearing and dentition, obesity, early dementia, thyroid and respiratory problems.	**DYSPHAGIA** Difficulty or inability to swallow. 85% of pwld have this problem. Can be diagnosed by Speech & Language Therapist. In the community where an individual has deteriorated in their ability to eat or drink which is affecting their nutritional state
E	**EARS - WAX** A build up of ear wax in pwld is very common but often undiagnosed and attributed to poor hearing. Regular health checks should include examination of the ears and a hearing test. Ear infections could also be the cause of behaviour changes i.e. head banging or face slapping.	**EARLY DISCHARGE** People with learning disabilities are more likely to be discharged early from hospital, often with inappropriate discharge summaries or aftercare plans.	**EATING DISTRESS/DISORDERS** Greater awareness of these issues needs to be raised as the effects are far wider than expected.	**EPILEPSY** 50% of people with learning disabilities have epilepsy compared to 1% of the general population. The incidence rises to 30% in people with profound and multiple disabilities.	**EQUAL RIGHTS** People with learning disabilities have equal rights to be included in all health targets and initiatives. Routine health screening and health promotion initiatives should also apply to people with learning disabilities. Don't leave them out!
F	**FEAR** Fear of unfamiliar surroundings, people and procedures is the biggest obstacle faced by people with learning disabilities when accessing healthcare services.	**FOLLOWING TREATMENTS** Treatments and advice given by health professionals should be simple and clear and in a format understood by the individual. Checking comprehension will help to clarify that information has been understood. **Write it down.**	**FITNESS** People need to be encouraged to become fitter through taking more exercise.	**PHYSICAL EXERCISE** 80% of this group of people do less physical exercise than is recommended. Immobility, lack of opportunity, poor staffing, financial and transport problems are often the cause. Boredom, apathy, depression and hostility can be helped with regular physical exercise	
G	**GASTRO-OESOPHAGEAL REFLUX (GORD)** Up to 50% of people with learning disabilities could be suffering from GORD. It may present as challenging behaviour as symptoms are quite painful.		**GASTRO-INTESTINAL CANCER** Higher rates of gastro-intestinal cancers can be found in people with learning disabilities and it is the most common form of cancer within this group. (48%-58% vs 25%).		
H	**HEARING IMPAIRMENTS** 40% of people with learning disabilities have hearing problems. Deafness is common and is often unrecognised and poorly managed. Impacted ear wax is a frequent problem overcome by regular health checks.	**HEALTH ACTION PLANS** "All people with learning disabilities will be offered a HAP by June 2005". (DOH 2001). Health Action Plans require a medical health check and thorough assessment of health needs. Health facilitators should also be identified for each individual.	**HELICOBACTER PYLORI** High rates of H-pylori can be found in people with learning disabilities who have lived in institutions (60-90%). It may be instrumental in increased mortality rates from stomach cancer and perforated ulcers.	**HIATUS HERNIA** This is where there is a hole in the diaphragm this is the muscle between the stomach and the chest – the top of the stomach moves into the hole causing a hiatus hernia – often goes undetected in ld population	**HEPITITUS B** 11 – 55% OF pwld have it.
I	**IDENTIFYING A LEARNING DISABILITY** A learning disability presents as a significantly reduced ability to		**IMMUNISATIONS** Research demonstrates that people with learning disabilities are less		

	understand new or complex information, learn new skills and cope independently. IQ is often below 70 and onset must have occurred before adulthood (age 18).		likely to receive regular immunisation. Influenza, pnenococcus, Hepatitis A + B are recommended for this group.		
J	**JOINT WORKING** Primary and secondary health services need to be working in partnership with specialist Learning Disability services to provide equitable services to people with learning disabilities.		**JARGON** Avoid jargon and use clear, simple language.		
K	**KERATATONAS** Means cone shaped cornea. Can be rectified by glasses or eventually a cornea graft	**KISS** **KEEP IT SIMPLE** – short phrases, visual prompts, clarify salient points and confirm comprehension. Speak slowly and clearly.	**KNOWLEDGE** There is a general lack of knowledge by doctors and nurses of the special needs of people with learning disabilities particularly around communication, behaviour and consent. 75% of GPs receive no training in learning disabilities issues.		
L	**LIFE EXPECTANCY** The life expectancy of people with learning disabilities is increasing over time (67 for men, 69 for women), 55 for downs) but is still less than that of the general population.		**LIFESTYLE** People with learning disabilities often lead unhealthy lifestyles are inactive, obese and have poor nutrition. Poverty, unemployment and social exclusion also affect/inhibit healthy lifestyle choices.		
M	**MEDICATION** Polypharmacy and inadequate medication review are acknowledged within this client group. Anti-psychotics can often be inappropriately prescribed and poorly reviewed.	**MENTAL HEALTH** Psychiatric disorders are more prevalent in people with learning disabilities compared with the general population. Schizophrenia, depression, anxiety, self injury and pre-senile dementia are all common in this group.	**MOBILITY** People with learning disabilities are more likely to have a physical disability then the general population. Early intervention and treatment of immobility can reduce the risk of secondary illnesses.	**MORTALITY AND MORBIDITY** People with learning disabilities have an increased risk of early death, although the life expectancy of this population is increasing over time.	**MUSCULAR PROBLEMS** Due to the genetic abnormalities associated with some causes of learning disabilities the following problems may be present in people with learning disabilities; ➢ Hypotonia ➢ Connective tissue dysplasia
N	**NATIONAL SERVICE FRAMEWORKS** NSF's for the general population also apply to people with a learning disability and must include this group in all delivery plans.	**NEUROLOGICAL PROBLEMS** Cognitive decline in people with learning disabilities can often be difficult to detect. Health checks should always include limb movement, tone and gait, seizure activity, declining function, memory loss or any changes in moods or behaviour.	**NPSA** The National Patient Safety Agenda lists 5 priority areas for keeping patients with a learning disability safe in hospitals. They are dysphagia, accessible information, vulnerability, use of physical intervention and mis-diagnosis.	**NUTRITION** Less than 10% of adults with learning disabilities eat a balanced diet. There is a general insufficient uptake of fruit and vegetables and a lack of knowledge and choice of availability of healthy food options.	
O	**OBESITY** Overweight People with learning disabilities living in the community are more likely to be obese (56% of men, 73% of women). Obesity is a special risk for adults with Downs syndrome and Prader-Willi syndrome.		**OLDER PEOPLE** Due to increased life expectancy this group of people are now more likely to have age related health problems such as strokes, heart disease and cancer	**OSTEOPOROSIS** Osteoporosis and osteomalacia are both increased in this population, particularly for people with small body size, hypogonadism and downs syndrome. There is also an increased risk of fractures and falling down. Osteomalacia is the result of vitamin D deficiency	

P	**PAIN** Due to associated problems with communication, pain can often be expressed in a behavioural change. Pain assessments for people with learning disabilities monitor physiological and behavioural symptoms as well as facial expressions	**PERSON CENTRED PLANNING** Person Centre Planning ensures that people will have control over their own lives and the services that they receive. The Health Action Plan may form part of the person centred plan.	**POSTURAL CARE** Postural care assessments are recommended for people with complex disabilities. Correct postural management will reduce long-term need for surgery or equipment and ultimately reduce pain and improve body function.	**PNEUMONIA** Disease causing inflammation or congestion of lungs. People with ld prone to aspiration pneumonia due to reflux – swallowing difficulties.	**Primary Care Framework** Removed by student
Q	**QUALITY OF LIFE** Sadly there is still evidence of doctors making value judgements about the quality of life of people with profound and multiple disabilities. Denying treatments, failure to make life saving interventions and automatic DNR notices are still occurring.				
R	**READ CODES** Valuing people have recommended that READ Code E3 (Mental Retardation) be used in GP practices. The term 'mental retardation' however is inappropriate and some practices prefer to use the code Eu81z) (learning disability nos).	**REGISTERS** Valuing People states that all people with a learning disability should be registered with a GP by June 2004. Each practise needs to be able to identify their learning disabled population using the appropriate Read Code.	**RESPIRATORY DISEASE** This is the leading cause of death for people with learning disabilities (52%). Aspiration and respiratory tract infections can be caused by congenital defects, vomiting, epilepsy, coughing, feeding, breathing and swallowing difficulties, regurgitation and gastroesophageal reflux.		
S	**SCREENING** People with learning disabilities are often excluded from national screening programmes.Women with a learning disability are about 4 times less likely to undergo cervical smear tests than the general population (24% vs 82%). They are also less likely to have breast examinations or be invited to attend for a mammogram.	**SCHIZOPHRENIA** 3% of people with learning disabilities compared to 1% of the general population, have schizophrenia. Presentation of mental health problems will depend on cognitive, communicative, physical and social functioning within this client group.	**SEXUAL RELATIONSHIPS** It cannot be assumed that people with learning disabilities do not have sexual relationships. They should be included in all screening programmes. Some women may have experienced sexual abuse and should be called up for smear tests.	**SKELETAL PROBLEMS** Due to the genetic abnormalities associated with some causes of learning disabilities the following skeletal problems may be present in people with learning disabilities; ➢ Scolosis ➢ Atlanto Occipital+ ➢ Atlanto axial instability	**SKIN DISORDERS** There are many skin problems that are associated with people with a learning disability including; ➢ Eczema ➢ Haemangioma
T	**TRAINING** A recent MENCAP paper reported that 75% of GP's had received no training to help treat people with learning disabilities. Lack of training and skills among healthcare staff results in people with learning disabilities having poor access to health services and poor health outcomes.		**TEETH** Poor oral health is one of the most frequent health problems in this population – one study found that 86% of people with a learning disability had dental disease. They have poor oral hygiene, untreated dental caries and more extractions than the general population.	**THYROID** Children and adults with Down syndrome are at increased risk of thyroid dysfunction, particularly hypo thyroidism. Thyroid disease can be difficult to diagnose in people with learning disabilities, and often presents itself as a change in behaviour being the only 'symptom'.	

U

UNMET HEALTH NEEDS

Health screening of adults with learning disabilities registered with GPs reveals high levels of unmet physical and mental health needs. Their health needs often go undetected or undiagnosed due to problems with communication, assertiveness and low expectations.

Underweight

See Weight

V

VALUING PEOPLE

'Valuing People' is a White Paper published in March 2001. The 4 key principles running through the paper are based on social inclusion, civil rights, choice and independence. The health targets focus on GP registers, Health Action Plans and Health facilitation.

VISION

Approximately 30% of people with learning disabilities have a significant impairment of sight. Adults with Downs syndrome often present with cataracts, keratoconus and retinal pathology. Regular monitoring of vision is important in this client group, who rarely complain of poor vision.

VULNERABLE

"People with learning disabilities are amongst the most vulnerable and socially excluded in our society" (DOH 2001). They are often marginalised or excluded and have poor life choices. Prejudice, discrimination and isolation are often experienced by this group of people.

W

WEIGHT – see also Obesity

Underweight

Under nutrition is more prevalent in institutional settings and in people with dysphagia or eating and drinking problems. The use of PEG feeding is increasing in this population.

X

X-RAY

See also "Screening"

People with learning disability will often need additional support and time to be able to access a range of investigations. This can include visits to gain familiarity with the hospital, additional time for appointments so that waiting times are kept to a minimum and that acute staff are aware of the individual's needs. Each individual will need different levels and type of support.

EXTRA TIME

Extra time and patience is often needed from Health professionals when consulting with people with learning disabilities. Longer appointments and consultations will enable effective communication and comprehension for both patient and health professional

Y

YOUNG ADULTS

Young adults with a learning disability are often not transferred from children's to adult services with adequate health care plans, particularly those with complex and profound health needs. This could result in exclusion from adult services.

Z

ZERO TOLERANCE

TO:

- discriminatory practice
- exclusion from health initiatives
- inequitable services
- inaccessible services

References and Bibliography

Lenox et al – Health Guidelines for Adults with an Intellectual Disability.
Hatton et al – 'Key Highlights' of Research Evidence on the Health of People with Learning Disability
Barton et al – Cervical screening uptake in women with learning disabilities in Shropshire.
DOH 2001 – Valuing People – A new Strategy for Learning Disability for the 21st Century.
Prasher & Janicki – Physical Health of Adults with Intellectual Disabilities.

Poster produced by Esia Dean, Health Facilitation Team, Gloucestershire Partnership NHS Trust
Updated by – Health Access Team (South Staffs & Shropshire NHS Foundation Trust) – 2008

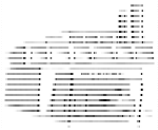
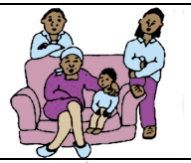
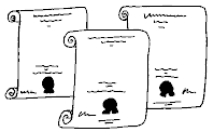
SYNDROME SPECIFIC CHECKLIST

(of recognised potential medical complications)

	Down's Syndrome	Fragile X	Neurofibromatosis	Phenylketonuria	Prader-Willi	Sturge-Weber	Tuberous Sclerosis
Audio / visual	Visual Impairment Bi-annual Optician assessment recommended. Hearing Impairment Ear Wax/Middle Ear Infections. Bi-annual Hearing assessment recommended.	Visual Impairment Hearing Impairment	Hearing Impairment (Glioma affecting auditory nerve)	Non-specific	Bi-annual checks recommended	Glaucoma	Retinal tumors Hearing assessments recommended
Endocrinology	Thyroid Disorder Annual Thyroid Function Test (TFT) recommended	Autistic spectrum features	Non-specific	Unable to produce phenylanalaline	Diabetes Mellitus (secondary to obesity)	Non-specific	
Psychiatric / Psychological	Alzheimer's type dementia. Clinical onset not uncommon before 40 years	Attention Deficit Hyperactivity Disorder in Social Functioning. Difficulties through Autistic Spectrum Disorder	Variable intellectual capacity	Variable intellectual capacity Disabilities in Social Functioning	Over Eating Behavioural problems Self Injury	Variable intellectual capacity	Variable intellectual capacity. Tendency for bi-polar disorder & schizophrenia. Autistic features are common.
C.N.S	Epilepsy in later life not uncommon. Associated with Dementia.	Epilepsy in 10 – 30% of population.	Epilepsy	Epilepsy uncommon. Hyperactivity	Non specific	Epilepsy – often severe/refractive. Variable clinical phenomena depending on site of angioma	Cerebral astrocytomas (calcification). Epilepsy – 75% of people.
Cardiovascular	Congenital Heart Disease. Often treated as children, poor peripheral circulation.	Aortic dilation Mitral Valve Prolapse(related to connective tissue dysplasia).	Hypertension leading to arterial stenosis	Poor peripheral circulation	High blood pressure	Non-specific	Cardiac Rhabdomydomas (benign growth of heart muscle)
Muscular / Skeletal	Atlanto Axial instability	Connective tissue dysplasia. Scolosis	Skeletal abnormalities especially Kyphoscolosis	Hypotonia	Hypotonia. Small hands & feet.	Non-specific	Non-specific
Other	Skin disorders Obesity Sleep apnoea (Hypoplastic Pharynx) Increased susceptibility to respiratory conditions.	Herniae Abnormalities of speech and language Hand flapping Severe LD	Variable clinical phenomena depending on the location of neurofibroma. Tumors are susceptible to malignant change Other varieties of tumors may be associated	Eczema Adults to follow PKU diet strictly.	Severe obesity. Promote dental checks. Skin picking. Sleep apnoea. Undescended testes.	Haemangioma (mainly skin and meninges) (Port wine stain).	Kidney and Lung Harmartomas Polycystic Kidneys
Inheritance	Most cases are sporadic 2% due to translocation involving chromosome 21 or mosaicisn.	Most common identifiable cause of inherited LD.	Autosomal dominant	Autosomal recessive Inherited metabolic disorder.	Chromasome 15	Sporadic (congenital)	Autosomal Dominant

Ref: "Contact a Family Directory" (2004)

Advice for Hospital & Health Professionals

1		**Beware of missing serious illness.** Important medical symptoms can be ignored because they are seen as part of someone's disability.
2		**Be more suspicious** that the patient may have a serious illness and take action quickly.
3		**Find out the best way to communicate.** Ask family friends or support workers for help. Remember that some people use signs and symbols as well as speech.
4		**Listen to parents and carers.** Especially when someone has difficulty communicating. They can tell you which signs and behaviours indicate distress.
5		**Don't make assumptions about a person's quality of life**. They are likely to be enjoying a fulfilling life.
6		**Be clear on the law about capacity to consent.** When people lack capacity you are required to act in their best interests.
7		**Ask for help.** Staff from the Learning Disability Liaison Team can help – 01273 696955 ext 4975
8		**Remember the Disability Discrimination Act.** It requires you to make "reasonable adjustments" so you may have to do some things differently to achieve the same health outcomes.

References and Acknowledgments

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http://valuingpeople.gov.uk/dynamic/valuingpeople144.jsp download - Top 10 Tips for Consultations with people with learning disabilities

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HMSO: London

Department of Health (1999) Once a Day. NHS Executive : London

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Department of Health (2001) Seeking Consent: working with People with Learning Disabilities. Department of Health: London

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World Health Organisation (1992)
The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines. World Health Organisation : Geneva

NHS (2004) "National Patient Safety Agency: Listening to People with Learning Difficulties and Family Carers talk about Patient Safety".

Mencap (1998) "Treat me right, better health care for people with Learning Disabilities"

Mencap (2007) "Death by Indifference"

Useful websites

Downs Syndrome Association (UK) – www.dsa-uk.com

Fragile X Society – www.fragilex.org.uk

Prader Willi Association (UK) – www.pwsa-uk.demon.uk

Rett's Association (UK) – www.rettsyndrome.org.uk

Tuberour Sclerosis Association – www.tuberous-sclerosis.org

Asperger's Syndrome – www.aspergersyndrome.co.uk

National Autistic Society (UK) – www.nas.org.uk

Cerebral Palsy – www.scope.org.uk

British Epilepsy Association – www.epilepsy.org.uk

Intellectual Disability Health Information – www.intellectualdisability.info

British Institute of Learning Disabilities – www.bild.org.uk

Foundation for People with Learning Disabilities – www.learningdisabilities.org.uk

Mencap – www.mencap.org.uk

Unique – www.rarechromo.org

Valuing People – www.valuingpeople.gov.uk

BRIGHTON AND HOVE AREA

CONTACT DETAILS LEARNING DISABILITY SERVICES:–

Learning Disability Services

Community Learning Disability Team
86 Denmark Villas
Hove
BN3 3TY

01273 295550

EAST SUSSEX AREA

CONTACT DETAILS LEARNING DISABILITY SERVICES:–

Developmental Services

Community Learning Disability Service
The Bellbrook Centre
Bell Lane
Uckfield
East Sussex
TN22 1QL

01825 744123

Community Learning Disability Service
Gambier House
Eversfield Centre
West Hill Road
St Leonards on Sea
East Sussex
TN38 0NG

01424 710133

WEST SUSSEX AREA

CONTACT DETAILS LEARNING DISABILITY SERVICES:–

Learning Disability Services

Community Team for People with a Learning Disability (North)
78 Crawley Road
Horsham
West Sussex
RH12 4HN

01403 225130

Community Team for People with a Learning Disability (South)
1 St Georges Road
Worthing
West Sussex
BN11 2DS

01903 843350

Community Team for People with a Learning Disability (West)
72 Stockbridge Road
Chichester
West Sussex
PO19 2QJ.

01243 813400

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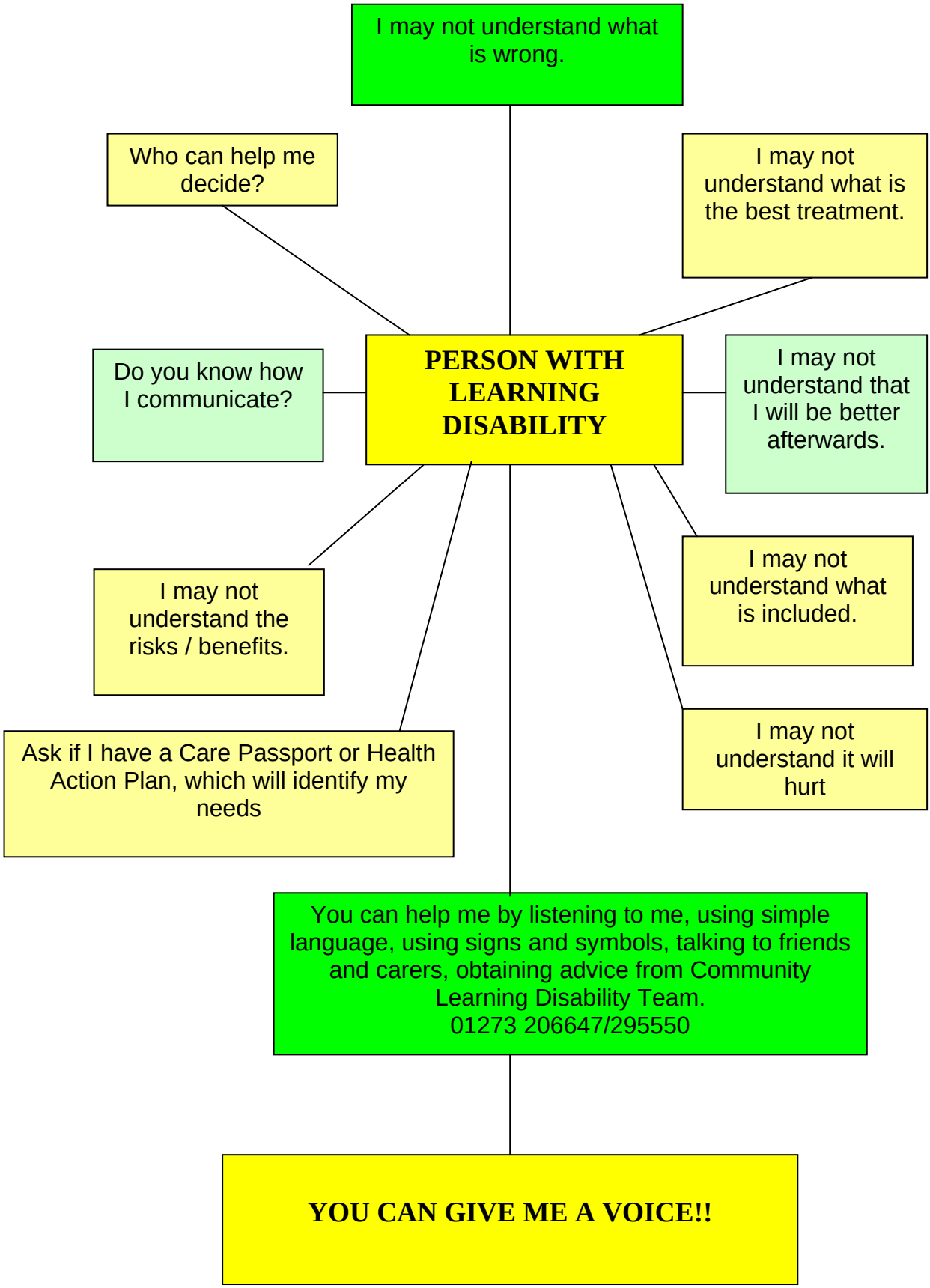
September 2007

The Valuing People Website provides further information and resources
www.valuingpeople.gov.uk


I may not understand what is wrong.
Who can help me decide?
I may not understand what is the best treatment.
PERSON WITH LEARNING DISABILITY
Do you know how I communicate?
I may not understand that I will be better afterwards.
I may not understand the risks / benefits.
I may not understand what is included.
Ask if I have a Care Passport or Health Action Plan, which will identify my needs
I may not understand it will hurt
You can help me by listening to me, using simple language, using signs and symbols, talking to friends and carers, obtaining advice from Community Learning Disability Team.
01273 206647/295550
YOU CAN GIVE ME A VOICE!!

THINGS TO CONSIDER WITH MEDICATION

Give explanation of what medication is for, don't presume the person or carer knows what it is for, especially if new tablet / liquid.

MEDICATION

Medication form
- **Tablet**
- **Capsule**
- **Syrup**
- **Solu-tab**

Is it appropriate for the person. Consider choking risk or inability to swallow tablet with water.

As required medication
- is the person able to indicate the need for additional medication such as pain relief.

Methods of administration
- **Independent**
- **Needs prompting**
- **Some people have their medication in food / drink.**

Carers will be aware of this - usually agreed via multi disciplinary discussion.

Intra - venous
or
Intra - muscular route

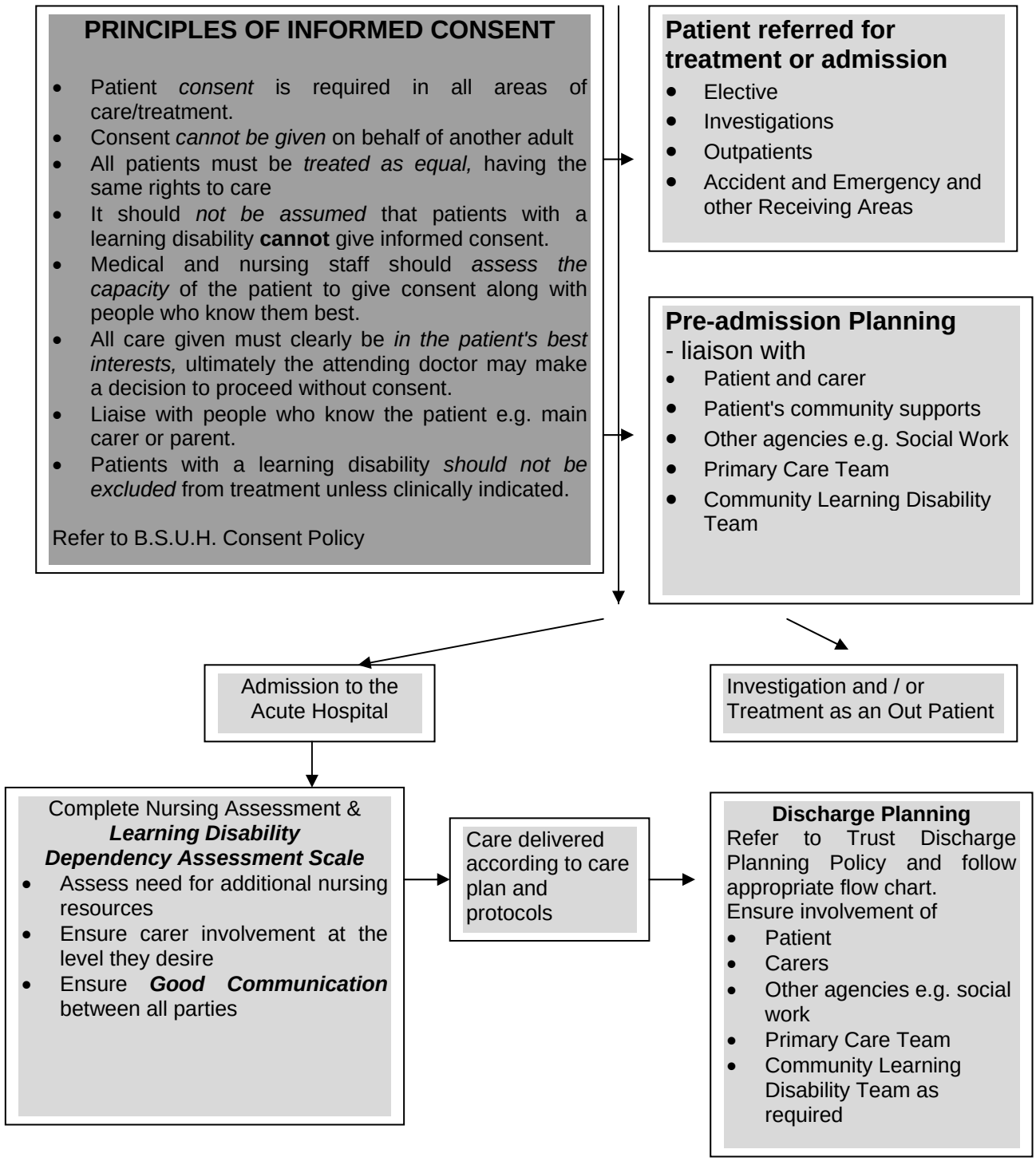
- **Consider needle phobia, may need sedation or continuous re-assurance.**

Always consider the person's level of understanding

Care of a Patient with a Learning Disability
In the Acute Hospital

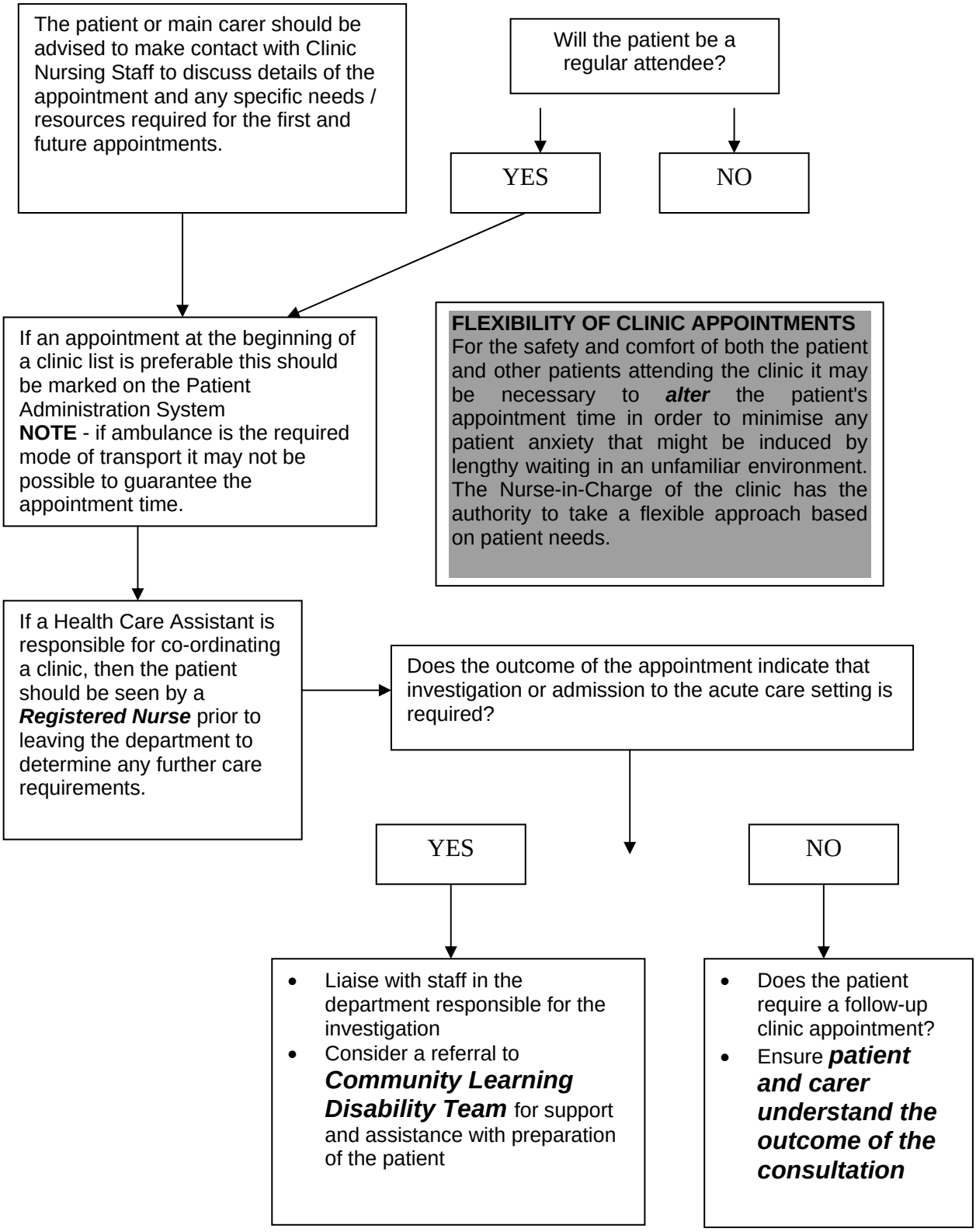
The following five Care Pathways are taken from the Protocol for Caring for Patients with a learning disability in the acute hospital.

Core Principles



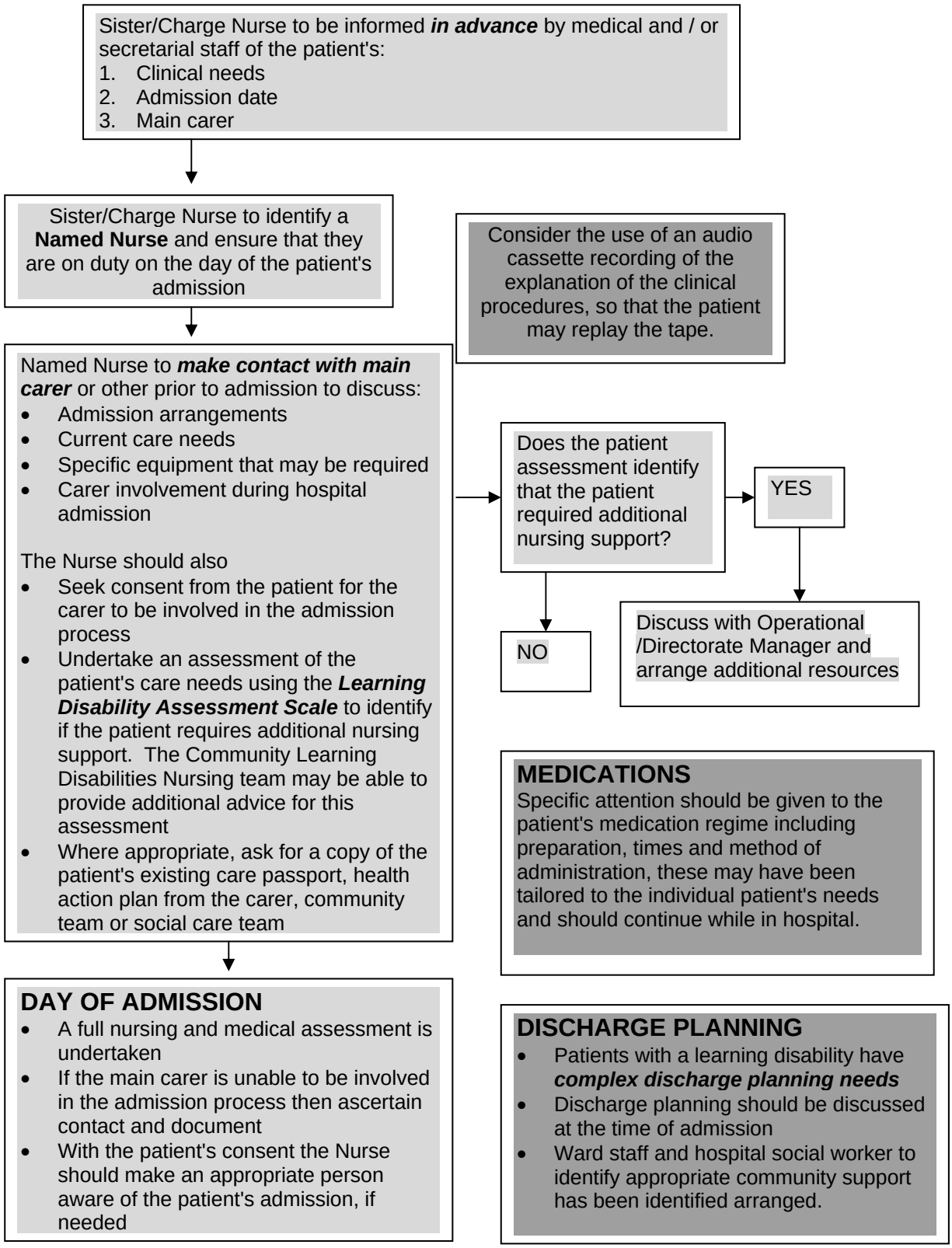
Care of a Patient with a Learning Disability in the Acute Hospital

Out-Patient Attendance



Care of a Patient with a Learning Disability in the Acute Hospital

Elective Admission



Care of a Patient with a Learning Disability in the Acute Hospital

Emergency elective operation, procedure or investigation

Nursing staff from the patient's ward should contact the appropriate Operating Theatre *24 hours in advance* where possible to discuss any specific patient needs. This information should also be conveyed to the ***Recovery Room*** staff

Theatre staff will inform the ***Acute Pain Nurse*** and request a pre-operative visit.

Patient to make a pre-operative visit to Recovery room if possible or (photographs shown)

Explanation of procedure - through use of visits, photographs may assist if consent being sought

Is the procedure or investigation to take place under ***local anaesthetic?***

YES

Arrange, if possible, for the patient to be accompanied to theatre by ***someone known to him or her***

BOX 1 - PREPARATION FOR THEATRE

The following issues should be discussed during the pre-op / domiciliary visit between patient, nursing staff and main carer

- The patient's previous experience of anaesthesia and surgery
- Behavioural patterns during recovery of anaesthesia
- The patient's communication needs

The main carer, parent or guardian may wish to ***accompany the patient to anaesthetic room*** and/or be ***in attendance during recovery***

The ward nurse should remain in the anaesthetic room to provide continuity

BOX 2: RECOVERY

Once the procedure is complete the recovery nursing staff should contact the ward to notify the main carer that the procedure is complete. If necessary the main carer may be present in the Recovery Room.

Where possible, the patient should be escorted back to the ward by a recovery nurse or ward nurse who is known to them

Care of Patient with a Learning Disability in the Acute Hospital

Emergency Admission