



UNIVERSITY
of
GLASGOW

THE CONTRIBUTION OF PRACTICE NURSES TO SUPPORT THE HEALTH OF PEOPLE WITH LEARNING DISABILITIES



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PREFACE

"People with learning disabilities have the right to fulfil their maximum health potential in order to live as full a life as possible."

Promoting Health, Supporting Inclusion
(The Scottish Executive, 2002)

Nurses have a strong tradition of adapting to changes in society, and of responding to new health care needs. Greater Glasgow NHS recognises the valuable contribution Practice Nurses make to developing new and innovative models of practice and care, working across different professional groups and agencies. To this end the Trust is committed to supporting the continuing professional development of all nurses, to assist them in delivering high quality health care to all health care groups. I believe this training initiative will assist Practice Nurses in developing existing skills and acquiring new knowledge, to help improve access to services and increase quality of health care to people with learning disabilities.

Ms Eileen Burns
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SECTION 1 : THE TRAINING PACK

A Training Pack for Practice Nurses

This training pack has been specifically designed for Practice Nurses, to help in your work with persons with learning disabilities. The training pack covers:

- The health needs of people with learning disabilities.
- The contribution of practice nurses.
- Communicating with people with learning disabilities.
- The care and support of people with learning disabilities.
- Additional resources and contacts.

These are the themes that were identified as training needs by the 201 Practice Nurses who returned the questionnaire we mailed to all 292 Practice Nurses in Greater Glasgow, in April 2002.

We have designed this training pack in such a way that you will be able to use it:

- To build on your existing knowledge of working with persons with learning disabilities.
- To think how you can make your service more accessible to people with learning disabilities.
- For reference purposes.
- To source other information and resources to help in your work.

We have also included the following throughout the text:

- *Case studies*, to demonstrate points and provide you with opportunities to reflect on your own practice.
- *Activities*, to provide you and your team with opportunities to test and develop your own knowledge and awareness.

Activity : Answer the Questions Below Whilst Working Through the Pack

Q. How good is my knowledge of the health needs of people with learning disabilities?

No Knowledge | _____ | Excellent

Q. How well do I adopt different methods of communication with people who find this difficult?

Poorly | _____ | Very Well

Q. How accessible is our service for people with learning disabilities?

Not at all | _____ | Fully accessible

Q. How well do specialist learning disabilities and primary care services collaborate?

Poorly | _____ | Very Well

Using the Training Pack

We believe that to get the most out of the pack it is best to:

- Read the entire pack and highlight any specific areas that catch your interest. Try to answer the questions as you work through. It is important to stop, think and reflect on how the different topics apply to your practice.
- A few days later re-read the pack. If you feel that you would like further information on a topic consult the appendices that list useful resources.
- Use the pack as a useful resource to refer back to as you meet people with learning disabilities in your daily practice.

We hope you enjoy using the pack and find it useful.

SECTION 2 : DEFINITIONS AND CONTEXT

Policy and Historical Context

There has never been a more important time to consider the health needs of people who have learning disabilities. For the first time in over 20 years national policy makers have developed and produced two significant documents which offer over 50 recommendations that affect the services we all provide to people with learning disabilities. *The Same As You?* (Scottish Executive, 2000) outlines the direction of travel for all services for people with learning disabilities within Scotland, whilst the recent review of the contribution of all nurses – *Promoting Health; Supporting Inclusion* (Scottish Executive, 2002), offers specific recommendations about meeting the health needs of people who have learning disabilities. These are welcome documents. For many years people with learning disabilities have been disenfranchised, socially excluded and disempowered by both society and services alike. The large Victorian institutions (once the only service available) are closing. Philosophies of care are shifting to a model of reducing health inequalities and improving social justice. This demands that all services respond in an appropriate and socially inclusive manner.

What is Learning Disabilities?

Learning disabilities is the term used in this country for persons with special needs in several areas of their life that have been apparent throughout their development. In other countries, intellectual disabilities is used as an equivalent term. In older casenotes you may come across other historical terms for learning disabilities which are now outdated, stigmatising, and can cause offence, and so should not be used.

The Same As You? defines learning disabilities as “*a significant lifelong condition that started before adulthood, affected development, and means that an individual needs help to:*

- *understand information;*
- *learn skills; and*
- *cope independently.”*

ICD10 Definition of Learning Disabilities

- IQ less than 70.
- Impairment of skills (diminished ability to adapt to the daily demands of the normal social environment).
- Problems identified before the age of 18.

Although IQ can be measured, assessing a person's range of skills provides a more useful way to work out the extra support they may require. An IQ of 20 correlates with a mental age of 3 years. However, if the person is 35 years old, they will also have had 35 years of lifetime experience to learn from, may also have benefited from some specific training, and will have the motivations and biological drives of adulthood. People have different levels of ability and differing needs, depending whether their learning disabilities is mild, moderate, severe or profound, and depending on their life experiences.

There are thousands of different causes of learning disabilities. Some people will have an identifiable genetic, metabolic, traumatic or infective cause for their learning disabilities such as Down's syndrome. For the majority of people with learning disabilities, the underlying cause is unknown. Whilst it is certainly necessary for us to be able to recognise and understand the specific and individual needs of people with learning disabilities, it is also important for us to be aware that some people with learning disabilities feel that labels are stigmatising.

Activity : Learning Disabilities

Take a few moments to think about persons with learning disabilities you work with.

- Q. What does it say about their learning disabilities in their notes?**
- Q. What skills do they have?**
- Q. What support do they have?**

Case Study : Martha, aged 28 years

Martha lives with a boyfriend and works as a shop assistant. She lives independently and hates it when people label her as having mild learning disabilities. Martha has been trying to get some help with family planning, but has difficulties filling in the forms and reading the written information at her clinic. She doesn't get the advice she needs.

The Learning Disabilities Population

In Greater Glasgow, every General Practice has people with learning disabilities registered. The average number of people registered per practice is 16. By implication, this means that we all provide services to this population of people. General prevalence figures suggest that within Scotland, 2-3% of the population will have some degree of learning disabilities. The average lifespan of people with learning disabilities is increasing. Whilst this is also true for the whole of the population, demographic changes are more marked amongst people with learning disabilities. The majority of people with learning disabilities can now expect to live to middle or old age. This is due to healthier lifestyles, improving access to health care and treatments, and better community integration and support. At all levels of ability people are living longer: very premature babies are now surviving through infancy, sometimes with extensive health needs as well as severe or profound learning disabilities. Some people with profound learning disabilities now achieve old age, as do some people with Down's syndrome (who typically have a slightly shorter life expectancy than the average person with learning disabilities). These demographic changes mean that health services are increasingly required to support the needs of a growing population.

SECTION 3 : THE HEALTH NEEDS OF PEOPLE WITH LEARNING DISABILITIES

Types of Health Needs

People with learning disabilities experience the same everyday health problems as the rest of the population. In addition, many people with learning disabilities can experience extra health needs due to their learning disabilities (particularly with regards to accessing health services) and a proportion of people with learning disabilities have additional complex health needs (multiple, severe, coexisting physical and mental health needs). Therefore, people with learning disabilities experience a much higher level of health need than the general population. Many people with learning disabilities also experience barriers accessing appropriate health service support for their needs, resulting in health needs remaining unrecognised and not optimally managed. There are many reasons for this, and Practice Nurses have an important role within primary care in addressing health needs and removing barriers to access. This can make a difference to a person's quality of life.

Key Points : Prevalence of Health Needs

- Health needs are more common in people with learning disabilities.
- Some of the underlying causes of learning disabilities have specific health problems associated with them.
- Social disadvantages and adverse life experiences can contribute to the health needs of people with learning disabilities, and can be addressed.
- Health checks / health screening can be a useful means to improve health.

People with learning disabilities have everyday health needs, just like everyone else. These include needs for management of chronic diseases, diagnosis and management of acute illnesses and infections, and access to screening programmes and health promotion programmes. Practice Nurses are increasingly the first point of contact with services. You may be running nurse-led clinics and take a key role in the management of chronic diseases such as asthma and diabetes : you may have persons with learning disabilities attending these clinics.

Activity : Health Needs of Your Patients

Think about your patients who have learning disabilities.

- Q. Do any have any health problems?**
- Q. Would they be able to tell you if they had symptoms of health problems?**
- Q. What impact would these problems have if they were left untreated?**

Special Considerations

Activity : Communicating Health Problems

- Q. If you were in pain and couldn't tell people about it or receive appropriate help, how would this make you feel?**
- Q. How would you communicate your distress?**
- Q. Can you think of some of the ways in which health problems may present in someone with limited verbal communication skills?**

People express their distress in different ways. Therefore it is important not to make assumptions about changes in a person's behaviour. Some individuals may be able to point to a part of the body bothering them, but for others a change in behaviour or daily activities may be the only indication of a problem. Always use your skills to take a history and conduct an examination, as this may provide clues as to the cause of the problem. Try to speak to a relative or support worker who knows the person well, for background information.

Case study : Andrew, aged 45 years

Andrew has severe learning disabilities and limited verbal communication skills. Over the past few days he has been screaming, banging his head against the wall and has been uncooperative with personal care. His support workers are very concerned. You notice that Andrew has some bruising around his left wrist, won't let you touch it and isn't using that arm. An X-ray shows he has a fracture.

Key Points : Recognition of Health Needs

- Health needs are under-recognised in people with learning disabilities.
- Health problems often have unusual presentations e.g. a change in behaviour.
- Communication problems can make it difficult for the person to complain of symptoms.
- Lack of knowledge of carers, support workers and health professionals can contribute to under-recognition of need.

Once health needs have been identified, special considerations may be needed to provide appropriate treatment and interventions. Persons with learning disabilities may find it difficult to understand their health needs and comply with treatments. They may not be able to say whether or not they feel better with the treatment. People with learning disabilities are often on multiple drugs, due to many co-existing health problems, and appear to be more sensitive to side effects – but may be unable to communicate this. This means that support workers, relatives and health professionals are required to be more proactive in assessing compliance, treatment response and drug side effects, and must work in partnership.

Activity : Managing Hypertension

Think about one of your patients who has hypertension.

- Q. If they had learning disabilities, how could you help them to understand why they needed medication every day?**
- Q. Who could help you with this?**
- Q. How could you check if the person was experiencing any drug side effects?**

Mental Health Needs

People with learning disabilities experience higher rates of mental ill-health than other people, with a lifetime prevalence of about 50%. This is because of biological, psychological, social and developmental risk factors in excess of those experienced by the general population. Some causes of learning disabilities are associated with particular mental health needs (a “behavioural phenotype”) e.g. Down’s syndrome is associated with depression and dementia. People with learning disabilities may experience the full range of problems seen in the general population, including depression, schizophrenia, severe anxiety disorders, delirium and dementia. Communication difficulties and lack of awareness by carers and professionals can lead to these remaining undiagnosed for long periods. Another possible reason for lack of recognition is *diagnostic overshadowing*. This term refers to a change in a person’s behaviour, mood or level of functioning being inaccurately attributed to his / her learning disabilities with the failure to recognise the additional health need. In view of its high prevalence, mental ill-health should always be considered as a possible cause of any change in a person’s behaviour. Aggression is a common symptom of mental ill-health in adults with learning disabilities.

Areas that can be Affected by the Onset of Mental Health Problems

- Physical appearance – hygiene, general health.
- Biological functions – sleep, appetite and bodily functions.
- Behaviour – new or changed behaviour, or reduction in long-standing behaviours.
- Activity and energy levels, and level of arousal.
- Verbal and non-verbal communication.
- Mood and emotional reactions.
- Attitudes.
- Relationships.
- Perceptions of other people and the world around them.
- Attention, concentration, thinking and memory.
- Self confidence and esteem.

Mental ill-health and epilepsy often co-exist in adults with learning disabilities. The differentiation between symptoms caused by mental ill-health, epilepsy or anti-epileptic drug side effects is often complex and requires specialist skills across these areas.

There are effective treatments and supports for most types of mental ill-health, including various types of psychotherapies and medications.

Key Points : Mental Health

- People with learning disabilities experience the same types of mental ill-health as the general population.
- These can present in unusual ways.
- People with learning disabilities also experience some types of mental health needs which are uncommon in the general population e.g. problem behaviours, psychogenic vomiting disorder, attention deficit hyperactivity disorder of adults.
- Some people will find it difficult to tell others about their symptoms or side-effects of medication. Side effects can present late and hence be severe.
- Health professionals need to be vigilant for signs of mental ill-health which is common.

Problem Behaviours

It is important for health professionals to be vigilant for the emergence of new problem behaviours or changes in existing behaviours. Such changes may represent the presentation of a physical or mental health problem and like other symptoms need to be assessed fully. As has been stated previously, if someone has difficulties with verbal communication their only means of conveying distress, due to toothache for example, may be to bang their head against a wall or hit their support worker. By asking about changes in behaviour during every contact with people with learning disabilities, hidden health needs can be identified and met.

Some people with learning disabilities have longstanding problem behaviours such as self-injurious behaviour or aggression. There are many possible reason for this. Some problem behaviours are genetically determined e.g. people with Prader-Willi syndrome have propensity for skin-picking. Problem behaviours may be a communication style that has been learnt over many years, may reflect distress or a need, poverty of social environment or lack of occupational and recreational opportunities. Problem behaviours may also be due to personality development shaped by damaging adverse experiences in early life, or are sometimes best understood using a developmental model.

It is often possible for specialist health professionals to work effectively with people with problem behaviours even when these have been longstanding, to improve quality of life.

Epilepsy

Epilepsy affects around 25% of people with learning disabilities. In individuals with more severe learning disabilities or autism, rates are even higher, at about 50%. Effective management of epilepsy requires a multi-disciplinary approach and co-ordinated services that optimise self care and involve primary, secondary and in some cases tertiary health care services. In your clinical practice you might come across someone presenting with epilepsy for the first time or be involved in the ongoing care of someone already known to have epilepsy.

Although ideally we would want people to take as few anti-epileptic drugs as possible, some people require two or more. These drugs have many possible side-effects. If you are concerned that someone may be experiencing side-effects, speak to the person's GP or one of the learning disabilities specialist epilepsy nurses. Drugs such as Phenobarbitone, Primidone, and Phenytoin are now infrequently used, due to their poor side effect profile which includes effects on communication, concentration and learning. If a person with learning disabilities has such a prescription, check if this has recently been reviewed. If a person's epilepsy is optimally managed, they still require an annual review. If a person is experiencing frequent seizures and has not had any recent attempts to improve this, this warrants review. Epilepsy management includes a balance between frequency of the different seizure types and drug side effects to optimise quality of life, together with risk assessment, risk management and education.

Key Points : Epilepsy

- Assessment, diagnosis and management of epilepsy in people with learning disabilities can be complex.
- Multiple seizure types and poorly controlled seizure frequency are common.
- Diagnosis and treatment is often complicated by coexisting mental ill-health and psychotropic drug use.
- Side effects of drugs are more commonly experienced, often present late and hence can be severe.
- Epilepsy management extends beyond seizure treatment with medication.

Autistic Spectrum Disorders

This term is used to describe a range of developmental disorders that share some common features. They are lifelong conditions that often lead to complex needs. The two most common conditions are autistic disorder and Asperger's syndrome. Most definitions of Asperger's syndrome state that individuals do not have learning disabilities so this description focuses on autistic disorder.

The three core features of autistic disorder are :

- Atypical social development leading to problems in interpersonal interactions.
- Language and communication problems.
- Rigidity of thinking and behaviour.

Despite these similarities, presentations vary greatly between individuals, depending upon the degree of learning disabilities, personality factors and the presence of additional disorders. Furthermore, as someone develops, the clinical presentation often changes. Epilepsy is more common amongst individuals with autistic disorder.

People with autistic spectrum disorders find it difficult to access and make use of health care services. As they have difficulties with communication and social interactions they find it difficult to describe any symptoms they are experiencing. In addition, busy clinical settings can provoke significant anxiety and distress, making communication even more difficult. Therefore, people supporting and working with individuals with autistic spectrum disorders need to pay particular attention to the environment they are working in and their own methods of communication.

Older People with Learning Disabilities

People with learning disabilities are living longer than ever before and older people with learning disabilities have higher levels of health needs than the general population. This is because they have risk factors for :

- Health needs that can affect the whole population.
- Health needs related to ageing.
- Health needs related to having learning disabilities.

About two-thirds of elderly people with learning disabilities have an additional mental health need. This can be any of the full range of mental health needs, including developmental disorders such as attention deficit hyperactivity disorder of adults and autistic spectrum disorders, problem behaviours that have persisted through adult life, mental illnesses that are either of recent onset or which are enduring, and acquired dementia.

Dementia is about four times more common in people with learning disabilities. It is particularly common in people with Down's syndrome, about half of whom will acquire clinical dementia in middle or older age. There are advantages to detecting the onset of dementia as early as possible. This allows access to cognitive-enhancing drugs, and also to a range of other biological plus psychological, social and developmental approaches designed to improve quality of life, and to support carers. The specialist services provided through the Area Learning Disabilities Teams can advise on assessment, interventions and supports.

Physical ill-health is also common amongst older people with learning disabilities and benefits from assessment and interventions. Some such needs are related to the person's underlying learning disabilities : other health needs relate to ageing and are similar to those experienced by older people of average ability.

Older people with learning disabilities live in a diverse range of settings where they are usually in a minority. Diagnostic overshadowing is a particular issue for the older person – in learning disabilities settings additional health needs are often inappropriately attributed to old age; whereas in old age settings additional health needs are often inappropriately attributed to the person's underlying learning disabilities. This can result in failure to address needs.

Older people with learning disabilities differ from the older general population and younger people with learning disabilities in usually not having close family supports. Service supports therefore must be robust.

Key Points : Older People

- Additional health needs are very common in older people with learning disabilities.
- Dementia can present as loss of skills, change in behaviour, withdrawal from activities, reduction in communication, problem behaviours, social withdrawal as well as forgetfulness.
- Carers do not always act on health needs due to 'diagnostic overshadowing'.
- Older people with learning disabilities often do not have close family supports.

Sensory Impairments

People with learning disabilities are prone to both sight and hearing problems – particularly if they have Down's syndrome, rubella syndrome or cerebral palsy. Several genetic syndromes which cause learning disabilities also cause visual or hearing impairment. Around 40 per cent have eye problems, and 40 per cent of people with severe learning disabilities have hearing problems.

Health Alert!

Many people with learning disabilities go through their lives unnecessarily handicapped because carers have not recognised hearing loss or visual problems or have not tried to get help. They may wrongly assume that it is impossible to test vision or hearing in people with learning disabilities or that nothing can be gained from such a test.

People with learning disabilities are now living longer and so may also acquire hearing or visual problems as part of the ordinary ageing process. People with Down's syndrome acquire some of the symptoms of ageing earlier in life than the general population, and so need careful monitoring from early middle years onwards. Have the persons with learning disabilities you work with had their vision and hearing checked recently?

Ear Health

Poor aural hygiene and abnormally shaped ear canals (a feature of some causes of learning disabilities) place many people with learning disabilities at risk of ear wax build up and recurrent infection. Aural examination is recommended, and treatment if required. There may be a need to offer training to carers in aural hygiene and management of hearing disorders. Hearing aid maintenance is essential. In addition to screening hearing in childhood, routine screening on entering adult services, in middle age and later life is recommended.

Eye Health

Visual impairment is common; causes include refractive errors, cataracts and cerebral visual impairment. The first two of these may be easily correctable; the third may benefit from advice on environmental approaches. Eye tests by an optician are recommended every two years – some people may require testing by specialist services if there is difficulty with the equipment routinely used by community opticians. Eye infections are common, especially in people with Down's syndrome, and benefit from standard treatment.

Important Information

The RNIB Multiple Disability Service has produced a number of FOCUS fact sheets with guidelines on how to help people with learning disabilities feel comfortable:

- Wearing glasses.
- Using prescribed eye drops.
- Having an eye test / surgery.

Download these, or order free copies, at www.rnib.org.uk.

They are also producing a UK wide directory of opticians who are interested in working with people with severe learning disabilities.

Activity : Sensory Impairment

- 1. Ear infections can cause problem behaviour amongst people with severe learning disabilities and this should be investigated when establishing the reason why someone's behaviour has changed. Which of the following may indicate that the person has an ear infection?**
 - a. Ear-bending.
 - b. Puts objects into ears.
 - c. Stealing.
 - d. Bangs or slaps side of face.
- 2. People in which of the following groups have a higher than average risk of developing cataracts?**
 - a. People with Rubella syndrome.
 - b. Older people with learning disabilities.
 - c. People with Down's syndrome.
 - d. People with homocysteinuria.
- 3. Why do people who eye poke, bank their head, or face slap need careful monitoring?**
 - a. They are at risk of damaging their eyes.
 - b. They are likely to become aggressive to others.
 - c. It may indicate other physical or mental ill-health which would benefit from treatment.
 - d. Psychological interventions may be effective in reducing the behaviour.
- 4. Which of the following may indicate the person has a previously unrecognised hearing impairment?**
 - a. She / he does not turn when her / his name is called.
 - b. She / he does not startle to loud noises.
 - c. The person's attention is best gained by touching her / him rather than just speaking.
 - d. The person responds more appropriately when you look her / him in the face when speaking, rather than standing beside or behind her / him.
- 5. Which of the following may indicate the person has a previously unrecognised visual impairment?**
 - a. The person does not anticipate being fed, except when food is close enough to smell.
 - b. The person does not smile at familiar faces, unless the person speaks or touches her / him first.
 - c. The person does not reach out for carers / family members.
 - d. The person has difficulty navigating around objects or if objects are moved, and can be "clingey".

Nutrition

The nutritional status of people with learning disabilities varies according to level and cause of disabilities and the quality of support received. Communication, cognitive ability, social skills, behaviour, activity levels, mental health, physical disabilities and medication can all contribute to nutritional vulnerability. There is a higher prevalence of both overweight and underweight amongst people with learning disabilities, compared with the general population. These problems can negatively impact on a person's general health and quality of life.

Underweight

Low weight is often not identified due to lack of weight monitoring, or it not being seen as a problem. Carers may prefer a lighter weight for ease of lifting and handling. The management of underweight is the same as for the general population. An emphasis on increased frequency of energy-dense meals and snacks should be the initial advice, with use of supplementary nutritional products and referral to Dietetics as a secondary measure.

Overweight

As with all nutritional problems in people with learning disabilities, causes of overweight are multi-factorial. Some causes of learning disabilities are associated with obesity e.g. Down's syndrome, Prader-Willi syndrome. Side effects of some medication may also cause weight gain, e.g. antipsychotic drugs, as can lack of physical activity and ignorance of health messages. Advice for obesity should focus on education of carers and the person with learning disabilities about healthy eating and exercise, with regular weight monitoring.

Caution!

Carers may feel guilty when the person they support is identified as being overweight or underweight. They may worry that care has been deficient in some way and may even resent the implication. It is important to ensure that guidance is supportive rather than negative.

Eating and Swallowing Problems

Problems with swallowing are common in people with severe or profound learning disabilities. They are often neurological in origin or sometimes due to drug side effects. Swallowing problems can lead to regurgitation, cough and recurrent chest infections. People with swallowing problems should be referred to the specialist learning disabilities service for a Dietetic and Speech and Language Therapy assessment. Some individuals may require supplementary nutrition via a Percutaneous Endoscopic Gastrostomy (PEG). Support, training and monitoring of this is provided by Specialist Learning Disabilities Dieticians.

Gastro-Oesophageal Reflux Disorder

Gastro-oesophageal reflux disorder (GORD), is a significant problem for 70% of people with profound learning disabilities or cerebral palsy and 50% with severe learning disabilities. It causes pain and predisposes to oesophageal cancer. It can impact on a person's nutritional status by altering eating

habits. For people with no verbal communication skills it may present as disturbed sleep pattern, problem behaviour or borderline or low haemoglobin. Other symptoms include regurgitation, vomiting, haematemesis and depressive symptoms. In view of the very high prevalence of GORD in selected groups, any suggestion of symptoms warrants a 3 month treatment trial of a protein pump inhibitor e.g. omeprazole.

Case Study : Elaine, Keyworker

We didn't realise that Norman had GORD at first. We couldn't make sense of why he was awake at night screaming, and losing weight.

Constipation

Constipation is common in people who have learning disabilities. The most frequent cause of constipation is lack of fluid or dietary fibre; poor mobility and drug side effects (e.g. some antidepressant and antipsychotic drugs and long term laxative use) can also contribute. Advice is always to increase fluids in the first instance and increase fibre as per healthy eating guidelines. An educational approach with carers and the person with learning disabilities is important.

Key Points : Nutrition

- Overweight and underweight are common and standard management approaches can be beneficial.
- Referral to the learning disabilities dietetic service is necessary if there are compliance problems, training needs for staff, or if the person has swallowing problems.
- GORD is extremely prevalent and may present atypically as sleep disturbance, problem behaviours or low Hb.

Health Needs Associated with Specific Causes of Learning Disabilities

Many causes of learning disabilities have associated extra health needs that differ according to the individual genetic syndrome. There are thousands of known causes of learning disabilities, the majority of which however are very rare. If you meet someone in your clinical practice with a known cause to their learning disabilities it is worth considering whether they have any of the additional health needs that are specific to that condition. Knowledge of these associations is important, both to prevent problems occurring and to improve detection of health needs at an early stage. A few of the more common causes of learning disabilities follow.

Down's Syndrome (www.dsscotland.org.uk or www.dsa-uk.com)

This is the commonest identifiable cause of learning disabilities. It is estimated that 20% of adults with learning disabilities have Down's syndrome – approximately 700 people within Greater Glasgow. Individuals with Down's syndrome can present with a change in behaviour or ability to function in particular situations, when there is an unrecognised medical problem. Knowledge of the type of

problems that people with Down's syndrome are at risk of as well as good clinical skills is essential to identify problems early. The following health needs are common in people with Down's syndrome:

➤ *Hypothyroidism.*

Hypothyroidism is common and increases with age. It is often undetected, and can present atypically, such as by skill loss. Annual monitoring of thyroid function tests is recommended.

➤ *Visual and hearing impairment.*

Visual and hearing problems can present at any age and often in unusual ways. Cataracts, conjunctivitis, otitis externa and media and impacted ear wax are common.

➤ *Recurrent respiratory tract infections.*

➤ *Sleep apnoea.*

Sleep apnoea is common in people with Down's syndrome and can cause a range of daytime symptoms such as irritability, poor concentration, tiredness and aggression.

➤ *Obesity.*

➤ *Skin disorders.*

➤ *Dementia.*

Approximately half of all adults with Down's Syndrome will acquire dementia if they live to middle age and beyond. Depression, hypothyroidism and sensory impairments can present in a similar way to dementia.

➤ *Depression.*

➤ *Congenital heart disease.*

Cardiac problems, although usually detected in childhood, should be excluded if the individual has any change in behaviour, level of functioning or exercise tolerance.

N.B. *Low blood pressure* and *raised MCV* are normal findings in people with Down's syndrome.

Prader-Willi Syndrome (<http://www.pws-uk.demon.co.uk/>)

This is a genetic disorder which has several associated extra health needs:

➤ *Obesity.*

Overeating is a clinical feature of the syndrome and can lead to severe obesity and associated problems, such as diabetes. This is generally managed through a combination of behavioural strategies, environmental manipulation and education. Involvement of a specialist dietician is recommended at an early stage.

➤ *Problem behaviours.*

Skin picking and other types of self injurious behaviours are common. These may present as recurrent sores or bruises and may respond to psychological interventions.

➤ *Pain threshold.*

People with Prader-Willi syndrome can have a very high pain threshold, and don't usually complain of pain. If there are any subtle changes in behaviour a medical cause should be ruled out.

➤ *Depressive episodes with psychotic symptoms.*

Interestingly, reduction in appetite can be a presenting feature of this, so should alert carers to the need for a full psychiatric assessment.

Fragile X Syndrome (www.fragilex.org.uk)

Fragile X syndrome can result in mild or more severe learning disabilities. Associated health problems include :

➤ *Recurrent otitis media.*

➤ *Myopia and 'lazy eye'.*

➤ *Flat feet and joint laxity* resulting in orthopaedic difficulties.

➤ *Epilepsy* (in 20% of men).

- *Gastro-oesophageal reflux disorder.*
- *ADHD* in childhood and adolescence.
- *Autism.*
- *Social anxiety and gaze avoidance.*

Tuberous Sclerosis (www.tuberous-sclerosis.org)

Tuberous sclerosis is a multi-system genetic disorder that causes benign tumours to grow in the brain and other vital organs such as the kidneys, heart, eyes, lungs, and skin. It commonly affects the central nervous system and results in a combination of symptoms. Tuberous sclerosis is frequently unrecognised and can be misdiagnosed for years. Additional health needs associated with tuberous sclerosis include :

- *Epilepsy.*
- *Problem behaviours.*
- *Skin lesions.*
- *Hypertension.*
- *Renal lesions.*

These causing intraperitoneal or renal haemorrhage (presenting as abdominal pain, haematuria or shock), or renal failure.

- *Polycystic kidney disease.*
- *Giant cell astrocytoma.*

This occurs in up to 5% of people with tuberous sclerosis, causes raised intracranial pressure and so is a medical emergency. Urgent MRI of the brain and surgery is indicated.

- *Cardiac arrhythmias.*

They occur in infants rather than adults.

- *Pulmonary complications.*

Phenylketonuria (www.pkunews.org)

Phenylketonuria is an inherited error of metabolism : if it is not detected and treated with careful dietary supervision in early infancy severe or profound learning disabilities will result. Specialist dietetic advice is required. The special diet itself is not without problems and can cause nutritional problems. Additional health needs associated with phenylketonuria include :

- *Weight loss.*
- *Poor wound healing or bed sores.*
- *Osteoporosis.*
- *Hair loss.*
- *Depressive episodes.*
- *Anxiety.*
- *Overactivity.*

Activity: Cause of Learning Disabilities

Think about your patients with learning disabilities.

- Q. Does anyone have a specific cause for their learning disabilities?**
- Q. How much do you know about these underlying causes?**
- Q. Does anyone have any additional health needs?**

Profound and Multiple Disabilities

People with profound learning and multiple physical disabilities have a complex range of needs, and require considerable support from relatives, support workers and health professionals. Commonly associated health needs include: sensory impairments, physical disabilities, immobility, limited speech or communication, swallowing problems, gastro-oesophageal reflux disorder, epilepsy, incontinence and constipation. Many are at greater risk for osteoporosis and fractures. Multi-disciplinary care is essential. Access to Physiotherapy, Occupational Therapy, Speech and Language Therapy and in some instances Dietetics is important, as well as medical and nursing input. Support for seating systems, aids and adaptations, electronic communication aids and dietary advice may be required and will be lifelong.

In the Practice setting consideration of physical environment is important, as is access to suitable equipment for assessment. This might include a hoist and wheelchair scales.

Relative careers will require support, including practical support such as access to respite care and continence services.

Activity : Profound and Multiple Disabilities

John's support worker is concerned that he might be losing weight, because his clothes are starting to look too big for him. They have been unable to check his weight. His appetite seems fine but recently he has been complaining of a sore tummy. He has not opened his bowels for 5 days. John uses a moulded wheelchair and has no verbal communication skills.

Q. How would you assess John?

SECTION 4 : HEALTH PROMOTION AND SCREENING

The Importance of Health Promotion

Health promotion activities aim to increase the knowledge and understanding of health, illness, and health-related procedures or services. These activities correct any misunderstandings that a person may have about their health and may increase the uptake of health screens and services. *Promoting Health, Supporting Inclusion* (2002) highlights the special needs of people with learning disabilities within all health promotion programmes.

The *Feeling Good Pack* available from the Glasgow Healthy City Partnership is a useful resource for health promotion. The Health Development Agency also produces accessible health promotion information and holds a database of resources for people with learning disabilities (<http://www.hda-online.org.uk/>).

Activity : Health Promotion

You can either reflect on these now or read through the next section first for suggestions. (You could do both and gauge your before and after responses).

- Q. What health promotion initiatives has your Practice undertaken for its patients to date?**
- Q. Have you included any of your patients with learning disabilities in these initiatives?**
- Q. What problems are you (or would you be) faced with by including your patients with learning disabilities and how can you work towards overcoming them?**
- Q. Who can help you?**

Sexual Health

The majority of people with learning disabilities live with their parents or paid carers. Carers have an important role to play in the development and expression of sexuality. People with learning disabilities are often de-sexualised by a society which treats them as children. This then makes it difficult for the person with learning disabilities to have an adult sexuality. This impedes their ability to make appropriate choices and decisions about sex and sexuality.

Sex Education

There have been improvements in sex education for people with learning disabilities as well as for the general population. This means that people with learning disabilities can make informed choices and develop meaningful relationships. Sex education is being addressed in schools and colleges, and in some areas of Glasgow in Adult Training Centres. Glasgow is working towards a Sexuality and Learning Disabilities Policy which will allow more staff and provider organisations to be supported to offer opportunities for people with learning disabilities to understand their sexuality. Specialist local services are available from the Sandyford Initiative in Glasgow. Additionally, the Family Planning Association organise courses that address this issue.

Sexual Abuse

People who have learning disabilities have an increased vulnerability to abuse due to their dependence on other people, difficulties in communication and lack of sexual knowledge. If you have concerns that someone is being abused, this should be referred to the person's Care Manager at the Area Learning Disabilities Team.

Contraception

Persons with learning disabilities may consult you for contraception. It is important to be sensitive to the balance between that person's needs and rights, and their vulnerability to abuse. Professionals within specialist learning disabilities services and the Sandyford Initiative are experienced in this work and could offer further help.

Women's Health

Breast and cervical screening uptake by women with learning disabilities is less than that of women in the general population. Uptake can be improved by the use of accessible appointment letters and preparation appointments to explain procedures and dispel any fears.

Some Available Resources for Women's Health

- NHS Cancer Screening Programmes – *Having a Smear Test and 50 or Over? Breast Screening is for You*
- FAiR/HEBS – *Keep Yourself Healthy – a Guide to Examining Your Breasts* (available in booklet or interactive CD Rom format).
- Royal College of Psychiatrists - *Keeping Healthy Down Below and Looking After My Breasts*, (available as a picture book).
- The Primary Care Liaison Team *Learning Disability Fact Sheet* gives advice on obtaining consent for these procedures.

Menopause occurs earlier than usual in some women with learning disabilities, particularly women with Down's syndrome. A woman with limited verbal communication skills may not be able to complain of the associated distressing symptoms, so vigilance is needed. HRT and appropriate lifestyle advice should be offered, as for all other women.

Men's Health

Men's health issues have not been well addressed for men with learning disabilities. Knowledge of self examination is poor.

Some Available Resources for Men's Health

FAiR/HEBS – *Keep Yourself Healthy – a Guide to Examining Your Testicles* (available in booklet or interactive CD Rom format).

Action

- Make sure people with learning disabilities are included in Well Women and Well Men clinics or groups. This can be facilitated by using pictures and other accessible information.
- Try offering preparatory visits explaining procedures on a group or individual basis.

Osteoporosis

Osteoporosis is more common in adults with learning disabilities than the general population, and warrants health promotional activities and bone-density screening for high risk groups. Risk is higher in those individuals who do not undertake weight-bearing exercise (because of poor mobility), have poor nutrition, failure of development of secondary sexual characteristics (which is associated with some syndromes), take a phenylketonuria diet or are post-menopausal and not taking HRT. If osteoporosis is confirmed, drug treatment together with dietary and physiotherapy advice is indicated.

Smoking and Alcohol

The same guidelines apply for the learning disabilities population as for anyone else. People with learning disabilities may not be aware of the importance of not smoking and limiting alcohol intakes. Simplified information and inclusion in smoking cessation groups is important in awareness raising and ensuring that choice is well informed.

Exercise

Physical activity is important for physical and mental wellbeing. It has an essential role to play in weight management, osteoporosis, etc. Ensuring adequate activity levels in the general population is a major public health initiative. People with learning disabilities may have problems accessing council run leisure facilities, because of physical access, information formats and the types of classes / sports or equipment offered. The GP exercise referral scheme may overcome these barriers.

Healthy Eating

The national guidelines, *The Balance of Good Health* apply to people with a learning disabilities, and the importance of this advice is greater than for the general population in view of the higher prevalence of obesity compounded by lack of education and understanding of healthy eating. People with learning disabilities are more likely to rely on carers making and preparing food choices.

Action

- Include carers in any healthy eating groups / advice that you offer. Accompany this advice with simple key messages for the person with learning disabilities in order that they can make informed choices.
- Invest in easy to understand dietary leaflets: the *Balance of Good Health*, and *Keep Yourself Healthy – Guide to a Healthy Heart* (FAiR / HEBS).
- Link with other community groups e.g. “Get Cooking” Information on Community Health Projects can be obtained from your Public Health Practitioner.

SECTION 5 : COMMUNICATION AND CAPACITY

Communicating with People with Learning Disabilities

People with learning disabilities experience problems with communication. For some people this is apparent e.g. they can't speak or their speech is unclear. It is worth remembering though that for many more people their communication difficulty is less obvious. They may not be able to understand everything that is said or written down and they may not hear things. This affects the person's ability to communicate successfully, which in turn affects their ability to participate fully in everyday activities.

Since communication is a two way process, it can become a lot more successful if you have an awareness of what makes interaction and communication difficult and what you can do to help. This usually involves making positive changes to your own communication. For example, many people with learning disabilities understand more easily if you point, gesture or mime along with spoken language, or if you use pictures, photographs or symbols. We can adapt our communication methods and individualise these to a person's developmental level. This is achieved by keeping communication simple. Think about the physical environment of your consultation room also – it is comfortable and quiet?

Keep Communication Simple

- **Be specific** - avoid giving unnecessary information
- **Be concise** - longer sentences are harder to understand.
- **Avoid jargon** - use everyday words.
- **Use familiar words** - someone may understand *jag* but not *injection*
- **Keep it personal** - use sentences that relate directly to a person e.g. "You need a blood test"
- **Be positive** - negative words like no, not, can't, won't and don't, make information difficult to understand. It can be easier to explain what is, rather than what isn't, going to happen.
- **Keep things in order** - explain things in the order they will happen e.g. "You will have your blood test and then go home" is clearer than "You can go home, after your blood test"
- **Deal with the present** - some people with learning disabilities have difficulties with the concept of time.
- **Use visual aids** - pictures and photos can help understanding.
- **Use reminders** - it is helpful for someone to take away a reminder of what happened at their appointment or when their next appointment is. Always try to explain the information to the person and ask them to repeat it back to you to make sure it has been understood.

Consent to Treatment

Adults with learning disabilities have often been excluded from making decisions about their own health, ranging from general health screening to reproductive health. There has also been a mistaken view that the relatives and carers of adults with learning disabilities are entitled to make decisions for them. (Some relatives and carers have even been invited to sign consent forms on behalf of the adult with learning disabilities, even though such proxy consent has no validity in law). It is important that people with learning disabilities are involved in decision making about their health, to the limit of their capacity for this.

Case Study : Mary, 24 years

My mum said that I was to keep away from the boys at the Day Centre...not go out with them. She said I had to go on the needle so I wouldn't have babies...yes, I do like children...my sister has a baby and a husband too...sometimes...I get jealous sometimes.

Accessible Information

Having information about the need for and nature of treatment is one of three elements of the ethical criteria for *informed* consent, along with voluntariness and competence. It is important therefore that adults with learning disabilities have access to usable information about their health.

It is also important to be aware that the majority of people with learning disabilities, particularly those who are dependent on their relatives or carers, will rely on the *advice* of these and other people in the *process* of making their own decisions about their health. The process of consent involves understanding, believing, and then deciding.

Case Study: Jean, 53 years

I didn't know it was important to have your boobs checked. I thought it was rude...until Susan, my key worker, showed me a picture book about it. Susan went with me to meet the nurse at the clinic too. She came in on her day off and everything. Susan and the nurse helped me understand. I didn't mind having the X-ray. It's important.

Choice and Negotiation

If a person has capacity to make an informed decision, she / he does have the legal and moral right to refuse medical advice or treatment, even if others disagree with or consider the refusal contrary to their best interests. It may be that the person will refuse some but not all aspects of advice or treatment.

Case Study: Margaret's Keyworker

She has mental health problems too...as well as her disabilities. She has put on loads of weight since she moved here from the hospital...she eats far too much...constantly. She is physically aggressive to the staff, and she chooses to lie in bed all day. She's incontinent of urine and that isn't helping her ulcers.

- Q. Can you devise a proposed plan of treatment and action for Margaret?**
- Q. Can you think of alternative options if Margaret refuses your proposed plan?**

Using choice as a reason for non-intervention in all health care situations may signal a departure from the legal and ethical duty of care that is owed to vulnerable adults. This is especially so when:

- The person's ability to make a particular health choice has not been assessed.
- Alternative options that would provide some health care have not been explored.
- The person with learning disabilities has not declined all possible interventions.

Adults with Incapacity (Scotland) Act, 2000

The introduction of the Adults with Incapacity (Scotland) Act is a way of keeping centralised records of what decisions have been made about a person's capacity to make a particular decision at a particular point in time. It aims to protect vulnerable people. Where a person lacks capacity, health care decisions may have to be made if they are in the person's best interest. In these cases you will need to speak with the person's GP who should implement the Act if indicated after assessment of capacity.

What is Incapacity?

The Act defines incapacity as: "*being incapable of:*

- (a) *acting; or*
- (b) *making decisions; or*
- (c) *communicating decisions; or*
- (d) *understanding decisions; or*
- (e) *retaining the memory of decisions,*

... by reason of mental disorder or of inability to communicate because of physical disability; but a person shall not fall within this definition by reason only of a lack or deficiency in a faculty of communication if that lack or deficiency can be made good by human or mechanical aid (whether of an interpretative nature or otherwise)."

General principles of the Act are that actions carried out under the Act should :

- Benefit the Adult.
- Take account of the adult's wishes, both past and present, if these can be ascertained.
- Take account of the views of relevant others as far as it is reasonable and practicable to do so.
- Minimise the restriction of the adult's freedom while achieving the desired benefit.
- Encourage the adult to use existing skills or develop new skills.

The Act covers 5 main areas: Powers of Attorney, Accounts and Funds, Management of Resident's Finances, Medical Treatment and Research, Intervention Orders and Guardianship orders. Of these, all parts will affect healthcare professionals as they are asked to assess capacity, but perhaps the most important to your practice will be Part 5 of the Act regarding Medical Treatment and Research, which came into force in July 2002. This encompasses all medical procedures and treatments, wherever they are provided.

The Code of Practice States That:

"When assessing capacity, it is unlikely that a decision can be reached instantaneously, and the Consultant or GP should be prepared to talk this over with other professionals, including any doctors, nurses, speech and language therapists, clinical psychologists and social workers, amongst others, who are working with the adult. Relatives and carers who know the adult, and people appointed to look after the adult's interests, e.g. Welfare Attorneys or Welfare Guardians should also be consulted, where practicable."

Decision about the capacity of an individual will be multidisciplinary and you should be prepared to take part in this. In assessing capacity we are not making a global decision that refers to every decision a person makes. Instead, we are considering that person's capacity to make an informed decision with reference to one specific situation. For example, someone may have the capacity to make decisions about whether or not to have a blood test but be unable to give or withhold informed consent to a major surgical intervention. Remember that acquiescence is not the same as consent.

There are several pieces of documentation provided with the Act that give guidance. The Code Of Practice, Explanatory Notes and Aide-Memoire for Doctors are all available at <http://www.scotland.gov.uk/justice/incapacity>, or from the Scottish Executive by telephoning 0131-244-4212. The Primary Care Liaison Team also can supply you with an accessible leaflet about the Act.

SECTION 6 : CARE AND SUPPORT FOR PEOPLE WITH LEARNING DISABILITIES

Social Supports

Supported living arrangements and social supports for people with learning disabilities have undergone changes in recent decades, as a result of new ways of thinking about the relationship between people with disabilities, society and services. From normalisation, the concept of social role valorization has developed and has led to Scotland's commitment today to inclusion and social justice. People with learning disabilities should enjoy a quality of life that is equal to, and valued by, non-disabled people.

O'Brien described five accomplishments (targets) for service delivery. These emphasise the importance of individual choice and control and have been influential in service development.

O'Brien's Five Accomplishments for Service Delivery

- **Community Presence.** All individuals should make use of ordinary, mainstream services.
- **Choice.** All individuals should have support to make their own choices about day-to-day matters and major life events.
- **Competence.** Opportunities should be created for all individuals to reach their full potential by developing a range of skills.
- **Respect.** All individuals have the right to occupy a valued role within a network of reciprocal roles.
- **Community Participation.** The importance of being part of a growing network of friends.

In Greater Glasgow, most people with learning disabilities who do not live in their parents home, benefit from supported living. Supporting living enables people to live in their own homes and participate in their communities. The person with learning disabilities holds the tenancy or joint tenancy on her / his accommodation, and a service provider organisation delivers a support package through a small team of support workers - this can be for a few hours per week or 24 hours per day, depending on need. Most support workers do not hold a professional qualification. Support packages are monitored by a Care Manager. Care Managers are qualified professionals, usually a Social Worker or Nurse, based at the local Area Learning Disabilities Team.

Case study : Arthur, aged 56 years

I am supported by staff in my own home. The staff refer to me as the tenant because I rent my home myself. I like that, it makes me feel proud. My key worker has explained to me that if my support service ever changes, if they can't help me do the things I want to do at home anymore for any reason, I will not have to move out. My home and my support are two separate things. This has put my mind at rest. I had a lot of changes in my life in the past, moving from ward to ward in the hospital, and I didn't like it.

Delivery of care to people with learning disabilities who have moved from a long-stay institution into their own ordinary homes has become similar to the delivery of care to people with learning disabilities who always lived in the community with their families. There is an expectation that comprehensive health care services for people with learning disabilities will be developed and provided locally.

Activity : Social Model of Disability

The social model of disability located disability (what it actually means to be disabled) in the interaction between the individual and the social and physical world. In this model, the job of services is not to “fix” the individual but to reduce the restrictions they face and support them in leading their own life. A typical example of a social / service restriction placed on people with learning disabilities would be a public building e.g. a sports centre or library that does not have access facilities for wheelchair users.

- Q. Can you, along with other members of your team, identify any social and / or physical restrictions that your patients with learning disabilities face in trying to access services at your Practice?**
- Q. What measures can you take to minimise these restrictions?**

The principles of ordinary living for people with learning disabilities also incorporate a strong commitment to zero rejection. This assumes that all individuals are ready to live like others, regardless of their abilities, and that support, expertise and protection should be matched to need.

- Q. Do you have any patients with learning disabilities who, despite having a high level of needs, are supported by staff in their own home?**

Area Learning Disabilities Teams

In most areas there are locality-based teams of specialist learning disabilities professionals who have expertise and knowledge of working with adults with learning disabilities. They will usually take referrals from any member of a primary health care team, and also take self-referrals. They are also a resource for advice and support.

Through the Area Learning Disabilities Teams you can often access Community Learning Disability Nurses, Epilepsy Nurses, Speech and Language Therapists, Learning Disabilities Psychiatrists, Dieticians, Podiatrists, Psychologists, Physiotherapists, Occupational Therapists and Social Workers. Some of the Learning Disabilities Nurses, Occupational Therapists and Social Workers provide a Care Manager role.

Activity : Area Learning Disabilities Teams

- Q. Can you think of any instances when you would need to contact one of your patient's Care Manager? Do you already have their contact details on file?**
- Q. Are you familiar with the Area Learning Disabilities Team in your Practice's area? Do you have their contact details?**
- Q. Have you ever thought that the Area Learning Disabilities Team was involved with one of your patients with learning disabilities and later found out that they weren't? What measures can you and your team take to ensure that this doesn't happen?**

The Primary Care Liaison Team

In Greater Glasgow, a Primary Care Liaison Team (PCLT) has been set up to facilitate primary care and ensure equity of service provision for people with learning disabilities. A health-screening programme for people with learning disabilities is currently being undertaken by the PCLT. Their work so far suggests that people with learning disabilities often have unrecognised health needs, a greater need for health promotion e.g. immunisation and well woman / man programmes, and participation in healthy lifestyle programmes.

Making Primary Care Services Accessible

Primary health care teams are the main point of contact with health services for people with learning disabilities.

Primary care services predominantly function on a reactive rather than proactive basis, relying on people with learning disabilities and their relatives / support workers to both identify a problem and actively seek consultation. This can be problematic for persons with communication difficulties or dependant upon inexperienced support workers who do not know her / him well.

Other problems that people with learning disabilities face in being able to access equivalent services with the rest of the population include e.g. time constraints during actual consultations and assumptions being made about them e.g. that they do not drink, smoke, experience stress, or have sexual relationships.

Lack of training and knowledge of primary health care professionals, particularly in relation to the health needs and different ways of communicating of people with learning disabilities, can also be a barrier to accessing primary health care services effectively. As only has a small number of persons with learning disabilities are registered with each General Practice, opportunities for developing expertise in working with persons with learning disabilities, in day-to-day practice, are few.

Some Barriers To Accessing Services

- **Physical barriers** – poor accessibility to health facilities.
- **Administrative barriers** – short appointments and long waiting times.
- **Communication barriers** – difficulties in describing symptoms contributing to diagnostic overshadowing.
- **Attitudinal barriers** – negative assumptions and attitudes about people with learning disabilities.
- **Knowledge barriers** – limited theory and practice experience of the health needs of people with learning disabilities.

Case Study: Practice Receptionist

Jimmy has learning disabilities. We give him appointment times on the hour...at 4 O'clock say, instead of 4.15 or 4.30. It is easier for him to remember his appointment time then...to recognise and remember the number 4.

The immediate things that spring to mind when we talk about having an accessible service for people with learning disabilities are ramps and other physical adaptations to the environment. These are important but most practices have already done this. When people with learning disabilities are asked about their experience of using health services the key themes that emerge are communication and flexibility of services. By looking at the way we provide information and communicate with persons with learning disabilities, and their carers, and by thinking about ways in which we can adapt our services, we improve accessibility for people with learning disabilities.

Activity

Think about the last time you or a family member visited a GP practice. Imagine you hadn't been able to understand what was being said.

- Q. How would this make you feel?**
- Q. How would you know what was wrong or what you were supposed to do about it?**
- Q. What would you do the next time you felt unwell?**

In fact, relatively small changes can change the experience of visiting your practice. For example some practices have developed symbolised appointment cards like the one below. The name, address and phone number of the surgery is printed on the reverse. Other simple measures are to put photographs of members of staff on the door of the room they use. In that way someone who can't read the name will still be able to find the right room when they are called through. There are many different ways to improve the accessibility of your service so we hope to start you thinking about these issues.

Name _____	Doctor	Nurse				
You have an appointment with the						
on	Monday	Tuesday	Wednesday	Thursday	Friday	
	Date _____					
at	_____	am/pm				

Increased flexibility can also have an impact on people with learning disabilities accessing health services. You may already have started allowing longer appointment times for people with learning disabilities. As some people with learning disabilities find it difficult to wait in a busy area perhaps you have made changes that ensure they are given appointments when it is quieter or they don't have to wait. There are several possible options to improve accessibility. As each practice is unique we believe that, if you and your colleagues start to think about your own service, this will allow the most useful changes to be made.

Case Study : Practice Receptionist

Frank has learning disabilities, and he finds it difficult to retain information. He forgets things easily. When he telephones to make an appointment he uses a dictaphone to help him remember the information I am giving him, the appointment time and day, later. I help him do this. I get him to repeat the information back to me over the phone, just to make sure it is being recorded.

Activity : Making Primary Care Services Accessible

To reduce anxiety for patients needing sensitive procedures e.g. a cervical smear, there may be benefits in liaising with specialist learning disabilities nurses or support workers, to do some preparatory work.

Q. Can you think of other preparatory steps for your appointments with your patients with learning disabilities?

Accessible information can be achieved e.g. by using simple jargon-free language, larger type and short sentences.

Q. Can you think of other ways to make information more accessible to people with learning disabilities?

Q. What about people who cannot read or write?

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APPENDIX 1 : WEB ADDRESSES FOR FURTHER INFORMATION

Accessible Information Resources

The Royal College of Psychiatrists

www.rcpsych.ac.uk/publications/bbw

The *Books Beyond Words* series are a useful resource for providing accessible information to people with learning disabilities.

The Elfrida Society

www.elfrida.com

A range of leaflets and videos on the specific health and support needs of people with learning disabilities are available from the Elfrida Society. Of special interest to health care professionals may be the leaflets on blood tests, CT scans, EEGs and MRI scans, the drug pack, and accessible information about mental health.

Health Education Board for Scotland (HEBS)

www.hebsweb.com

HEBS produces a variety of accessible resources for use with adults with learning disabilities, many of which are free to those living and working in Scotland.

British Institute of Learning Disabilities (BILD)

www.bild.org.uk

BILD offers a range of services to support learning by professionals, care staff, service users and their families.

Epilepsy

National Society for Epilepsy

www.epilepsynse.org.uk

This site is very useful and has sections for members of the public as well as professionals.

Epilepsy Action

www.epilepsy.org.uk

The British Epilepsy Association has recently changed its name to Epilepsy Action. This site provides information to people with epilepsy of all ages and those working with them.

Genetics

OMIM – Online Mendelian Inheritance in Man

www.ncbi.nlm.nih.gov/Omim

This site provides a vast catalogue of genetic disorders with up to date medical reviews on each, as well as a useful list of allied resources.

Health Guidelines and Health Information

Learning about Intellectual Disabilities and Health

www.intellectualdisability.info

Excellent site with a section on the health needs of people with learning disabilities. Highlights include the Top Ten Tips for Effective Consultation.

The International Association for the Scientific Study of Intellectual Disabilities (IASSID)

<http://www.iassid.org/>

The *IASSID Health Guidelines for Adults with an Intellectual Disability* are available here.

Online Learning Disabilities Textbook

www.ldbook.co.uk/Book.htm

This is an online textbook covering most areas of interest to health care professionals working with people with learning disabilities.

The Foundation for Learning Disabilities

www.learningdisabilities.org.uk

This site has a wealth of information on the lives of people with learning disabilities.

European Association of Intellectual Disability Medicine (MAMH)

www.mamh.net

MAMH is a European group whose aim is to promote all aspects of the study of the medical (including psychiatric) needs of people with learning disabilities. This site provides a long list of links, as well as an interesting description of services in various countries.

Rare Disorders

Contact a Family

www.cafamily.org.uk

This site is a main source of information about rare disorders in particular, and it is easily accessible to parents, carers and professionals.

Sensory Impairment

Royal National Institute of the Blind (RNIB)

www.mib.org.uk

This site provides a wealth of information for people working with adults with learning disabilities and sensory impairment. The Multiple Disability Service's FOCUS fact sheets in particular offer useful guidelines and suggestions.

The Royal National Institute for the Deaf (RNID)

<http://www.rnid.org.uk/>

This site covers many topics of relevance to people with learning disabilities.

Sense Scotland

www.sensescotland.org.uk

This site includes relevant information on sensory impairments.

Sexual Health

NHS Cancer Screening Programmes

www.cancerscreening.nhs.uk

Order *Good Practice in Breast and Cervical Screening for Women with Learning Disabilities* (2000) and other accessible information on screening.

Ann Craft Trust

<http://www.anncrafttrust.org/>

This association is dedicated to the protection from abuse of adults and children with learning disabilities.

Specific Conditions

National Autistic Society

www.nas.org.uk

The National Autistic Society is the largest UK charity working for people with autistic spectrum disorders. This site has a useful list of publications, information and comprehensive links to autism sites.

Down's Syndrome Association UK

www.dsa-uk.com

The aim of this site is to make as much of their information accessible to as many people as possible around the world. There are many useful contact addresses and links, and it is an essential site for people concerned with the rights of people with Down's syndrome.

The Fragile X Society

www.fragilex.org.uk

The Fragile X Society is the UK support organisation for people with Fragile X syndrome and their families.

Phenylketonuria

www.pkunews.org

This site contains a range of news and information about phenylketonuria.

APPENDIX 2 : USEFUL CONTACTS, ORGANISATIONS AND RELEVANT SCOTTISH DOCUMENTS

Autism

The National Autistic Society is the largest UK charity working for people with autistic spectrum disorders. It has a useful list of publications, information and comprehensive links to autism sites.

National Autistic Society

393 City Road
London EC1V 1NG
Tel: 020 7833 2299

www.nas.org.uk

British Institute of Learning Disability (BILD) Resources

BILD produces a wide range of resources related to working with people who have Learning Disabilities including accessible information on a range of subjects, reading lists and research bulletins.

Campion House, Green Street
Worcestershire DY10 1JL
Tel: 01562 723010
Fax: 01562 723029
E-mail: enquiries@bild.org.uk
Website: <http://www.bild.org.uk>

Capability Scotland

Capability Scotland is Scotland's largest disability organisation. Specialising in supporting people with cerebral palsy, they also support adults and children with a wide range of disabilities. They provide a range of residential services, day services and advice services, as well as advocacy and befriending services.

Capability Scotland
11 Ellersly Road, Edinburgh
EH12 6HY
Tel: 0131 313 5510
Fax: 0131 346 1681
Textphone: 0131 346 2529
E-mail: capability@capability-scotland.org.uk
Website: <http://www.capability-scotland.org.uk/>

Cancer Screening

Accessible information on breast and cervical screening is available.

NHS Cancer Screening Programmes

The Manor House

260 Ecclesall Road South

Sheffield S11 9PS

Tel: 0114 271 1060

www.cancerscreening.nhs.uk

Carers

There are several carer organisations operating in Glasgow. Most of them can be contacted via the Carers Support & Development Project or the Princess Royal Trust.

Carer's Support & Development Project

Killearn Resource Centre

29 Shakespeare Street, Maryhill

Glasgow G20 8TH

Tel: 0141-946-5612

Fax: 0141-945-4532

Princess Royal Trust

Dixon Community Carers, Carers Centre

656 Cathcart Road, Glasgow

G42 8AA

Tel: 0141-423-0728

Fax: 0141-423-5361

There are nine carers projects / centres in Glasgow. Carers can access them through the Glasgow Carers Support Line on 0141-353-6504 who can refer on to the appropriate project / centre. Each project aims to provide the following services: Information & Advice, Income Maximisation, Emotional Support, Short Breaks and Training as well as mechanisms which allow carers to "have a voice".

Common Knowledge

Common Knowledge is a learning partnership aimed at promoting inclusion for people with learning disabilities in the city. They are supporting people with learning disabilities to contribute to policies which affect them, supporting employers and local service providers to make services accessible, and offering training to people who want to support people with learning disabilities.

Common Knowledge

Killearn Centre

29 Shakespeare Street, Maryhill

Glasgow G20 8TH

Telephone: 0141 945 8046

E-mail: info@ckglasgow.org.uk

Website: <http://www.ckglasgow.org.uk>

Down's Syndrome

Down's Syndrome Scotland is the organisation which has a specific remit to work with and campaign for the rights of children and adults with Down's syndrome.

Down's Syndrome Scotland

158-160 Balgreen Road,

Edinburgh EH11 3AU

Tel: 0131-313-4225

Fax: 0131-313-4285

E-mail: information@dsscotland.org.uk

Website: <http://www.dsscotland.org.uk>

The Elfrida Society

The Elfrida Society is a London based organisation that is involved in many different areas of work with people who have learning disabilities. They publish a range of leaflets and videos around specific health and support issues aimed at adults who have learning disabilities. Of specific interest to health professionals may be the leaflets about blood tests, CT scans, EEGs and MRI scans, the Drug Pack and accessible information about Mental Health Medication.

Publications Dept.

The Elfrida Society

Tom Blyth Centre

34 Islington Park Street

London N1 1PX

Tel: 020 7359 7443

Fax: 020 7704 1358

E-mail: elfrida@elfrida.com

Website: <http://www.elfrida.com>

Enable

Enable nationally provides varied services for both children and adults such as employment and training, social and leisure activities and advocacy services. There are three local branches within Greater Glasgow but all can be contacted via the address below. To support their campaigns about issues affecting people with learning disabilities, Enable produces a range of leaflets about learning disabilities and related issues, a list of which can be obtained from Enable.

Enable Glasgow

Curran House, 9 Lynedoch St

Glasgow G3 6EF

Tel: 0141-332-7420

E-mail: information@Enable.org.uk

Website: <http://www.enable.org.uk>

Feeling Good Pack

This is a health resource pack for people who have learning disabilities. More information and copies of the pack can be obtained from Glasgow Healthy City Partnership.

Glasgow Healthy City Partnership
Glasgow City Council, City Chambers
Glasgow, G2 1DU
Tel: 0141-287-9995
Fax: 0141-287-9996

Fragile X Syndrome

Fragile X syndrome is the most common cause of inherited learning disability. It affects girls and boys causing a wide range of difficulties with learning and problem behaviours. The Fragile X society is the UK support society for those affected by Fragile X syndrome.

The Fragile X Society,
53 Winchelsea Lane,
Hastings, East Sussex,
TN35 4LG
Tel: 01424-813-147
E-mail: lesleywalker@fragilex.k-web.co.uk
Website: <http://www.fragilex.org.uk/>

Glasgow Healthy City Partnership (GHCP)

Glasgow Healthy City Partnership is a World Health Organisation designated “Healthy City Project” bringing together a range of voluntary and statutory agencies working within Glasgow to work towards improving the general health of the city.

Glasgow Healthy City Partnership Office
Glasgow City Council, City Chambers, George Square
Glasgow G2 1DU
Tel: 0141-287-4678 or 0141-287-4317
Fax: 0141-287-5551

Health Education Board for Scotland (HEBS)

HEBS produces a variety of health promotion resources, some of which are suitable for use with adults with learning disabilities. Single copies of materials are free to those living and working within Scotland.

Health Education Board for Scotland (HEBS)
Woodburn House, Canaan Lane
EDINBURGH EH10 4SG
Tel: 0131 536 5500
Fax: 0131 536 5501
E-mail: publications@hebs.scot.nhs.uk
Website: <http://www.hebs.com>

Incapacity Act (Adults with Incapacity (Scotland) Act, 2000)

“It’s Your Decision” leaflet outlining the principles of the Adults with Incapacity (Scotland) Act 2000 in simple language is produced by *Enable* for the Scottish Executive.

Information on the Adults with Incapacity (Scotland) Act 2000 (including the full text of the Act and all relevant codes of practice) is available on the web at the following address:

<http://www.scotland.gov.uk/justice/incapacity>

More information can be requested by telephone on: 0131-244-4212.

Glasgow Learning Disability Partnership

Glasgow Learning Disability Partnership is the partnership of interested parties in provision of learning disabilities services in Glasgow. For more information, contact

Glasgow Learning Disability Partnership
Killearn Centre, 29 Shakespeare Street, Maryhill, Glasgow G20 8TH

There is an award winning, accessible website at:

<http://www.ixseed.org.uk>

NHS Health Scotland

The aim of NHS Health Scotland is to improve health and reduce inequalities. In 2004, NHS Health Scotland published the *Health Needs Assessment Report. People with Learning Disabilities in Scotland*. The report identifies the inequalities experienced by people with learning disabilities and makes recommendations to promote health improvement.

Copies of the report are available at:

<http://www.healthscotland.com>

Once a Day

Once A Day is the document produced by the NHS Executive in March 1999, aimed at Primary Care staff teams. It is aimed at promoting good practice in enabling people with learning disabilities to access and receive good quality services from primary health care teams. Unfortunately the document is now out of print, but it can be downloaded free off the World Wide Web at the following address:
<http://www.doh.gov.uk/nhsexec/onceaday.htm>

PAMIS

PAMIS is a registered charity which provides information, advice and training to families caring for a child or an adult with profound and multiple disabilities.

PAMIS

PAMIS
Springfield House, 15/16 Springfield
University of Dundee, Dundee
DD14JE

Tel: 01382 345 154
Fax: 01382 227 464
Email: pamis@dundee.ac.uk

<http://www.dundee.ac.uk/pamis>

Promoting Health, Supporting Inclusion

This is the national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities, published by the Scottish Executive, 2002. It is available from :
The Stationery Office Bookshop
71 Lothian Road
Edinburgh EH3 9AZ
or can be downloaded from <http://www.scotland.gov.uk>

Royal National Institute of the Blind (RNIB)

RNIB provide a range of services for adults with learning disabilities including assessment and consultancy, as well as producing a range of health promotion materials around visual impairment and eye testing. A range of printed and taped materials specifically aimed at Adults with a learning disabilities uses illustrations to support ideas such as *Getting New Glasses* and *Getting Your Eyes Tested* are available.

RNIB Scotland
Dunedin House, 25 Ravelston Terrace,
Edinburgh EH4 3TP
Tel 0131-311 8500
Fax 0131-311 8529
Website: <http://www.rnib.org.uk>

Same As You

The Same As You? is the report into the review of services for people with learning disabilities in Scotland. “The Same As You” Document is available at:
<http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>

Scottish Consortium for Learning Disability

The SCLD has been set up by people and organisations who are involved with people who have learning disabilities in Scotland. The job of SCLD is to help individuals, families, organisations, service providers, staff, local authorities, health services and the Scottish Executive achieve those goals set out in “*The Same As You?*”

Room 16,
Adelphi Centre, Commercial Road,
Glasgow G5.
Tel: 0141 418 5420
Fax: 0141 429 1142
E-mail: administrator@scld.co.uk
Website: <http://www.scld.org.uk/>

Sense Scotland

Sense Scotland is part of the UK National Deaf Blind and Rubella Association and provides a range of functions.

Sense Scotland
5th Floor, Clydeway Centre,
45 Finnieston Street,
Glasgow G3 8JU.
Tel : 0141 564 2444
Website: <http://sensescotland.org.uk>

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