

Access to Primary Care for People with Learning Disabilities

A Resource Pack for Primary Health Care Staff



Defining

Learning Disability

'Learning Disability' is a term used to describe a group of people who have an overall pattern of intellectual functioning that is significantly lower than that of the general population, with associated impairments in social functioning. (www.ldbook.co.uk)

Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (Impaired Social Functioning);
- Which started before adulthood, with lasting effect on development.

Descriptions of

Learning Disabilities

Category of Learning Disability	IQ	Typical Abilities
Mild	50-70	Hold conversation. Full independence in self-care. Practical domestic skills. Basic reading and writing. Many adults will be able to maintain good social relationships and employment.
Moderate	35-50	Limited language. Need help with selfcare. 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. Movement problems common. Ongoing support/supervision required.
Profound	Below 20	Unable to understand requests, very limited communication. Little or no self- help skills. Usually incontinent with severe impairment to mobility. Will require support to fulfil all daily living skills.



Incidences of

Learning Disability

There is a real need to identify numbers of people who have learning disabilities in order to develop a detailed picture of service needs and to ensure all these people are offered the opportunity to access care.

The 'Valuing People' strategy 2001 suggests that there are approximately 210,000 people in the country with severe or profound learning disabilities and some 1.2 million who have moderate to mild learning disabilities. The strategy also anticipates a 1% increase per annum for the next 15 years due to a number of factors:-

- Increased life expectancy particularly amongst people with Down's Syndrome.
- Increased numbers of children with complex and multiple disabilities surviving into adulthood,
- A sharp rise in the reported numbers of children with autistic spectrum disorders, some who will also have a learning disability,
- Greater prevalence among some minority ethnic populations of South Asian origin. These individuals are mainly living in the Caldmore/Palfrey areas of Walsall.

It is expected that on average 2% of people on a G.P's list will have some level of learning disabilities, for example, a practice list of 2000 will have about 40 patients with learning disabilities. Of these 40, approximately 8 will have severe disabilities and the remaining 32 will have moderate to mild problems. (Department of Health, 1999).

Prevalence of severe learning disabilities is considered to be evenly spread across all social-economic groups with links to an increased incidence of mild to moderate learning disabilities within deprived areas (DOH 2001).

The current learning disability register indicates that there are approximately 950 people residing in Walsall who have a learning disability (these are only the ones that we know).

Valuing People

The White Paper 2001

'Valuing People' the strategy for learning disabilities for the 21st century was presented in March 2001.

The four key principles of Rights, Independence, Choice and Inclusion provide the framework of objectives and targets that need to be met nationally.

One of the principle aims of 'Valuing People' is to ensure that people with a learning disability have the 'same right of access to mainstream health services as the rest of the population' and 'to be able to access a health service designed around their individual needs with fast and convenient care delivered to a consistently high standard with additional support where necessary' (Valuing People 2001).

Key actions from Valuing People 2001

- Action to reduce Health Inequalities: explore feasibility of establishing a confidential inquiry into mortality among people with learning disabilities.
- Action to challenge discrimination against people with learning disabilities from minority ethnic communities.
- Health facilitators to be identified by Spring 2003.
- All people with a learning disability to be registered with a G.P. by June 2004.
- All people with a learning disability to have a Health Action Plan by June 2005.
- NHS to ensure that all mainstream hospital services are accessible to people with learning disabilities.
- Development of local specialist services for people with severe challenging behaviour to be a priority for the capital element of the Learning Disability Development Fund.
- Mental Health NSF will bring new benefits to people with learning disabilities.
- New role for specialist learning disability service.



The Story so far . . .

Valuing People - A New Strategy for Learning Disability for the 21st Century

Health inequalities affecting people with learning disabilities and high levels of unmet health needs have been well documented in recent years (Disability Rights Commission 2006; Healthcare Commission 2005)

The causes of poor health in people with learning disabilities are diverse. A higher biological risk of chronic medical conditions such as thyroid dysfunction, respiratory disease and mental health problems act as barriers to accessing appropriate healthcare. (Elliot et al 2003, National Patient Safety Agency 2004)

Individuals with learning disabilities are less likely to have health checks, have their sight or hearing tested or receive appropriate health promotion advice (Healthcare Commission 2005)

There is an above average death rate among younger people with learning disabilities however as life increases, age related diseases such as chronic respiratory disease and cancer are of particular concern. (Elliot et al 2003) Higher mortality rates from coronary heart disease, the second most common cause of death for people with learning disabilities highlight an additional factor, relating to the need for support in managing medication and changes to lifestyle (Alborz et al 2003, Lunskey et al 2002)

There is evidence that people with learning disabilities also experience 'diagnostic overshadowing' that is, reports of physical ill health being treated as a consequence of learning disability and so not being investigated or treated. (Disability rights Commission 2006)

Health Screening and Health Checks

Regular health checks have been shown to identify significant unmet health needs amongst people with learning disabilities and there is evidence that subsequent health checks a year later may uncover further, sometimes serious needs (Disability Rights Commission 2006)

Health Action Planning

The government white paper "valuing People" set aims and objectives to ensure that people with a learning disability have the same right of access to mainstream health services as the general population and for all to have a Health Action Plan.

A Health Action Plan (HAP) is a personal plan about what a person with learning disabilities can do to keep healthy. It will list what help someone needs to keep healthy and safe and help to get the services and support they need.

Walsall Integrated Learning Disability Team has developed a Health Action Plan.

We think Health Action Plans are a great idea because they help doctors and other health professionals understand what help and support someone who has a learning disability needs to maintain good health.

What makes a good Health Action Plan?

- The plan is individual for the person
- Takes account any relevant broader detriments of health
- Pays attention to individual lifestyle, culture and health issues
- Supports the White paper values of rights, independence, choice and inclusion
- Involves primary care, and other generic health service staff
- Is done with the person with learning disabilities
- Where appropriate involves people close to him/her
- The person concerned knows what is in the plan and is actively involved in implementing it
- Is 'live' with the focus on action, not just the plan
- The role and responsibilities of everyone involved in the plan are clear
- Implementation of the plan is monitored
- Reflects any relevant national or local initiatives aimed at improving health, including actions to reduce health inequalities and National Service Frameworks

(Adapted from Department of Health guidance (Department of Health 2002))



Pacesetters

Working in collaboration to promote health equality and discrimination free environment for patients and staff

About the Pacesetters programme

The Pacesetters programme is a partnership between local communities who experience health inequalities, the NHS and the Department of Health. Working with strategic health authorities (SHA) it aims to deliver:

- Patient and public involvement in the design and delivery of services
- Reduce health inequalities for patients and service users
- Promote working environments that are fair and free of discrimination

Inequalities can be those that arise from discrimination on account of age, disability, ethnicity, gender, religion and sexual orientation or gender identity.

Each SHA and its trust will work on a range of local and core issues. The 'local' elements will be determined as a result of national and local evidence, audits and consultation and the 'core' elements will be suggested by the Department of Health.

Access to Health Screening Programmes

Preventative approaches such as health education and health promotion campaigns which focus on 'risk behaviour' in the general population have seldom been targeted at people with a learning disability. Strategies such as routine screening for preventable conditions occur far less frequently. Studies have shown that people with learning disabilities are screened significantly less than the general population, although there is strong evidence to show that this population group have a significantly higher number of health needs, notable complexities of health needs and extensive unmet health needs.

What is needed?

- Provision of good, accessible information to enable people with learning disabilities to make their own decisions about whether to accept an invitation to screening
- Ensure that invitations to screening is appropriate and comprehensible
- To ensure individuals know what to expect when they attend for screening so that it is a positive experience
- To understand the consequences of screening or not screening
- To understand and be aware of changes in their own bodies

Walsall

Service Development

In order to establish and action the work that needs to be completed to meet these objectives a Health Facilitator has been appointed to look at Health Facilitation and Health Action Plans.

It has been identified by the Integrated Learning Disability team that the role of Health Facilitation will be an intrinsic part of the Learning Disability Community Nurse Role.

There are a number of areas that need to be developed in order to establish a framework from which Community Nurses will be able to offer and provide Health Action Plans for individuals that have a Learning Disability.

These are:-

- To work with GP practices to raise awareness about learning disabilities and to provide advice and guidance in relation to Health Action Plans
- To educate and raise the awareness within the primary care teams and acute services as to the needs of people with Learning Disabilities
- To identify a tool in order to monitor and audit the health status of people with learning disabilities relative to the general population and to work alongside public health colleagues to reduce identified health inequalities
- To assist services to become culturally competent and meet the health needs of people with Learning Disabilities from Black & Ethnic minority communities
- To audit discriminatory practice in access to healthcare, including access to mainstream screening programmes and acute healthcare and linking to clinical governance responsibilities
- To audit healthcare information i.e. leaflets relating to health promotion and to identify easy-read versions for people with Learning Disability.

Your Health Facilitator is

Contact: The Allen's Centre
Hilton Road
New Invention
Willenhall
WV12 5XB

Tel: 01902 413006 Fax: 01902 413081

Email:

Walsall Integrated Learning Disability Team members

Consultant Psychiatrists in Learning Disabilities	Dorothy Pattison Hospital	01922 858060
Two Locality Teams consisting of Community Nurses, Social Workers and Health & Social Care Facilitators		
North/ West Team Bloxwich, Dudley Fields, Goscote, Leamore, Blakenall, Moxley, Mossley, Bentley, Short Heath, New Invention, Willenhall & Darlaston	The Allen's Centre	01902 413006
South/East Team Brownhills, Pelsall, Rushall, Aldridge, Caldmore, Streetly, Pheasey, Paddock, Palfrey, Pleck & St Mathews	Broadway North Centre	01922 649088
Health Facilitation	The Allen's Centre	01902 413006
Transition team Planning the move forwards from children's to adults services	The Allen's Centre	01902 413006
Forensic Team	Broadway North	01922 649088
Person Centre Planning	Moxley Peoples Centre	01902 353983
Behavioural Support Services	The Allen's Centre	01902 413006
Occupational Therapy	North/West South/East	01902 413006 01922 649088
Physiotherapy	The Allen's Centre	01902 413006
Speech & Language Therapy	Greybury House	01922 858726
Welfare Rights Officer	Broadway North Centre	01922 649088
Adult Placement Team	Moxley Peoples Centre	01902 353983
Older Carers Support	Moxley Peoples Centre	01902 353983

How an Individual with a Learning Disability may communicate

Verbal

- Individuals who have a learning disability may be able to comprehend (understand) more than they can articulate.
- They may be repetitive.
- If they are anxious or upset their speech may become quicker or louder.
- They may use inappropriate language or speak out of context.
- 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 in relation 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 as many factors can impair communication i.e. noise, distractions.
- Waiting is often difficult when a person is anxious about something. Fear may build up causing unco-operative or difficult to manage behaviour.



Good Communication

Good communication is essential when dealing with individuals who have a learning disability. A person with a learning disability may have limited communication, comprehension and social skills. In order to reduce distress, poor co-operation and difficult behaviours we need to ensure that we are effective in our communication and that we communicate at a level that is understood by the individual.

Language

- Language should be kept simple.
- Keywords should be emphasised.
- Long words, abstract ideas, comparisons and euphemisms should be avoided.
- Be aware of the language that the individual uses.
- Be honest.

Tone

- Be aware of your voice, conveying confidence, patience and care will help an interaction.
- Take time to explain things to the individual.
- You may need to repeat the information many times.
- Waiting should be kept to a minimum.

Non Verbal body language

- You should be aware of your body, a relaxed, confident manner will be more re-assuring to an individual.
- Facial expressions 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 personal 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.
- The main signs that are used come from MAKATON which has been developed from British Sign Language.
- The main symbol system is RHEBUS.
- You may need to use gestures to emphasise verbal language.

Consent to Treatment

For a person's consent to be valid, the person must be:

- Capable of taking the particular decision ('competent')
- Acting voluntarily (not under pressure or duress from anyone)
- Provided with enough information to enable them to make that decision

(DOH - Seeking Consent: Working with people with learning disabilities - 2001)



Capacity

- Need to be able to comprehend and retain information material to the decision, especially to the consequences of having or not having the intervention in question, and
- Be able to use and weigh this information in the decision making process.

Methods of assessing comprehension and ability to use information to make a choice include: -

- Exploring the patients ability to paraphrase what has been said (repeating and rewording explanations as necessary)
- Exploring whether the patient is able to compare alternatives, or to express any thoughts on possible consequences other than those that you have disclosed;
- Exploring whether the patient applies the information to his or her own case.

(DOH – Seeking Consent: Working with people with learning disabilities -2001)

What information do people need?

People need information about:

- The benefits and the risks of the proposed treatment.
- What the treatment will involve?
- What the implications of not having the treatment are?
- What alternatives may be available?
- What the practical effects on their lives of having, or not having, the treatment will be?
- This information needs to be provided in a form that the particular person can understand. This may involve using pictures or explaining in simple terms and short sentences and being willing to repeat and reword explanations.

Acting Voluntarily

It is important to ensure that the person's decision is truly their own. Professionals and carers have a role to play in discussing the options with the individual but they should take care that people do not feel forced into making decisions they are not happy with or are simply agreeing out of a desire to comply with authority.

Barriers to Accessing Health Care

It has been well documented that this group of people have greater health needs than the general population, however, a significant proportion still do not access mainstream services. WHY?

- The individual may not understand the process of consultation.
- The individual may not understand the importance of attendance at appointments.
- Fearful of doctors and nurses.
- Fearful of surgery/hospital.
- Communication problems – comprehensive and responsive.
- Low expectations of health both of the individual and carers.
- Difficulty with long waiting times in crowded surgeries.
- Access to building.
- Directions around the building may be confusing.
- Limited understanding of learning disabilities by primary and secondary health care staff.
- Limited communication and joint working between primary and secondary health care workers and community learning disability teams.

How do we overcome these barriers?

- Simple explanation of process using a variety of communication aids i.e. pictures.
- Speaking slowly use of appropriate tone of voice/body language and facial expressions.
- Offering opportunities to look at equipment that may be used in the procedure.
- Allowing individuals time to meet with team members that they may come into contact with.
- Arrange visits to the surgery/hospital in order to familiarise the individual (this may take a number of visits).
- Health promotion – increase knowledge/confidence and self esteem.
- Offer first or last appointments.
- Offer double appointments.
- Identify individuals who have a learning disability that are registered with your practice. Use Read code E3/Eu81z-1
- Learning disability team to offer awareness training for primary and secondary health care workers.
- Networking and sharing of information between primary/secondary care and the Integrated Learning Disability Team.

Walsall Integrated Learning Disability Service

Walsall Integrated Learning Disability Team have an eligibility criteria to ensure that the service is targeted effectively, with an equitable resource allocation and prioritisation. Access to social care and health care is determined by Social Services and Continuing Health Care Eligibility Criteria. The implementation of 'Fair Access to Care Services'¹ guidance will ensure that access to an assessment of needs and resource allocation is equitable and fair, and is intended to ensure that there is consistency across service user groups.

People with Learning Disabilities can access services provided or funded by Social Services and the NHS in the same way as other vulnerable people.

6. Eligibility Criteria

- 6.1 Access to the Walsall Integrated Learning Disability Service is determined by the diagnosis of a learning disability.
- 6.2 A learning disability is indicated by a significant, and permanent, reduced ability to understand new or complex information or skills normally present by or in childhood. This places a range of constraints on the person's ability to function independently. People with learning disabilities may have a number of other health and social care needs and should be supported by the relevant mainstream services, with specialist support and advice available from the Integrated Learning Disability Service. In particular, priorities for support from the integrated service will include people cared for by young carers, and people with learning disabilities who are themselves parents.
- 6.3 The Integrated Learning Disability Service will not accept referrals for people who have a 'learning difficulty', who do not have a diagnosis of 'learning disability'. This includes:-
 - People who may have average I.Q levels, but who have a specific learning difficulty such as Dyslexia or Attention Deficit Disorder 'Fair Access to Care Services'
 - People with profound physical disabilities or sensory impairments who do not have a specific learning disability
 - People with Aspergers Syndrome or Autistic Spectrum Disorder who do not have an associated learning disability
 - People who have mental health problems, personality disorder, drug or alcohol problems but who do not have a permanent learning disability
 - People with acquired brain injury during adulthood.
- 6.4 It is recognised that a small number of people will have cross-cutting needs where it is difficult to establish whether the person has a learning disability. The Integrated Learning Disability Service will work jointly with Adult and Mental Health colleagues whilst this is established.

Identification of Learning Disabilities

The following indicators may lead to identification of a significant Learning Disability in an individual. The individual may be:-

- Unable to tell the time
- Unable to distinguish between different coins
- Unable to do simple arithmetic
- Unable to say how old they are or know their date of birth
- Have difficulty recognising numbers particularly over ten
- Have difficulty reading simple words and sentences
- Which school did the person attend? (e.g. special school)
- Where does the person live? (e.g. sheltered accommodation)
- What does the person do for a job? (e.g. Attends Adult Training Centre)
- Confused behaviour following aggressive outbursts. Blank periods with person stopping talking mid sentence (query temporal lobe epilepsy).

NB: A person who does not read or write does not necessarily have a Learning Disability.

This information is very broad and a basic outline of possible alarm signals. It is important to remember that each person is a different individual and should be treated as such. If you still have concerns about the individual please contact Walsall Integrated Learning Disability Service for further advice/support.



Cerebral Palsy

Cerebral Palsy is a condition caused by damage to the brain, usually occurring before, during or shortly following birth. It can range from mild to severe. 'Cerebral' refers to the brain & 'Palsy' to a disorder of movement or posture.

Causes

- Illness of mother during pregnancy
- Lack of oxygen to the baby
- Accident, lead poisoning, viral infection, child abuse or other factor

Characteristics

Cerebral Palsy is characterised by an inability to fully control motor function. Dependent on which part of the brain has been damaged and the degree of involvement of the central nervous system, one or more of the following may occur;

- Spasms
- Tonal problems
- Involuntary movements
- Disturbance in gait
- Abnormal sensation and perception
- Impairment of sight
- Hearing or speech impairment
- Learning disabilities

There are three main types of **Cerebral Palsy**:

- People with spastic cerebral palsy find that some muscles become stiff and weak, especially under effort
- People with athetoid cerebral palsy have some loss of control of their posture and they tend to make unwanted movements
- People with ataxic cerebral palsy usually have problems with balance. They may also have shaky hand movements and irregular speech.

For further information please contact:-

SCOPE
6 Market Road,
London, N7 9PW

Tel: 0808 8003333 Email: cphelpline@scope.org.uk

Downs Syndrome

Cause

Down syndrome is a genetic disorder. It is identified by the presence of an additional chromosome 21.

Characteristics

- Muscle hypotonia, low muscle tone
- Flat facial profile, depressed nasal bridge and a small nose
- Upward slant to the eyes
- Abnormal shape of ears
- A single deep crease across the centre of the palm
- An excessive ability to extend the joints
- Small skin folds on the inner corner of the eyes
- Excessive space between large and second toe
- Enlargement of tongue in relationship to size of mouth

For further information please contact:-

Down Syndrome Association
Langdon Down Centre
2a Langdon Park
Teddington
TW11 9PS

Tel No: 0845 230 0372

E-mail: info@downs-syndrome.org.uk

Downs Syndrome and Dementia Screening

Many of the health issues facing an older person with Downs Syndrome are the same as for everyone else. In many places however comprehensive services for older people with learning disabilities are sadly lacking. GP's may be aware of the fact that people with Down's syndrome can suffer from Alzheimer's disease, but may not realise, the risks associated with early onset.

For each one of us, getting older is associated with many changes, both biological and social. For someone with Down's Syndrome these changes can be particularly daunting and difficult. Dementia is the name given to a collection of illnesses that have a characteristic pattern of signs and symptoms and generally occur later in life. The main signs of dementia are deterioration in the persons memory (usually of recent events) and loss of other abilities such as finding ones way round, communicating through language and performing particular tasks, such as getting dressed. In Downs Syndrome this may occur when the individual reaches their forties. Far too often in the past the signs of dementia would be ascribed to the person's learning disability rather than their dementia, particularly when being assessed by strangers.



Walsall Integrated Learning Disability Team has initiated a comprehensive screening tool for adults with Downs Syndrome.

- The dementia screening tool will be used with all individuals who have a diagnosis of Downs Syndrome
- It will be completed in conjunction with an individual who knows the person well i.e. parent/carer.
- An initial assessment of their skills and abilities will be undertaken in order to establish an individuals baseline cognitive functioning.
- Assessments will be offered from the age of eighteen, and re assessed every five years. After the age of thirty five years the assessments will be undertaken every two years.
- The outcome of each assessment will be evaluated using 'The Adaptive Behaviour Questionnaire' by Dr V Prasher which will give an indication as to whether dementia is present.
- If the screening tool indicates deterioration in individual's skills the assessor needs to ensure that all possible physical reasons have been investigated.

For more information on the Downs Syndrome and Dementia Screening tool please contact the Health Facilitation Team Tel: 01902 413006

Fragile X Syndrome

Fragile X syndrome is the most common cause of inherited learning disability

Characteristics

- It affects males and females and shows itself in a wide range of learning difficulties and behavioural problems.
- Learning disabilities varies form educational delays to severe learning disabilities.
- The most striking feature of Fragile X is the challenging behaviour.
- Males with fragile X may be inattentive, easily distracted, impulsive and overactive.
- Females are usually less affected but have similar learning disabilities. They are often extremely shy and socially withdrawn.
- Many have autistic like features, a dislike of eye contact, difficulty in relating to other people, anxiety in social situations often leading to tantrums, insistence on familiar routines and hand flapping or hand biting.
- Speech and language is usually delayed with continuing speech difficulties.
- Physical features include a largish head and prominent ears but these are rarely obvious in young children. It is because of this lack of obvious physical features that diagnosis is often missed or delayed.

Klinefelter's Syndrome

Klinefelter's syndrome is a chromosome disorder that affects males. It occurs in 1 in 500 male babies and is one of the most common abnormalities of the sex chromosomes known as the XXY syndrome.

Characteristics

- Infertility - may only be diagnosed when an apparently 'normal' male is seen because of infertility problems
- Reduced testicle size - testicles may not have developed properly
- Late Puberty - not enough of the male hormone testosterone is produced and puberty may be late

Klinefelter's may go undiagnosed at birth however some signs and symptoms may be come apparent during puberty.

- Small penis
- Small testicles (hypogonadism)
- Difficulties with sexual functioning
- Lack of facial, pubic and underarm hair
- Enlarged breasts (gynaecomastia)
- Slim physique
- Disproportionately long legs compared to length of body
- Single crease in palm (simian crease)
- Slight intellectual impairment
- Occasional speech and hearing difficulties

It should be noted that individuals who have Klinefelter's have an increased risk of certain conditions/diseases. These include:-

- | | |
|----------------------------|---------------------|
| • Breast cancer | • Diabetes Mellitus |
| • Infertility | • Leukaemia |
| • Non - Hodgkin's Lymphoma | • Osteoporosis |
| • Pulmonary Disease | • Thyroid Disease |
| • Tooth Decay | • Varicose Veins |

For Further Information Please Contact:

National Coordinator
Klinefelter's syndrome Association
56 Little Yeldham Road, Halstead, Essex C09 4QT

Tel No: 0845 230 0047

Email: parents/families_coordinator@ksa-uk.co.uk

Prader-Willi Syndrome

Causes

Prader-Willi syndrome is usually sporadic and in approximately 70% of cases due to a deletion affecting chromosome 15 of paternal origin.

Characteristics

Prader-Willi syndrome is characterised by two phases

- Under six month's hypotonia, sleepiness and feeding difficulties are usually present.
- Thereafter, hypotonia becomes less, feeding difficulties stop and hyperphagia (over eating) begins, usually between the ages of two and four years.

Other characteristics that may be present

- Short stature
- Cryptorchidism (undescended testicles and under development of genital organs)
- Strabismus (squint)
- Almond shaped eyes
- Very small hands and feet
- Developmental delay in walking and speech
- Sleep apnoea
- Mild to moderate learning disabilities
- Behavioural problems

For further information please contact:-

Prader-Willi Syndrome
125a London Road
Derby
DE1 2QQ

Tel: 01332 365676

Email: info@pwsa.uk.demon.co.uk

Turner Syndrome

Causes

Turner Syndrome is a chromosome abnormality affecting only females. This is caused by the complete or partial deletion of the X chromosome. The incidence of Turner syndrome is approximately 1:2000 live female births.

Characteristics

- Lymphoedema of hands & feet (puffy hands & feet).
- Broad chest and widely spaced nipples.
- Droopy eyelids.
- Low hairline.
- Low-set ears.
- Spoon shaped, small or hyperconvex nails.
- Short fourth toe and short fingers.
- Web neck.
- High arch palate (this may lead to feeding problems in babies with Turner syndrome).
- Short stature.
- Cubitus Valgus (carrying angle of the arms where it is difficult to straighten the elbow).
- Otitis media (middle ear infection).
- Hearing problems.
- Myopia (short sightedness).
- Pigmented naevi (moles).
- Infertility.
- High Blood Pressure.
- Kidney and urinary tract problems.
- Coarction (narrowing or constriction of the aorta).
- Thyroid problems.
- Small lower jaw (can lead to orthodontic problems).
- Osteoporosis (due to lack of oestrogen, a result of ovarian failure).
- Diabetes mellitus.
- Behavioural problems.
- Learning difficulties/spatial awareness problems.

For further information please contact:-

Turner Syndrome Support Society (UK)
12 Irving Quadrant
Hardgate
Clydebank
G81 6AZ

Tel No: 01389 380385



Further Reading:

Tackling Health Inequalities – A programme for Action (DH 2003)

Once a Day, NHS Executive (1999)

Developing Better Access to Primary Health Care Services for Adults with a Learning Disability, Janet Cobb NWTDT

Understanding the Patient Safety Issues for People with Learning Disabilities, National Patient Safety Agency (2004)

Valuing Health for All, Institute for Applied Health and Social Policy (2003)

Joseph Rowntree Foundation, Plain Facts magazine about research for people with Learning Disabilities and their supporters: includes an issue on healthcare decision making

www.plain-facts.org

Best Practice? Health Care decision making by, with and for adults with learning disabilities (1999) national Development Team, Manchester

Health for All Mencap (1998)

Signposts for Success NHS Executive (1998)

Valuing People: a new strategy for learning disability for the 21st century (DH 2001)

Learning Disabilities: the fundamental facts. Foundation for People with Learning Disabilities (2001)

Learning Disabilities: towards inclusion. Edinburgh: Churchill Livingstone (2003)

Physical Health of adults with intellectual disability. Prasher VP and Janicki M (2002)

Health Care Provision and People with Learning Disabilities – A guide for Health Professionals by Jo Corbett (2007)

This Resource Pack has been produced with support from the Department of Health Pacesetters Project.