****

**Marsh Gardens, Honley, Holmfirth, HD9 6AG**

# Identification of Patients with Learning Disabilities Protocol

**Introduction**

This protocol sets out the practice’s approach to the creation and management of the learning disability register and the patients on it.

The protocol is consistent with the requirements of the Learning Disabilities Directed Enhanced Service (DES) which was launched in 2008. The DES has since been extended and allows practices to offer medicals to patients aged 14 or older, and requires practices to produce a health action plan. The guidance for the DES, along with any updated guidance and audit requirements document are routinely published on the NHS Employers website.

**Nature of Learning Disability**

This definition comes from the Department of Health Valuing People document: <http://www.archive.official-documents.co.uk/document/cm50/5086/5086.htm>

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 a lasting effect on development.*

This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence - such as some people with Asperger's Syndrome.

'Learning disability' does not include all those who have a 'learning difficulty' which is more broadly defined in education legislation.

People with learning disabilities have the right to the same level of medical and nursing care as that provided to the general population. This care must be flexible and responsive and any diagnosis or treatment must take into account any specific needs generated by their learning disability. Evidence suggests that those with a learning disability have more health problems than the general population.

Research has demonstrated that people with learning disabilities have greater health needs than the general population, may have difficulty accessing primary care and have lower uptake rates of routine screening than the general population.

Individual ‘learning styles’, ‘learning differences’, ‘academic problems’ and ‘test difficulty/anxiety’ in, and of themselves do not constitute a learning disability. It is important to rule out alternative explanations such as emotional, attentional, or motivational problems that may be interfering with learning but do not constitute a learning disability.

**DES Requirements**

The DES requires a register and an annual health check for all patients >14 years old, including those on the local authority register, using an agreed protocol such as the Cardiff Health Check.

Practices should approach their CCG to liaise with local authorities to produce a practice list from central records. These patients should then be assessed for possible inclusion on the register.To facilitate this, it is a normal requirement for nominated clinical staff to attend CCG organised training around learning disabilities.

Health checks will include:

* Health promotion
* Chronic illness enquiry
* A physical examination
* Epilepsy
* Behaviour and mental health
* Specific syndrome check
* Medication check
* Any secondary care coordination check
* Review of any transition arrangements

**Protocol**

The clinical lead within the practice for this register is Debbie Dyson (Lead Practice Nurse).

* A person with a learning disability should be identified in order to ensure that advance planning is undertaken to address any specific needs and where necessary to modify investigations or treatment to meet those needs.
* Where it is known that a person has a learning disability this will be coded into the clinical system [*918e*]. This will highlight to secretarial, clerical, nursing, medical and other professional staff that the person may require specific care or support.

The following points may indicate a learning disability:

* Learning disability can be mild, moderate or severe.
* Specific Syndrome e.g. Down’s, Fragile X, Angelman, Cri-Du-Chat, Prader-Willi, Edwards.
* It is useful to find out what sort of school the person attended.
* Problems with understanding.
* Has a Community Learning Disability Nurse.
* Has a Learning Disability Social Worker/Care Manager.
* Has been seen by Psychiatrist in Learning Disabilities.
* Former terminology – mental handicap, mental retardation, intellectual disability.
* People usually have a learning disability from birth or sometimes from early childhood.
* Lives in a residential or nursing home for people with learning disabilities.

A learning disability is not (*note: this list is not exhaustive*):

* Dyslexia (learning difficulty in educational legislation).
* People who have a learning difficulty (educational term).
* Presence of physical disabilities only.
* Stroke victims.
* Presence of mental health problem only.
* ADHD.

**Payment**

The Learning Disabilities Directed Enhanced Service scheme offers £140 for each patient aged 14 and over on the practice’s agreed Learning Disabilities Register who receives a compliant health check, as agreed by the contractual negotiations.

Payment is quarterly, but only one payment can be made per patient across the financial year. The service runs between 1st April and 31 March.

CQRS will calculate the quarterly payment based on achievement data either entered manually via CQRS or data collected by GPES when this is possible.

**Creation of a Register**

Valuing People (DoH, 2001) estimates that on average there are about 8 people with severe and 50 with mild/moderate learning disabilities on a practice list of 2000.

As an initial base, the register will be established of those clients currently known to the practice.

Patients with the following diagnosis will be considered as suitable to be invited to join the register;

* Asperger’s Syndrome
* Autism
* Downs Syndrome
* Educational difficulties
* Turners Syndrome
* Congenital abnormalities

Regular contact should be made with the following organisations in order for their special needs register to be cross checked:

* Community Learning disability team
* Local Social Services
* Social Education Centres

All members of staff and clinicians dealing with incoming post from allied agencies are asked to bring to the attention of Debbie Dyson (Lead Practice Nurse) any comments regarding learning disabilities and the conditions listed above. The diagnostician must have used *direct language* in the diagnosis of a learning disability; avoiding such terms as ‘appears’, ‘suggests’ or ‘is indicative of’ as these statements do not support a conclusive diagnosis. The evaluation must be performed by a professional diagnostician (i.e. licensed clinical psychologist, rehabilitation psychologist, learning disability diagnostician, etc.) trained in the assessment of learning disabilities.

**Benefits**

1. Offer of an annual ‘health review’
2. GP and staff training
3. Improved service to patients with learning disabilities, e.g. by allowing automatic extra time for appointments (if required), annual health checks etc.
4. To develop reference materials for clinicians, staff and patients

**Learning Disabilities Register – Patient Information - Contacts**

**Angelman**

**ASSERT** is a United Kingdom based support group run by volunteers who have direct contact with people with Angelman Syndrome. The majority of the trustee's are parents or relatives of children or adults with Angelman Syndrome

Web: [www.angelmanuk.org](http://www.angelmanuk.org)

Address: ASSERT

PO Box 4962

Nuneaton, CV11 9FD

Tel: 0300 9990102

Email: [assert@angelmanuk.org](mailto:assert@angelmanuk.org)

**Autism**

The National Autistic Society exists to champion the rights and interests of all people with autism and to ensure that they and their families receive quality services appropriate to their needs. The website includes information about autism and Asperger syndrome, the NAS and its services and activities.

Web: [www.nas.org.uk](http://www.nas.org.uk)

Address: The National Autistic Society

393 City Road

London, EC1V 1NG

Tel: 020-7833-2299, 0808 800 1050 (helpline)

Email: [nas@nas.org.uk](mailto:nas@nas.org.uk) or supportercare@nas.org.uk

**Cri-Du-Chat**

This support group:

* Provides support and friendship for families and carers throughout Britain
* Raises awareness of Cri-Du-Chat Syndrome amongst the medical profession and the public.
* Raises funds to promote research through carefully selected projects.
* Gives information and advice to families and professionals.
* Publishes a newsletter with general items of interest for families and carers.

Web: <http://.cridchat.org.uk>

Address: Cri du Chat Syndrome Support Group

PO Box 73631

London, SW14 9BS

Tel: 0845 094 2725

Email: [office@criduchat.co.uk](mailto:office@criduchat.co.uk)

**Edwards**

S.O.F.T UK provides support for families affected by Patau's Syndrome (Trisomy 13), Edward's Syndrome (Trisomy 18), partial Trisomy, mosaicism, rings, translocation, deletion, and related disorders.

Web: [www.soft.org.uk](http://www.soft.org.uk)

Address: SOFT UK  
 48 Froggatts Ride  
 Walmley  
 Sutton Coldfield, B76 2TQ

Tel: 0330 088 1384

Email: [enquiries@soft.org.uk](mailto:enquiries@soft.org.uk)

**Fragile X**

This society aims to

* Provide support and information for Fragile X families from those who share and understand their concerns and needs
* Educate, inform and advise the public and professional people about the prevalence and nature of Fragile X in order to raise awareness and understanding of the syndrome and improve the care of all people affected by Fragile X
* Encourage research into all aspects of the syndrome and publicise the results

Web: [www.fragilex.org.uk](http://www.fragilex.org.uk)

Address: The Fragile X Society

Rood End House

6 Stortford Road

Great Dunmow

Essex, CM6 1DA

Tel: 01371 875100

Email: [info@fragilex.org.uk](mailto:info@fragilex.org.uk)

**Prader-Willi**

A registered charity and the only organisation in the UK which is dedicated to supporting people with Prader-Willi syndrome (PWS), their families, carers, and the professionals who work with them.

Web: [www.pwsa.co.uk](http://www.pwsa.co.uk)

Address: PWSA (UK)  
 Suite 4.4, Litchurch Plaza, Litchurch Lane,  
 Derby, DE24 8AA

Tel: 01332 360401

Email: [admin@pwsa.co.uk](mailto:admin@pwsa.co.uk)

**Turner’s Syndrome**

The Society provides accurate and up to date information on Turner Syndrome and the many aspects of living with the condition on a daily basis.

Web: [www.tss.org.uk](http://www.tss.org.uk)

Address: The Turners Syndrome Support Society (UK)

12 Simpson Court, 11 South Avenue

Clydebank Business Park

Clydebank, G81 2NR

Tel: 0141 952 8006, 0300 111 7520 (helpline)

Email: [turner.Syndrome@tss.org.uk](mailto:turner.Syndrome@tss.org.uk)

**Down’s Syndrome**

“Helping people with Down’s syndrome to live full and rewarding lives is the only organisation in this country focusing solely on all aspects of living successfully with Down’s syndrome”. They provide information and support for people with Down’s syndrome, their families and carers, as well as being a resource for interested professionals.

Web: [www.downs-syndrome.org.uk/](http://www.downs-syndrome.org.uk/)

Address: Langdon Down Centre  
 2a Langdon Park  
 Teddington, TW11 9

Tel: 0333 1212300

Email: [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)