THE SCOTTISH HEALTH CHECK PROGRAMME for ADULTS WITH LEARNING DISABILITIES

This health check tool was developed by the health check group convened by the Primary and Community Directorate of the Scottish Government
It is designed to be used in primary care, with support from learning disabilities services

It is advisable that the adult with learning disabilities has a relative, support worker, friend or advocate supporting her / him during the health check

The appointment letter should advise the person to complete and bring the carer health questionnaire with them, together with a sample of urine

Appendix 1 provides additional information on a number of areas included in the health check

Appendix 2 provides contact details for the learning disabilities learning disabilities team and your local community/area learning disabilities team
They are there to help you and are always pleased to receive referrals

A. BEFORE THE APPOINTMENT

1. Send out the carer health questionnaire with the appointment letter, asking them to complete it and bring it with them to the appointment.

2. Review the person's records prior to or at their appointment.

3. Has the person previously had a comprehensive health check with the learning disabilities service? If so, review the summary letter for background information. If a prior health check has been done, are there any outstanding actions that are needed at this health check?

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4. Do any special arrangements need to be arranged in advance to communicate effectively with the person?

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5. What is the cause of the person's learning disabilities? If the person has a specific cause for their learning disabilities, check what the physical and mental health problems are that are associated with the syndrome. Consider if any syndrome-specific screening is needed. (Seek advice from your local learning disabilities service, or the learning disabilities primary care liaison team if you cannot find this information on the internet or in the person's records. Contact details are included in D, appendix 2)

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6. Does the person have any conditions in the QOF disease areas? For each one the person has, check if there are any outstanding items that need actioning.

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7. Does the person have any other current health problems that might need review/attention?

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8. Has the person had repeated hospital admissions? Might there be an underlying problem accounting for this that needs addressing, e.g. aspiration, gastro-oesophageal reflux disorder (GORD)?

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9. Is the person eligible for any of the national screening programmes e.g. cervical screening, breast screening? If so, is any action needed now?

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10. Review any Adults with Incapacity (Scotland) certificates. Are they up-to-date?

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B. AT THE APPOINTMENT

Clinical interview

Rephrase these questions in your own words, and explore them further as seems indicated on the basis of the information given. Section C, the appendix, contains background information that might be helpful on several of these areas.

1. Who is supporting the adult at this appointment, and how long have they known her/him? (to assess the likely accuracy of the following information).

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2. Ask if the person has brought the **carer completed health questionnaire** with them.

    a. If they have not, work through all the following questions with them.
    b. If they have, review the questionnaire with them, and focus on any issues it identifies. Have a high index of suspicion for vision and hearing impairments including impacted cerumen and cerebral visual impairment, GORD, constipation, mental ill-health/problem behaviours, sub-optimally managed epilepsy, skin problems, drug side-effect. Does their drug list match your list, and do they all seem indicated? Do their drugs need a review with the GP? Check if they have had an eyesight test in the last 2 years, a hearing test in the last 3 years if the person has Down syndrome, or otherwise in the last 5 years if aged over 40, and dental check in the last 6 months. Recommend they arrange this if they have not (and write it down for them to take away). WHEN YOU HAVE GONE THROUGH THE CARER COMPLETED HEALTH QUESTIONNAIRE, **SKIP TO QUESTION 22**.

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3. Check that **next-of-kin and welfare guardian** details are correctly recorded/have not changed.

4. Ask how the person's **health is in general**.

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5. Does the person/carer have **any health concerns** or worries, or new health symptoms?

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6. Ask what **health problems** the person has and review these.

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7. Review **medications**. Does this need an appointment with the GP to review medications? Is the practice record the same as the person/carer's list of medications? Are the indications clear? Are they still indicated? Any side effects? Any difficulty taking them? Does the person understand and consent to the prescriptions, or is a certificate needed as per the Adults with Incapacity (Scotland) Act? This is also relevant to the QOF.

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8. Does the person have **any other symptoms**? E.g. coughing, breathing problems, wheezing, phlegm, chest or leg pain on exercise, swollen ankles, skin or scalp problem, problems passing urine, frequency, hesitancy, dysuria, haematuria, incontinence onset, bowel problems, blood in motions. If so, do they need an appointment with the GP, or some other action/investigation?

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The following problems are commonly experienced by adults with learning disabilities, and often overlooked particularly in adults with limited verbal communication skills. Enquire specifically about each of them, and gauge whether any further intervention is needed. Further information is provided in the appendix.

9. Risk of **choking**? E.g. aspiration problems, trouble swallowing, spluttering, previous episode of choking, repeated chest infection, cough or dyspnoea, cyanosis after eating. If so, has this been assessed by the dysphagia service?

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10. **Constipation**?

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11. **Gastro-oesophageal reflux disorder**? E.g. regurgitation, vomiting, heartburn, indigestion, onset of disturbed sleep, onset of problem behaviours, regular coughing after eating, borderline/low Hb, dental erosions.

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12. **Visual impairment**? Increasingly, opticians will try to assess persons at all ability levels. Some areas also have specialist visual services. Further advice could be sought from the local learning disabilities service if needed. When did the person last have an eye sight test? If >2years ago, advise the person/carer to book to see an optician, and write this down for them to take away.

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13. Suspicion of **cerebral visual impairment**? Refer to ophthalmology, and/or your RNIB worker (sensory improvement project based at the learning disabilities primary care liaison team).

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14. **Hearing impairment**? Has hearing been assessed in the last 3 years? Does the person need a hearing check or hearing aid review?

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15. **Mental ill-health**? E.g. anxious, panicky, rituals, low mood, social withdrawal, less communicative, tearful, increased irritability, decline in self-care, change in energy, muddled, confused, forgetful, change in sleep pattern, change in appetite, change in energy, reduced concentration, increase in problem behaviours, reassurance seeking behavior, more suspicious or paranoid, hearing voices that no one else can hear.

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16. Some persons need extra support because of **problem behaviours**. Has the adult had any increase in problem behaviours e..g. verbal or physical aggression, destructiveness, self-injury? Sometimes this is caused by some other underlying mental or physical health problem. Consider if a referral is needed to your local learning disabilities service.

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17. **Accidents/falls**? Is there any underlying problem that could be addressed?

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18. Suitability of **wheelchair/special seating**, or special equipment/orthotics? Are any reviews or assessments needed as to suitability of these? Do carers need any training in use of equipment?

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19. **Arthritis** and pain?

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20. **Mobility problems**?

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21. **Social care**. Refer to your local learning disabilities service if the person/their carer would like a review of their respite care arrangements, day care, benefits, other aspects of their support package.

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22. At risk of **osteoporosis**? E.g. repeated fractures, impaired mobility, underweight, early menopause, antiepileptic or antipsychotic drugs, lack of puberty. A new bone health protocol for adults with learning disabilities will be available in Autumn 2011.

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23. A **change in behavior** often indicates an underlying mental or physical health problem, particularly for persons with limited verbal communication skills. Has the person changed in their behaviour in any way? If so, explore this in more detail.

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24. Is the person a **vulnerable adult**, with vulnerability needs maybe not being met? Is the adult at risk? If so, is advice/support needed from your local learning disabilities service?

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Review any general health issues you identified in your review of records prior to the appointment

25. Review/complete any outstanding issues from the last health check.

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26. Review/complete any required issues for any conditions which are **QOF disease areas**.

- If any other appointments are needed to be booked, write down what needs to be booked and give this to the person/carer, to reduce likelihood of it being overlooked by the carer.
- If the person has epilepsy, also consider if it is being sub-optimally managed e.g. a stable pattern of seizures over a long time such as one or two tonic-clonic seizures every couple of months, with no attempt to change medication to improve this. Has the person had an epilepsy risk assessment to consider their environment? Would a referral for one be helpful?
- Does the person need any specialist referrals?

27. Is any **syndrome-specific screening** needed because of the cause of person's learning disabilities?

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28. If a comprehensive health check has not yet been completed, estimate the person's **ability level**. The appendix suggests a quick way to get a rough estimate if the information is not already available (page 10).

Mild learning disabilities (IQ = 50 – 69; mental ability = 9 - 12 years)
Moderate learning disabilities (IQ = 35 – 49; mental ability = 6 - 9 years)
Severe learning disabilities (IQ = 20 – 34; mental ability = 3 - 6 years)
Profound learning disabilities (IQ < 20; mental ability = 0 -3 years)

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29. What is the person's **ethnicity**?.....

IF YOU HAVE ALREADY GONE THROUGH THE CARER COMPLETED HEALTH QUESTIONNAIRE, NOW **SKIP TO QUESTION 35.** IF NOT CONTINUE

Routine health promotion and screening – check if any of these are relevant for the adult. You may prefer to use the "health related behaviour" screen

30. **Oral health**. If the person has not seen a dentist in the last 6 months, advice they book an appointment, and write this down for them. Consider if support will be needed from your local learning disabilities service. If the person cannot access mainstream dentistry, consider referral to the special needs community dental service.

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31. **Smoking/**smoking cessation.

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32. Exercise.

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33. **Diet** and weight. Fruit and vegetables.

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34. **Alcohol**/drug use.

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35. **Influenza immunization**. High risk categories include persons with cerebral palsy, profound learning disabilities, living in residential homes, nursing homes, long-stay NHS hospital, or supported group living, and / or attending a day centre.

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36. **Hepatitis B immunization**.

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37. **Cervical screening**. Is this indicated? Is contraception advice needed?

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38. **Mammography**. For women over 50, have they taken up the invitation for mammography?

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Examination

1. **Urinalysis**.

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2. If not checked in the last year, **height**, without shoes (in metres and centimeters); **weight**, without shoes (in kilograms); Body Mass Index = Weight (kg) / Height $(m)^2$

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3. **Blood pressure** (mention that you might also repeat this later).

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4. **Pulse rate/rhythm**.

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5. Nurse's opinion: does the person have special needs related to **communication**?

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6. Look inside the person's mouth – **gingivitis**? Gross dental decay?

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7. **Eyes**. Advice booking an eye test if none in last 2 years.

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8. **Otoscopy**. Is the canal clear, or is wax obscuring the drum? **(**Impacted cerumen is common, and often needs management).

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9. **Hearing**. We can offer training in hearing tests at a time to suit your practice if you wish. From your general impression, or a whisper test, or rustling a sweet wrapper behind your back, might the person have a hearing impairment that needs a more complete assessment?

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10. **Peak flow**.
    - FEV1……..
    - FEV2……..
    - FEV3……..

11. If the person uses inhalers, check their **inhaler technique**.

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12. Any **contractures**? If so, is a physiotherapy care plan used?

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13. Repeat the **blood pressure** if previously raised.

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14. Check the person's **feet**. Is there infection or need for hygiene? Toe nail problem? Cracked heels?

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15. If the person has **PEG feeding**, check the stoma.

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16. Check any **blood tests** that are indicated. Have a low threshold for blood tests, as the person may not be able to report if she/he has a problem. Check TFTs if the person has Down syndrome.

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C. APPENDIX 1

Background information

People with learning disabilities comprise a significant minority of the UK population. Demographics are, however, changing and the population of people with learning disabilities is increasing (53% over the 35 year period 1960-95 ~ 1.2% per year with a further 11% from 1998-2008.) These changes are the result of improved socioeconomic conditions, intensive neonatal care, better access to healthcare, and increasing survival. The health needs of people with learning disabilities have an impact on primary healthcare services and all secondary healthcare specialties.

Terminology
In the earlier part of the last century, terms such as mental deficiency, subnormality, mental retardation and mental handicap were used rather than learning disabilities. You may come across such entries in older case records. However, as language has evolved these terms have become outdated, stigmatizing and can cause offence, so should not be used. (Unfortunately READ codes (Version 2) still use the term 'Mental Retardation')

Definition of learning disabilities
The definition of learning disability is dependent upon the person having an IQ below 70, together with continued impairment in adaptive behaviour / social functioning, and with the onset during the development phase (i.e. before the age of 18 years).

Learning disabilities is a significant, lifelong experience with three components:
- reduced ability to understand new or complex information or to learn new skills, due to IQ<70,
- reduced ability to cope independently, and
- onset before adulthood.

Learning disabilities refers to global disabilities, not specific disabilities like dyslexia.
918e. on learning disability register

Further information about ability levels
The average IQ for a person is set at 100, with a standard deviation of 15 points. The purely arbitrary cut-off used to indicate global learning disabilities is 70. Although a person's IQ can be measured, this is a limited way of considering a person's needs. Assessing a person's range of skills provides a more useful way of working out the extra support they require, and identifying goals for further learning and training. A person with an IQ of 20 could be said to have the mental age of 3 years. However, if the person is 35 years old, they will have had 35 years of lifetime experience to learn from, may also have benefited from some additional specific training, and will have the motivations and biological drives of adulthood. A person with an IQ of 69 could said to have a mental age of 12 years. However, many people with this level of ability will achieve independence in adult life and may not need additional support (so they could not really be thought of as having learning disabilities). Not all adults with learning disabilities will have undergone formal IQ and / or adaptive behaviour assessments – where this is the case, you need to make a judgment.

- Mild learning disabilities indicates an IQ = 50-70, or mental age of 9-12 years
- Moderate learning disabilities indicates an IQ = 35-49, or mental age of 6-9 years
- Severe learning disabilities indicates an IQ = 20-34, or mental age of 3-6 years
- Profound learning disabilities indicates an IQ = 20, or mental age of less than 3 years

E30.. Mild learning disabilities, IQ in range 50-70
E310. Moderate learning disabiliities, IQ in range 35-49
E311. Severe learning disabilities, IQ in range 20-34
E312. Profound learning disabilities with IQ less than 20

A quick way to gauge a rouge estimate of ability
Ask the person and their carer/support worker these 5 questions:

1. How much support does the person need with **eating and drinking**?

Totally independent	1	**[ ]**
Minimum assistance	2	**[ ]**
Regular prompting / supervision	3	**[ ]**
1:1 support required	4	**[ ]**
1:1 support required and special equipment / positioning or PEG feeding	5	**[ ]**

2. How much support does the person need with **intimate care** e.g. bathing, dressing?

Fully independent	1	**[ ]**
Minimum assistance	2	**[ ]**
Regular prompting / supervision	3	**[ ]**
1:1 support required, but able to contribute in a limited way - may require special lifting equipment	4	**[ ]**
1:1 support required, unable to contribute and totally dependent – requires special lifting equipment	5	**[ ]**

3. How much support does the person need with **personal safety**?

Aware of personal safety and acts accordingly	1	**[ ]**
Minimum assistance	2	**[ ]**
Some awareness / appropriate action, but requires some supervision	3	**[ ]**
Requires constant supervision to ensure safety	4	**[ ]**
Total dependency for personal safety	5	**[ ]**

4. How much support does the person require with **communication**?

Communicates clearly and independently	1	**[ ]**
Communicates reasonably clearly, including using signs / aids	2	**[ ]**
Requires staff support with communication	3	**[ ]**
Much time is required to understand and facilitate the person's communication	4	**[ ]**
Communication skills are extremely limited	5	**[ ]**

5. How much support does the person require with **decision making**?

Makes own decisions in an informed way	1	**[ ]**
Minimum support to make own decisions	2	**[ ]**
Can make some choices / decisions	3	**[ ]**
Support required for even simple decisions	4	**[ ]**
Total dependence on others for decision making / choices	5	**[ ]**

Now **Add up** the scores for questions 1 to 5 *(Use the numbers next to the boxes)* **[ ] [ ]**

5 - 8 = mild learning disabilities; 9 – 13 = moderate learning disabilities; 14 – 19 = severe learning disabilities; 20 – 55 = profound learning disabilities

But remember, the score is only a rough guide, and some things can artificially lower it e.g. cerebral palsy, stroke, blind, schizophrenia and dementia – so make allowances for these conditions.

Cause of learning disabilities

There are thousands of different causes of learning disabilities. Learning disabilities can be attributed to genetic, metabolic, traumatic or infective causes. Down syndrome is the single most common genetic cause of learning disabilities. Below some of these are listed, with their Read codes.

Specific causes of learning disabilities have associated phenotypes including specific physical and mental ill-health e.g.

- tuberous sclerosis and epilepsy
- Down syndrome and dementia and hypothyroidism
- Prader-Willi syndrome and affective psychosis
- congenital rubella and sensory impairments
- peri-natal trauma and impaired mobility.

Syndrome-specific health and screening information are often on the internet, or advice can be sought from your local learning disabilities service, or the primary care liaison team.

Down's syndrome	www.dsmig.org.uk
Prader-Willi syndrome	www.pwsa.co.uk
Fragile X syndrome	www.fragilex.org
Williams's syndrome	www.williams-syndrome.org.uk
Tuberous sclerosis	www.tuberous-sclerosis.org.

GENETIC / CHROMOSOMAL

PJ0z. Down's syndrome NOS
PJ0.. Down's syndrome - trisomy 21
PJ00. Trisomy 21, meiotic nondisjunction
PJ01. Trisomy 21, mosaicism
PJ02. Trisomy 21, translocation
PK5.. Tuberous sclerosis
PJyy4 Fragile X syndrome
C301. Phenylketonuria
C3043 Homocystinuria
C311. Galactosaemia
PKy93 Prader - Willi syndrome
PKyz5 Angelman syndrome
PKy4. William syndrome
PJ1z. Patau's syndrome NOS
PJ2z. Edward's syndrome NOS
PJ333 Smith-Magenis syndrome
C3723 Lesch-Nyhan syndrome
PJ31. Cri-du-chat syndrome
PKy60 Cornelia de Lange syndrome
PJ63z Turner's syndrome NOS
PJ7z. Klinefelter's syndrome NOS
PKy80 Noonan's syndrome
B927. Neurofibromatosis - Von Recklinghausen's disease
PKy73 Rubenstein - Taybi syndrome
F1013 Tay-Sach's disease
C3271 Gaucher's disease
C3272 Niemann-Pick disease
C3751 Hurler's syndrome
C3752 Hunter's syndrome

Eu842 [X]Rett's syndrome
P101. Arnold - Chiari syndrome
PK61. Sturge-Weber syndrome
PF550 Acrocephalosyndactyly (Apert)
PKy5C Treacher Collins syndrome
PKy64 Seckel syndrome
PKy63 Smith - Lemli - Opitz syndrome
C1zy2 Sotos syndrome
F1306 Aicardi Goutieres syndrome
PKy65 Aarskog syndrome
PKy1. Laurence-Moon-Biedl syndrome
PKy94 Zellweger's syndrome
PJ3y0 Velocardiofacial syndrome
PJX.. Sex chromosome abnormality, male phenotype, unspecified
PJyyz Other sex chromosome abnormality NOS
PJz.. Chromosomal anomalies NOS

INFECTIVE
Q400. Congenital rubella
Q4023 Congenital toxoplasmosis
Q401. Congenital cytomegalovirus infection
A90.. Congenital syphilis
F0304 Herpes simplex encephalitis
F0351 Encephalitis following measles

PREGNANCY AND BIRTH
PK80. Fetal alcohol syndrome
Q42.. Isoimmunisation of newborn
Q01.. Fetus or neonate affected by maternal complication of pregnancy
Q03z. Fetus or neonate affected by complications of labour or delivery NOS
Q20z. Birth injury NOS
Q115. Extremely low birth weight infant
Q112. Extreme immaturity

INFANCY & CHILDHOOD
F02.. Meningitis of unspecified cause
F03z. Encephalitis NOS
S646. Head injury
B7F0. Benign neoplasm of brain
B51.. Malignant neoplasm of brain
U60J6 [X] Adverse reaction to pertussis vaccine, including combinations
F034z Postimmunisation encephalitis NOS
A412. Subacute sclerosing panencephalitis

OTHER
P23.. Congenital hydrocephalus
P21.. Microcephalus
C03.. Congenital hypothyroidism
P203. Meningocele – cerebral
C0A.. Congenital iodine deficiency syndrome
C3033 Maple syrup urine disease
C3034 Hypervalinaemia

C307y Methylmalonic acidaemia
C3004 Hartnup disease
F1016 Sandhoff disease
C3271 Gaucher's disease
C3753 Sanfilippo syndrome
PKy92 Menke's syndrome
C3510 Wilson's disease
Other

OTHER
Unknown, never fully investigated
Unknown, despite investigation

Living and support arrangements
Almost all people with learning disabilities live either with their family who are family carers, or in rented accommodation with support from paid carers (who are employed by private/charitable provider organizations, not the NHS or social work). Some persons live independently without carer support.

Communication
Communication difficulties are prevalent amongst persons with learning disabilities. Limited communication affects people's ability to access healthcare:

- To read and understand appointment letters
- To convey information effectively to health staff
- To fully understand recommendations and guidelines given by health staff

People with communication difficulties can present as uncooperative, exhibit challenging behaviour, or can be vulnerable and socially isolated.

Indicators may include:

- The person repeats back what is said by others
- The person always talks about a favorite topic / says the same thing repeatedly
- The person answers “yes” to everything
- The person answers “no” to everything
- The person answers “don’t know” to everything
- When offered a choice, the person always chooses the last option
- The person is easily distracted, maybe walking away during conversation
- The person is a “loner” and doesn’t want to join in
- The person changes topic in the middle of a conversation
- The person does not use words

Health staff's awareness and use of helpful communication strategies can help achieve more effective communication. www.easyinfo.org.uk

ZV401 [V]Problems with communication, including speech

Adults with Incapacity (Scotland) Act 2000
Part V of the Act relates to medical treatment. Adults assessed as incapable of making decisions concerning specific medical treatment/investigations should have a Section 47 certificate issued.

Section 47 certificates should be renewed annually, unless the adult has severe or profound learning disabilities which are unlikely to improve, when they can be issued for up to three years.

13Im. Certificate of authority (S47) issued under AWI(S)A
13In. Has welfare attorney appointed under AWI(S)A
13Io. Has guardian appointed under AWI(S)A

Vulnerable adult
A vulnerable adult is someone who:

- Is aged 18 years or over
- Is, or may be in need of community care services by reasons of mental health or other disability, age or illness, and
- Is, or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation'.

Health needs
Compared with the general population, people with learning disabilities have:

- Health inequalities
- Higher levels of health needs
- More health needs that are unrecognised and unaddressed
- More health needs that are sub-optimally managed
- A different pattern of health needs
- Lower life expectancy
- Barriers in accessing and using health services
- Greater disadvantages when services are reactive rather than proactive.

A different pattern of health needs
People with learning disabilities have a different pattern of health needs compared with the general population.

- Much more commonly experienced are: risk of choking, epilepsy, gastro-oesophageal reflux disorder, constipation, sensory impairments, osteoporosis, schizophrenia, dementia, dysphagia, dental disease, musculoskeletal problems, accidents, and nutritional problems.
- Health problems related to smoking, alcohol, and use of illegal drugs are less common.
- Some problem behaviours, e.g. self injury and pica, are specific to learning disabilities and may be associated with specific genetic syndromes.

The commonest causes of death also differ compared with the general population.

- Respiratory disease followed by cardiovascular disease related to congenital heart disease are the leading causes of death.
- Cancer is lower ranked.
- The pattern of cancers is also different, with lower rates of lung, prostate, and urinary tract cancers, and higher rates of oesophageal, stomach, and gall bladder cancer and leukaemia.
- Swallowing problems are a significant risk factor for choking in this population.

Reactive rather than proactive models of care particularly disadvantage persons with learning disabilities.

- They rely on the person (who may have limited speech), or their carer recognising a possible health need, and seeking a GP appointment.
- How long the paid carer has known the person, and how much time they spend with the person, affects their likelihood of recognizing changes indicating possible health needs.
- How well information is shared between support team members/different teams (e.g. day centre staff and paid carers at the persons home) also affects likelihood of recognising possible health needs.
- These factors also influence how well medical advice/treatments are adhered to.

Common Health Needs

A recent health check programme in Greater Glasgow found that

- The commonest health needs in the population were visual impairment, epilepsy, constipation, obesity, mental ill-health, hearing impairment, gastro-oesophageal reflux disorder, impacted cerumen, problem behaviours, then hypertension.
- The commonest problems detected at the health check that weren't already known about were impacted cerumen, gastro-oesophageal reflux disorder, mental ill-health, obesity, xerosis cutis, visual impairment, constipation, then tinea. Problems were detected across the full range of bodily systems.

Specifically consider if the person has any of the health needs and disabilities which are commonly experienced by persons with learning disabilities, or any of the health needs included in the QOF, including:

Physical disorders and disabilities that occur commonly in persons with learning disabilities

Difficulty in swallowing
J10y4 Gastro-oesophageal reflux
19CZ. Constipation NOS
F25z. Epilepsy NOS
F23z. Congenital cerebral palsy NOS
16D1. Recurrent falls
TGz.. Accidents NOS
ZV4L0 [V] Poor mobility
ZV462 [V]Dependence on wheelchair
22K5. Body mass index 30+ - obesity
22K7. Body mass index 40+ - severely obese
R0348 [D]Underweight
N330z Osteoporosis NOS
H06z2 Recurrent chest infection
R083z [D]Incontinence of urine NOS
R076z [D]Incontinence of faeces NOS
F49z. Visual loss NOS
6688. Registered partially blind
6689. Registered blind
F59z. Deafness NOS
F504. Impacted cerumen (wax in ear)
N373z Kyphoscoliosis or scoliosis NOS
296Z. O/E - muscle contracture NOS

Mental disorders and problem behaviours

Recurrent depressive disorder, unspecified
Depression resolved
Eu31z [X]Bipolar affective disorder, unspecified
Eu2z. [X]Psychosis NOS
E140z Infantile autism NOS
Eu900 [X]Attention deficit hyperactivity disorder
Eu02z [X] Unspecified dementia
Ez... Mental disorders NOS
ZV40. [V]Mental and behavioural problems – (this should be used for problem behaviours)

Disorders within the QOF

F25z. Epilepsy NOS
G66.. Stroke and cerebrovascular accident unspecified
G65.. Transient cerebral ischaemia
H3z.. Chronic obstructive airways disease NOS
H33zz Asthma NOS
1Z1.. Chronic renal impairment
C10E. Type 1 diabetes mellitus
C10F. Type 2 diabetes mellitus
G3 Coronary Heart Disease
G58z. Heart failure NOS
G5730 Atrial fibrillation
G20.. Essential hypertension
C04z. Hypothyroidism NOS
BB02. [M]Neoplasm, malignant
Eu31z [X]Bipolar affective disorder, unspecified
Eu2z. [X]Psychosis NOS
Eu02z [X] Unspecified dementia
Repeat medicines review
Date of last blood pressure check
Record of smoking status/date

Health risks

Risk of choking

- Risk of swallowing and feeding problems is higher, especially for people with profound learning and multiple physical disabilities, cerebral palsy, or certain specific syndromes e.g. Down syndrome, Rett syndrome.
- These are significant risk factors for choking and death.
- Indicators include regurgitation, cough, recurrent chest infection.
- Multidisciplinary assessment of swallowing/feeding problems can reduce dehydration, aspiration and respiratory infections.
- If suspected, refer for assessment, and/or seek advice/support from your local learning disabilities service, or the learning disabilities primary care liaison team

Gastro-oesophageal reflux disorder

- 50% of people with severe and 70% with profound learning disabilities or cerebral palsy have GORD.
- Indicators include indicators of abdominal pain (e.g. onset of disturbed sleep, onset of problem behaviours), regurgitation, vomiting, regular coughing after eating, borderline/low Hb, dental erosions.
- It is painful, and can cause oesophageal strictures, swallowing problems, and increased cancer risk.
- A normal endoscopy does not exclude GORD.
- Many people with learning disabilities cannot describe their pain.
- If suspected, consider a treatment trial of a proton-pump inhibitor, then reassessment.

Osteoporosis

- Osteoporosis and lower bone density is more common in this population.
- Impaired mobility (lack of weight-bearing exercise), antiepileptic and antipsychotic drug use, genetic factors (syndromes associated with failure of sex-hormone production and delayed/lack

of puberty), early menopause (for all women with learning disabilities, and especially women with Down syndrome), poor nutrition, and underweight, all contribute.
- Some antiepileptic and antipsychotic drugs affect bone architecture.
- A bone health protocol for adults with learning disabilities will be available from late 2011. Refer to the local learning disabilities service, or the learning disabilities primary care liaison team if further advice/support is needed.

Impacted cerumen
- Impacted ear wax is common in this population.
- Congenital structural anomalies of the ear, and ear-poking behaviours contribute.
- This causes/exacerbates hearing impairment.
- Many persons with learning disabilities cannot communicate this additional disability.
- Check with otoscopy, then treat initially as for the general population. If almond oil is prescribed, arrange to recall for further otoscopy to check drops have actually been used/cerumen cleared.

Contractures
- Progressive contractures can cause further immobility, feeding difficulties, GORD, and choking.
- Physiotherapy can help with carer training; speech and language therapy/dietetic referral can reduce secondary sequalae. OT and wheelchair services may also be needed.
- If needed, refer to your local learning disabilities service for further advice/support.

Vision and hearing test
Compared with the general population:
- Sensory impairments are more common. About 30% have hearing impairment, and 50% visual impairment. They can be congenital, or acquired later in life.
- Sensory impairments are much more likely to be unrecognised. Paid carers in particular, under-report sensory impairments.
- Many learning disabilities syndromes have specific associations e.g. congenital cataracts, keratoconus, retinal abnormalities, optic atrophy, structural abnormalities of the eye, sensorineural damage, structural abnormalities of the inner ear.
- Down syndrome, mitochondrial disorders, congenital rubella are especially associated with sensory impairments. Age-related impairments occur earlier in persons with Down syndrome.
- Many can't self-report age-related impairments in hearing or vision. Persons with long-standing uncorrected refractive error may not know it can be corrected.
- Cerebral visual impairment is at particular risk of under-reporting.
- Vision and hearing can be assessed even in persons with the most profound learning disabilities.

Indicators of possible visual impairment
- The person does not follow your movement around the room if you do so silently.
- The person does not screw up their eyes when exposed to bright sunlight.
- The person does not react to your smile.
- The person does not reach out for objects held out in front of them.
- The person is not aware of a spoonful of food moved towards their mouth, unless it has a strong smell.
- The person is not aware of themselves in a mirror 6 foot in front of them.

Indicators of cerebral visual impairment include:
- Crowding i.e. difficulty differentiating between background and foreground visual information (e.g. can't see items if they are on a patterned table cloth).
- Problems with fast eye movements.

- Problems with detection of movement.
- Problems with depth analysis.
- Visual field defect – peripheral vision easier than central vision.
- Vision appears to be variable, changing with circumstances.
- Vision may be better when either the object or the person is moving.
- Close viewing is common, to magnify the object or reduce crowding.
- Substantial impairment in function and making sense of what is seen.
- Often able to see better when told what to look for ahead of time.

Colour vision is well developed, and visual acuity normal or sub-normal. Typically, paid carers inadvertently attribute the problems to poor attention or motivation. There are several causes, including cerebral palsy. If suspected, consider referral to ophthalmology or RNIB or the sensory improvement project at the learning disabilities primary care liaison team.

Oral health

- Persons with learning disabilities have high levels of unmet oral health needs.
- This includes gum disease, untreated dental caries and missing teeth.
- G.O.R.D. and anticholinergic drugs contribute to dental erosions.
- If the person has not had a dental check in the last 6 months, advise the carer to book an appointment. If mainstream services are not appropriate, seek advice from your local learning disabilities service, or the learning disabilities primary care liaison tem regarding alternatives.

Down syndrome and thyroid disease

- Thyroid disease, especially hypothyroidism, is common in persons with Down syndrome.
- Annual screening is recommended.

Autism

Indicators of autistic spectrum disorder include long-standing problems *out of keeping with the person's overall level of ability* in *all* the areas of:

- Impaired reciprocal social interaction (e.g. limited eye to eye gaze; limited feelings for others; difficulty making relationships or lack of interest in relationships).
- Impaired receptive or expressive language as used in social communication (includes abnormal use of language).
- Lack of empathy (e.g. abnormal responses to other people's emotions; unable to see things from other person's point-of view; lack of imaginative play / "let's pretend").
- Restrictive, repetitive and stereotyped patterns of behaviour, interests and activities (e.g. unusual attachments to objects; touches, smells, tastes things inappropriately; repetitive behaviours such as hand flapping, spinning, tiptoe walking; rituals; unable to cope with change in routine).

Health promotion initiatives for the general population

People with learning disabilities should be facilitated to access services designed for everyone in the population, where such services can be adjusted to meet their needs. Consider whether the person has needs related to smoking, alcohol use, weight managements, eating, exercise, then consider whether a referral is needed in the context of what local services are available. If mainstream services are not appropriate, seek advice from your local learning disabilities service regarding alternatives.

Health Screening Programmes

- Health screening programmes have been poorly accessed by persons with learning disabilities.
- Some women with learning disabilities are sexually active through choice, and others are unknown survivors of abuse.
- Breast awareness measures are probably lower, and may pass unnoticed.

- Refer to your local learning disabilities service if the woman may benefit from preparatory explanatory work in advance of a smear or mammography.

Immunisation

- Persons with learning disabilities are less likely to be immunised against influenza.
- Respiratory infections are common and can cause premature death from pneumonia, so influenza immunisation is particularly import for high risk groups.
- Persons living in or accessing services in group settings are at higher risk of acquiring hepatitis B infection, so consider immunization.

Assessment of capacity should cover the following areas:

- Does the person know the reason for the treatment and potential benefits?
- Does the person understand the potential consequences and risks if they did not have it?
- Does the person understand the possible side effects and risks the treatment may cause?
- Does the person understand what alternative options are available to them, and their possible benefits and risks?

D. APPENDIX 2

Contact details for the Learning Disabilities Primary Care Liaison Team

Learning Disabilities Primary Care Liaison Team
2 Whittingehame Gardens, 1091 Great Western Road, Glasgow G12 0AA
0141 2320030

Contact details for the Community Learning Disabilities Teams

Services Provided
Community Learning Disability Nursing, Learning Disabilities Psychiatry, Psychology, Physiotherapy, Occupational Therapy, Dietetics, Podiatry, Speech & Language Therapy

East Dunbartonshire
Kirkintilloch Health Care Centre, 10 Saramago Street, Kirkintilloch G66 3 BF
0141 3552200

East Renfrewshire
Barrhead Centre, 8 Calibar Road, Barrhead, Glasgow G78 1AA
0141 5773967

Inverclyde
Cathcart Centre, 128 Cathcart Street, Greenock PA15 1BQ
01475 499053/054

North East Glasgow
Stobhill Hospital, Former Trust HQ, 133 Balornock Road, Glasgow G21 3UW
0141 2014109

North West Glasgow
Unit 7B, The Qudrangle, 59 Ruchill Street, Maryhill, Glasgow G20 9PX
0141 2016200. Moving to Yarrow View on 19.9.11

Renfrewshire
Renfreshire Health & Social Care Centre, 2nd Floor , 10 Ferry Road, Renfrew PA4 8RU
0141 2077400

South Glasgow
South Portland Street Resource Centre, 44 South Portland Street, Glasgow G5 9JJ
0141 2763200

Berryknowes Resource Centre**,** 14 Hallrule Drive, Cardonald, Glasgow G52 2HH
0141 2762300

Unit 2, The Wedge, 1066 Barrhead Road, Glasgow G53 5AB
0141 2769760

West Dunbartonshire
Learning Disabilities Services, Beardmore Business Centre, 9 Beardmore Street, Dalmuir, Glasgow G81 4HA.
0141 5622333

Social Work

The above teams also include learning disabilities social work services except for the areas below:

East
Westerwood House, 1250 Westerhouse Road, Easterhouse, Glasgow G34 9EA
0141 2762470

West
Southbrae Resource Centre, 190 Southbrae Drive, Glasgow G13 1TW
0141 2767200

Contact details for RNIB worker, Laura McKenna (sensory improvement project)

Learning Disabilities Primary Care Liaison Team
2 Whittingehame Gardens, 1091 Great Western Road, Glasgow G12 0AA
0141 2320030