THE NATIONAL HEALTH SERVICE (SCOTLAND) ACT 1978

THE ANNUAL HEALTH CHECKS FOR PEOPLE WITH LEARNING DISABILITIES (SCOTLAND) DIRECTIONS 2022

The Scottish Ministers give the following Directions, in exercise of the powers conferred by sections 2(5) and 105(7) of the National Health Service (Scotland) Act 1978 **(a)**[1], and all other powers enabling them to do so.

1. Citation commencement and application

1.1 These Directions may be cited as the Annual Health Checks for People with Learning Disabilities (Scotland) Directions 2022 and come into force on 20 May 2022.

1.2 These Directions are given to Health Boards in Scotland and apply to Scotland only.

2. Interpretation

2.1 In these Directions—

“learning disability” means having a mild, moderate, severe or profound learning disability;

“mild learning disability” means an IQ in the range of 50-70, or a mental age of 9-12 years;

“moderate learning disability” means an IQ in the range of 35-49, or a mental age of 6-9 years;

“patient" means the person in respect of whom the Health Board or the provider are carrying out the annual health checks in accordance with these Directions;

“profound learning disability” means an IQ of less than 20, or a mental age of less than 3 years;

“provider” is a person with whom the Health Board has entered into an agreement to carry out annual health checks in accordance with these Directions;

“relevant data” means the information to be contained in any report that Health Boards must provide to Scottish Ministers in accordance with paragraph 6;

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[a] 1978 c29.

“Scottish Health Check for Adults with Learning Disabilities” means the document that forms Annex A; and

“severe Learning Disability” means an IQ in the range of 20-34, or a mental age of 3-6 years.

3. Annual Health Checks for People with Learning Disabilities

3.1 Each Health Board must ensure that an annual health check, as specified in these Directions, is offered to the following persons within the Board’s area –

(a) those aged 16 and over who are known by the Board to have a learning disability; and
(b) those aged 16 and over who identify themselves as having a learning disability (whether or not that learning disability has been formally diagnosed and regardless of whether it is mild, moderate, severe or profound).

3.2 A Health Board must take all reasonable steps to identify persons within its area who are aged 16 and over and who have a learning disability and, where the Board has identified such a person, must offer them an annual health check in accordance with these Directions.

3.3 A Health Board must take all reasonable steps to identify persons within its area who are under the age of 16 and who have a learning disability in order that an annual health check can be offered to them as soon as they attain the age of 16.

3.4 An annual health check carried out in accordance with these Directions must be undertaken by a registered nurse or registered medical practitioner.

3.5 In carrying out the annual health check, the registered nurse or registered medical practitioner may, if they consider it appropriate, seek assistance from any other health professional involved in the patient’s care.

3.6 Any patient must be permitted to have a nominated individual present with them during the health check provided that consent to that person being present has been obtained from either-

(a) the patient, or
(b) where the patient is unable to consent, someone who is legally able to consent on their behalf.

3.7 Annual health checks must have been offered in accordance with paragraphs 3.1 and 3.2 of these Directions by 31 May 2023.

4. Agreements to Provide Annual Health Checks

4.1 Annual health checks may be provided in accordance with these Directions by-

(a) a Health Board; or
(b) a provider.

4.2 Any agreement with a provider must include the information set out in paragraph 5.

4.3 Where the Health Board is carrying out the annual health checks directly, it must comply with the requirements set out in paragraph 5.

4.4 Where, at any time before these Directions come into force, a Health Board had entered into an agreement for annual health checks to be provided to persons within its area aged 16 or over who have learning disabilities, it must now take reasonable steps to bring the terms of any such agreement into compliance with paragraph 5.

5. Required Agreement Terms

5.1 Annual health checks must be offered to all persons aged 16 and over who have a learning disability (whether or not that learning disability has been formally diagnosed and regardless of whether it is mild, moderate, severe or profound).

5.2 The agreement must specify that the annual health check is undertaken by a registered nurse or registered medical practitioner, and, if they consider it appropriate, they may seek assistance from any other health professional involved in the patient's care.

5.3 The Scottish Health Check for Adults with Learning Disabilities must be used in carrying out the annual health check.

5.4 The provider must establish, review, update and maintain a register of adults aged 16 and over with learning disabilities.

5.5 The register must contain the following information in respect of each patient-

(a) their name;
(b) their date of birth;
(c) their sex;
(d) their CHI number;
(e) the severity and cause of their learning disability where this is known or, if this is unknown, then that should be stated;
(f) their next of kin;
(g) their living and support arrangements, specifying if the patient is an outpatient or receiving treatment from a different Health Board;
(h) whether the patient has capacity to provide consent, and where that is not the case, who is legally able to consent on their behalf;
(i) details of any known communication difficulties that the patient has;

(j) details of additional medical needs which may increase the risk of the patient developing medical conditions, including respiratory or heart conditions;
(k) the patient's emergency care summary and any information summary in so far as it is relevant to the care and treatment of the patient; and
(l) where the patient has epilepsy, details of their epilepsy care plan.

5.6 The provider must identify any persons already within their care who are under the age of 16 years and who have a learning disability and add any such persons to the register, along with details of the cause and severity of the learning disability, where this is known.

5.7 Subject to paragraph 5.8, the provider must, on the request of the Health Board, allow the Health Board access to the provider's register, in order that the Health Board may extract relevant data.

5.8 In the event that a patient does not respond to initial contact or fails to attend the health check, the provider must attempt to contact the patient at least two more times. Any non-attendance or non-compliance following these attempts must be recorded on the register, including any reasons identified for this.

6. Reporting to Scottish Ministers

6.1 Each Health Board must provide a report to the Scottish Ministers in accordance with paragraph 6.2 as follows-

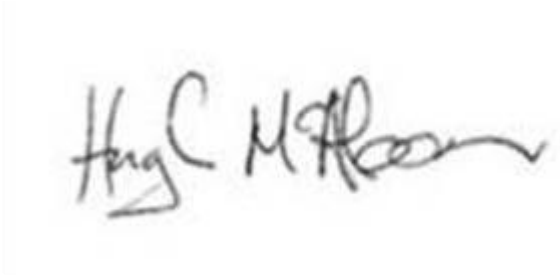
(a) at least once during each one year period, beginning on 20 November 2022; and
(b) otherwise when requested to do so by the Scottish Ministers.

6.2 The report must include the following information in respect of the Health Board's area -

(a) The number of people with learning disabilities on the providers' registers in the period since the last report was provided;
(b) The number of people with learning disabilities on the Health Boards' registers in the period since the last report was provided;
(c) The number of people with learning disabilities who have been offered annual health checks in the period since the last report was provided;
(d) The number of annual health checks that have been completed in the period since the last report was provided;
(e) The number of referrals made through the annual health checks and the services to which the referrals were made in the period since the last report was provided;
(f) The number of people with learning disabilities who are under the age of 16, who have been identified in the period since the last report was provided;
(g) The number of people with learning disabilities who will reach the age of 16 within one year of being placed on the register, who have been identified in the period since the last report was provided;
(h) The number of people with learning disabilities who have died, together with the cause of death, in the period since the last report was provided;

(i) In the period since the last report was provided, the number of annual health checks that have not been attended, and, where known, the reasons for this; and

(j) The type and number of agreements that the Health Board has entered into with a provider or providers to provide annual health checks in the period since the last report was provided.



Hugh McAloon
A member of staff of the Scottish Ministers

St Andrew's House
Edinburgh
19 May 2022

ANNEX A

1. The Scottish Learning Disabilities Health Check

This document can be made available in large print and any other language or format, upon request.

Name…….
Address…….
……....
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Date of birth…….

You are offered a health check at your GP practice. Please answer these questions before your health check. Let someone support you. Return this form to your GP practice before your health check.

Don’t worry if you can’t answer some questions.

Let the nurse know if they need to do something before the health check. Let the nurse know if you need someone to translate.

Who filled in this form?.....

If you are giving support, are you a family member or paid carer?.....

If you are a paid carer, how well and for how long do you know the person with learning disabilities?.....
……..……

What is today's date……

1. Can the nurse do something to help you at the health check? Are you deaf? Do you sign? Do you lip read? Are you blind? What is your language? Do you have physical access requirements?
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   ……..……
   .....
   .....

2. What is your ethnic background?.....
3. Please write a list of all your health problems or issues you may have.....
   ……..……
   ……..
   ……..……

4. List your drugs (medications, tablets, capsules, medicines, sachets, injections, creams)

Name	Dose	When do you take it?

5. Do you have any of these?
   a. Cough…….
   b. Breathing problem.……..
   c. Wheeze ……..…….
   d. Phlegm or snot.…….……
   e. Chest or leg pain when you walk or run…….……
   f. Swollen ankles…….……..……
   g. Skin, scalp, or foot problem…….……
   h. Problems peeing (passing urine). Peeing too often, or peeing in the night, or blood in your pee, or pain when you pee…….……..…….
      …….
   i. Not dry day and night (“incontinence”)? If so, is this long term or recent? Do you need pads or aids?.....
      …….

j. Bowel problem. Tummy ache, or change in bowel habit, or blood in your poo?……
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k. Pain……
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l. For women – painful/irregular periods and or other issues eg endometriosis or poly cystic ovaries……
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m. Menopause symptoms. Hot flushes, interrupted sleep
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6. Do you have seizures or epilepsy?
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a. How often are they?.....
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b. Are your carers trained to use "rescue" drugs for long seizures?.....

7. Do you have any problems going for a poo ("constipation")?.....
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8. Do you ever choke, or have problems when you swallow?

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9. Are you slow to eat a meal?.....

10. Do you need support and assistance to eat a meal?

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11. Do you have any of these issues (gullet problems)?
    a. Regurgitation or bringing food or drinks back up……
    ……
    b. Being sick or bringing up vomit……
    c. Heartburn……
    d. Indigestion……
    e. Do you get pain in your chest when you lie down?.....
       If the answer is yes, is the pain so bad that is stops you getting to sleep or it wakes you up?.....
    f. Coughing after eating……
    g. Frequent chest infections……
    h. Have you had advice on healthy eating and drinking……
    ……
    i. Have you had advice on how and what to eat and drink without choking? …….

12. Do you have sight problems? Do you wear glasses?.....
    ……

13. When was your last eye sight test?.....
    ……

14. Do you have hearing problems?.....
.....

15. When was your last hearing test or hearing aid check……
……

16. Do you have any of these issues?
    a. Anxious, or worried, or nervous, or stressed, or panic attacks…….
    ……
    b. Having to double check things, or doing things in a set order…….
    ……
    c. Feeling down, or depressed, or low…….
    d. Not wanting to mix with other people……..
    e. Not talking or joining in as much as in the past…..
    f. Tearful, or crying…….
    g. More irritable or ratty than in the past…….
    h. Not looking after yourself as well as in the past.……
    i. Loss of energy, or more energy than in the past…….
    j. More muddled up, or confused, or forget more than in the past …….
    k. More memory problems than in the past…….
    l. Sleeping less, or more, than in the past……..
    m. Gone off your food, or eating less than in the past……
    n. Loss of concentration, or focus…….

o. Change in the way you behave which might be seen as challenging others ……..

p. Needing more reassurance, or support, than in the past…..……

q. More suspicious, or trusting people less.……

r. Hearing voices that other people can't hear…….

s. Change in behaviour, this may need more explanation from you.……..

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17. Do you have walking problems?.....

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18. If you use one, when was your wheelchair last checked? Are your other aids or equipment useful? Do your carers need training?

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19. Do you have arthritis or pain?.....

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20. Do you have a lot of accidents or falls?.....

……..

21. Does your support package need a review? What needs reviewed?

    ……..…

22. When was your last dental check up?.....

23. Do you smoke? How much?.....

24. What exercise do you do in a week: go for walk, ride a bike, go to the gym, do an exercise class, dancing etc?.....

    .....

    Apart from this exercise, are you active in other ways, for example do you get out of the house a lot to go shopping or visit people/

    Yes most days……..

    yes some days……..

    no, not much……..

25. Do you eat fruit and veg every day? How many portions of fruit and veg do you eat? .....

26. Do you drink alcohol? How much?.....

27. Have you had a Covid vaccine? How many jags or jabs have you had?

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28. Do you have any Covid symptoms? Fever, or cough, or very tired, or loss of taste, or loss of smell, or feeling unwell?.....

29. Do you have a welfare guardian? Who are they?
    Name…….....
    Address……..
    ……
    Phone…….……

30. Do you have a next of kin? Who are they?
    Name…….....
    Address……..
    ……
    Phone…….……

31. May the nurse speak with your next of kin?
    Yes [ ] No [ ]

• THE SCOTTISH HEALTH CHECK
• for ADULTS WITH LEARNING DISABILITIES

This health check tool was developed by the health check group convened by the Primary Care Directorate and Mental Health Directorate of the Scottish Government,
with input from key learning disabilities stakeholder groups
It is designed for 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 for support during the health check

The appointment letter should advise the person to complete and return
the carer health questionnaire, and to bring a sample of urine, and their inhaler if they use one at the face to face appointment

The appendix (paper copy) or  provides additional information on several items included in the health check

Contact your community learning disabilities team if you need help with any of this health check – supporting primary care in health checks is part of their role

A. BEFORE THE APPOINTMENT

If you are using a paper copy of the Scottish Health Check, add the person's:

Name……

Date of birth……

CHI……

32. Send the carer health questionnaire with the appointment letter, asking them to complete and return it. Also send a urine sample bottle and ask them to bring it to the face to face appointment, and also their inhaler if they use one.

33. Before the appointment, review their records, and background information.

34. Has the person previously had a health check? If so, review the summary for background information. Are there any outstanding actions from the health check that are needed at this health check?

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35. Do any special arrangements (reasonable adjustments) need to be made or arranged in advance, to communicate effectively with the person, or to help the person take part? Do you have physical access requirements?

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36. What is the cause of the person's learning disabilities? If the person has a specific cause for their learning disabilities, check which physical and mental health problems are associated with the syndrome. Check if any syndrome-specific screening is needed. (Seek information from the internet, RCGP, or in the person's records, or from your community learning disabilities nurse.)

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37. Does the person have any long term conditions, e.g. diabetes, asthma, thyroid? For each long term condition, check if there are any outstanding reviews needed.(Use list of 36 plus LTCs developed by GPs)

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

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39. Has the person had repeated hospital admissions? For example, more than 2 admissions for chest infection in the last year. Might there be an underlying problem accounting for this that needs addressing, e.g. aspiration, gastro-oesophageal reflux disorder (GORD)?

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40. Is the person eligible for any of the national screening programmes e.g. Cervical, Breast, Bowel, Abdominal Aortic Aneurysm, Diabetic Eye screening? Check Screening | NHS inform for eligibility criteria. If so, is it up to date? Is any action needed now?

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41. Review any Adults with Incapacity (Scotland) certificates. Are treatment plans up-to-date?

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Signature……

Name……

Designation……

Date……

B. AT THE APPOINTMENT (virtual or face to face)

Clinical interview

Rephrase these questions in your own words, and explore them further as seems indicated on the basis of the information given.

The appendix (paper copy) or ℹ contains background information on several items in the health check and may be helpful.

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. Check if they returned the **carer completed health questionnaire**.

    a. If they have not, go to question 3, and work through all the following questions with them.
    b. If they have, review the questionnaire with them, and focus on any issues it identifies. If you need more information, scroll through the nurse health check questions 5-23 whilst reviewing the carer completed health questionnaire.
        i. Have a high index of suspicion for vision and hearing impairments including impacted cerumen and cerebral visual impairment, GORD, aspiration/choking, constipation, mental ill-health/change in the way you behave which might be seen as challenging others, sub-optimally managed epilepsy, skin problems, medication side-effect.

ii. Does their medication list match your list, and do they all seem indicated? Do their medications need a review with the GP?
iii. Check if they have had an eyesight test in the last 2 years or in the last year if aged over 60, a hearing test in the last 2 years or in the last year if the person has Down syndrome, and a dental check in the last 6 months. Recommend they arrange this if they have not (and write it down for them to take away).
iv. Check if they have had all their COVID vaccinations.
v. Check that **next-of-kin and welfare guardian** details are correctly recorded/have not changed.

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WHEN YOU HAVE GONE THROUGH THE CARER COMPLETED HEALTH QUESTIONNAIRE, SKIP TO QUESTION 24.

3. Check that **next-of-kin and welfare guardian** details are correctly recorded in the persons records.

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

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

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

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7. Ask what **health conditions** the person has and review these.

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8. 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? If they are on antipsychotic drugs, is there a clear indication?

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9. Does the person have **any other symptoms**? E.g.
    a. coughing,
    b. breathing problems,
    c. wheezing,
    d. phlegm,
    e. chest or leg pain on exercise,
    f. swollen ankles,
    g. skin, scalp, or foot problem,
    h. problems passing urine/peeing, frequency, hesitancy, nocturia, dysuria, haematuria,
    i. onset of incontinence. Are continence aids needed,
    j. bowel problems, blood in motions/stool, change in bowel habit,
    k. pain,
    l. for women – menopause symptoms e.g. hot flushes, interrupted sleep.

If any symptoms are present, 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.

10. If the person has **epilepsy**, ask about
    a. their type of seizures,
    b. when they occur,
    c. how often they are, and consider if it could be better controlled, e.g. when were their antiepileptic drugs last increased or changed?
    d. Do the people who provide support know how to use rescue medication for status/prolonged seizures?
    e. "Excellence in care" outcomes include that persons with learning disabilities and epilepsy should have an "epilepsy plan of care" which is annually reviewed and includes each of person/carer involvement, seizure description, risk assessment, and treatment review. Check if the person has one, and if it needs reviewing, refer to the learning disabilities nurses.

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11. **Constipation**? Sometimes constipation can be an underlying cause of death in people with learning disabilities. It may present as overflow diarrhoea. Sometimes medications contribute to constipation, and may need to be reviewed. Many factors can contribute, e.g. diet, fluid, mobility, and exercise: your community learning disabilities team can provide help.

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12. Risk of **choking**? E.g. aspiration problems, trouble swallowing, spluttering, previous episode of choking, repeated chest infection (two in the last year), cough or dyspnoea, cyanosis after eating, slow to eat a meal. If so, has this been assessed by the dysphagia service (speech and language therapist, dietician, physiotherapist for postural care)?

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13. **Gastro-oesophageal reflux disorder**? E.g. regurgitation, vomiting, heartburn, indigestion, onset of disturbed sleep, onset of behaviours that challenges others, regular coughing after eating, frequent chest infections, borderline/low Hb, dental erosions.

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14. **Visual impairment**? Opticians can assess vision in persons at all ability levels. Some areas also have specialist visual services. When did the person last have an eye sight test? If >2years ago (or >1 year ago if over age 60), advise the person/carer to book to see an optician, and write this down for them to take away.

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15. Suspicion of **cerebral visual impairment**? E.g. being able to see things, but not able to interpret, e.g. can't see objects on patterned backgrounds. Refer to ophthalmology.

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16. **Hearing impairment**? When did the person last have an audiology test? If >2years ago (or >1 year ago if the person has Down syndrome), refer to audiology or recommend booking a check by a high street provider. Does the person need a hearing aid review?

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17. **Mental ill-health/dementia**? E.g.
    a. anxious, panicky,
    b. rituals,
    c. low mood,
    d. social withdrawal,
    e. less communicative,
    f. tearful,

g. increased irritability,
h. decline in self-care,
i. change in energy,
j. more muddled, confused, forgetful, memory problems,
k. change in sleep pattern,
l. change in appetite,
m. change in energy,
n. reduced concentration,
o. increase in behaviours that challenge others
p. reassurance seeking behavior,
q. more suspicious or paranoid,
r. hearing voices that no one else can hear.

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18. Some persons need extra support because of **behaviours that challenge others**. Has the adult had any increase in 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 community learning disabilities service.

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19. **Mobility problems or a change in walking speed**?

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

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21. **Arthritis** and pain? (e.g. Any problems with sore joints or limbs?)

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22. **Accidents/falls**? Are there any underlying problems that could be addressed, or medication that is contributing and needs reviewing?

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23. **Social care**. Refer to your local health and social care learning disabilities service if the person's support package needs a review. What needs reviewing?

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IF YOU HAVE NOW GONE THROUGH THE CARER COMPLETED HEALTH QUESTIONNAIRE, REJOIN THE HEALTH CHECK HERE

24. At risk of **osteoporosis**? E.g. repeated fractures, impaired mobility, underweight, early menopause, antiepileptic or antipsychotic drugs, lack of puberty. Follow the bone health protocol for adults with learning disabilities.

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25. 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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26. Is the person a **vulnerable adult**, with vulnerability needs maybe not being met? Is the adult at risk; in need of adult support and protection? If so, is advice/support needed from your local health and social care learning disabilities service?

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

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

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28. Review/complete any required issues for any long term conditions e.g. diabetes, asthma, thyroid.
    - 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 to the community learning disabilities team for one be helpful?
    - Does the person need any specialist referrals?

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

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30. If not already in the person's medical records, estimate the person's **ability level**. The extra information suggests a quick way to estimate this.

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- years)

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IF YOU HAVE ALREADY GONE THROUGH THE CARER COMPLETED HEALTH QUESTIONNAIRE, NOW SKIP TO QUESTION 37. IF NOT CONTINUE

Routine health promotion and screening – check if any of these are relevant for the adult.

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

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32. **Smoking/**smoking cessation advice.

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33. **Exercise.** People with learning disabilities take less exercise and are more sedentary than other people. They may want advice or signposting for advice.

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34. **Diet** and weight. Fruit and vegetables. People with learning disabilities are more likely to be obese than other people, which is associated with high risk for many other conditions. They may want advice or signposting for advice. Some people with learning disabilities are very underweight and need help from a dietician.

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35. **Alcohol**/drug use, and signposting for advice.

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36. **COVID vaccination.** How many vaccinations has the person had? Adults with learning disabilities are at high risk for poor outcomes including severe infections and mortality. Learning disabilities nurses can help with vaccination.

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37. **Influenza vaccination**. 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. Has the person had their annual vaccination?

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38. **Hepatitis B vaccination**. People with learning disabilities in residential care, or using day centres, and people with severe/profound learning disabilities may be at increased risk of infection. Consider vaccination.

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39. **Human papillomavirus vaccination**. Was the person vaccinated when at school? If not, consider HPV vaccination for women under 25 years, and men under 45 years who have sex with men.

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40. **Cervical screening**. Routine screening is every 5 years for people with a cervix aged 25- 64,. Is contraception advice needed?

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……..….

……

41. **Breast Screening**. Every 3 years for women aged 50-70 Has the person taken up the invitation ? Genetic assessment available if at high risk of breast cancer.

……

…….

.……

42. **Bowel screening.** For people aged 50 – 74 every 2 years have they done their bowel screening within the last 2 years?

……

……

……

43. **Abdominal Aortic Aneurysm screening**. For men aged 65, one off screen, have they taken up this screening?

……

……

……

44. **Diabetic Eye Screening.** Every year to people with diabetes over the age of 12, have they attended this screening?

Signature……

Name……

Designation……

Date……

C. AT A FACE TO FACE APPOINTMENT

Physical examination

Use your practice's COVID protocol before and during the face to face appointment. Delay the appointment if the person has COVID symptoms.

1. **Urinalysis**. UTIs are common.

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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 $(m)^2$. Wheelchair scales may be needed.

……
……

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

……
……

4. **Pulse rate/rhythm**.

……
……

5. Nurse's opinion: does the person have support needs related to **communication,** needing reasonable adjustments at appointments?

……
……..
……

6. Look inside the person's mouth – **gingivitis**? Gross dental decay? Pain? Advise dental check if not done in previous 6 months.

……

……

……

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

……

……

……

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

……

……

……

9. **Hearing**. 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? Formal audiology is also required every 2 years (or annually for people with Down syndrome), and may need a referral, or advise to book an appointment.

……

……

……

10. **Peak flow**. Repeat if the person has difficulty on the first attempt.
    - FEV1……
    - FEV2……

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

……

……

…..……

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

……

……..……

……

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

……

……

……

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

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……...…

……

15. Any **pressure sores or ulcers**? **Eczema?**

……

……....…

……

16. Any **tremor**? If so, consider drug side effects.

……

……

……..

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

……

……

……

18. 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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……

CONSIDER IF THE PERSON SHOULD SEE THE GP FOR ANY FURTHER EXAMINATION, E.G. ABDOMINAL EXAMINATION, OR FOR ANY OTHER ADVICE, BASED ON THE RESULTS OF YOUR CLINICAL INTERVIEW AND EXAMINATION

SUMMARISE THE HEALTH CHECK OUTCOMES

CODE THE READ CODE FOR COMPLETION OF A LEARNING DISABILITIES HEALTH CHECK READ code to use is : 69DB. Learning disability health examination

SUMMARY OF HEALTH CHECK OUTCOMES

Identified problem or health monitoring or health promotion need	Action taken and advice given	Further action that is needed and whom is responsible for this?

Signature…… Name……

Designation…… Date……

ADDITIONAL INFORMATION

Guidance on the Scottish health check for adults with learning disabilities Information to sit beside the health check

READ Code 69DB. Learning disability health examination

The Scottish health check for adults with learning disabilities has three parts:

- A health questionnaire to be completed in advance by the person with learning disabilities and their carer/support worker, and returned to the practice nurse.
- Additional information that practice nurses may wish to follow to conduct the health check, either remotely or in person. This has sections on:
- What to do before the health check.
- Prompts to guide nurses through conducting a health check. As the most common problems experienced by people with learning disabilities differ from the general population, the focus and emphasis is shifted towards those needs. The health check also provides a check on whether reviews of long term conditions are up-to-date, and to book into relevant practice clinics for these if needed, and on health promotion. Further information about people with learning disabilities and the health needs relevant to adults with learning disabilities.
- A framework that practice nurses may wish to follow at a face-to-face appointment, to conduct the physical examination part of the health check.

The reason for the initial health questionnaire is so carers and support workers spend some time with the person with learning disabilities thinking about the person's health and any health concerns in advance of the health check. This is so the appointment with the nurse can be more productive, more focussed, and shorter in duration. There will however, be some people who cannot complete the questionnaire (e.g. family carers who cannot read). So the health check framework for the practice nurse includes these same areas, with prompts to skip over them if the carer has completed the initial health questionnaire.

The health check framework is a guide on the important areas to cover. It does not have to be rigidly followed. Stimulating people with learning disabilities and their carers to consider health, and to spend time with a practice nurse who has information about the common unmet needs of this population is a positive experience for people with learning disabilities and improves their health.

Some things we suggest you cover may seem unfamiliar to you; do not hesitate to contact your local community learning disabilities nurses for help

if you need this – they view supporting primary care as part of their core role.

We recommend you allow 30-45 minutes for each health check.

A summary to record your findings is provided, if you wish to use it. But please record the health check appointment in your clinical records in any way your practice finds most useful.

Why has the Scottish Government introduced annual health checks for people with learning disabilities? Information to sit beside the front cover

- The Equality Act (2010) places obligations on the public sector to advance equality, including making reasonable adjustments for disabled persons. For many reasons, adults with learning disabilities have poorer health and poorer access to health-care than other people. Health checks are an evidence-based reasonable adjustment to change this.
- People with learning disabilities have more health conditions and comorbidities than other people, due to different aetiologies and health-related behaviours.
- Clinical presentations are often atypical.
- Undiagnosed health conditions are common.
- Professionals often inappropriately attribute health conditions to the person's learning disabilities rather than diagnosing and treating them, causing unnecessary suffering and long term consequences.
- Conditions tend to present late, at more severe stages of disease progression, leading to poorer outcomes.
- Long term conditions tend to be less well managed, and hence have poorer outcomes.
- Limited verbal communication skills and being reliant on carers recognising problems and seeking out help, and following through with professional advice, contribute to high level of unmet health needs.
- The Scottish Government funded a randomised controlled trial using this Scottish health check for adults with learning disabilities, which found the health check was clinically and cost effective.
- This is why the Scottish government is paying general practices to conduct annual health checks with their patients with learning disabilities.

Living and support arrangements Information to sit beside section A Q1

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.

Background information
People with learning disabilities comprise a significant minority of the UK population. Demographics are changing and the population of people with learning disabilities is increasing. 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 see 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; the correct terminology now is people with learning disabilities, or people with intellectual disabilities.

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. More detailed information is provided in the section on disorders of intellectual development in ICD-11.
918e. on learning disability register

Communication Information to sit beside section A Q4 and section C Q5
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 behaviours that may challenge others, 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

Communication difficulties can be compounded by additional problems such as hearing impairment, visual impairment, and autism. Some people find easy-read materials and pictures/symbols helpful. The Equality Act (2010) places obligations on the public sector to advance equality, including making reasonable adjustments for disabled persons. You may need to adapt your communication style and length of appointment as reasonable adjustments to facilitate communication with your patient with learning disabilities.

Health staff's awareness and use of helpful communication strategies can help achieve more effective communication. (easyhealth.org.uk)

ZV401[V] Problems with communication, including speech

Cause of learning disabilities Information to sit beside section A Q5 and section B Q29

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.

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

- tuberous sclerosis and epilepsy, hypertension, and raised intracranial pressure
- Down syndrome and sensory impairments, dementia, hypothyroidism, and sleep apnoea (which can also cause problem behaviours)
- Prader-Willi syndrome and affective psychosis and obesity (due to insatiable appetite)
- 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 community learning disabilities service. The Royal College of General Practitioners provides some syndrome specific health check guidance (Down syndrome, cerebral palsy, foetal alcohol syndrome, fragile X syndrome, Prader-Willi syndrome, Rett syndrome, Williams syndrome). NHS NES TURAS will host links to further guidance.

Down 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
Unknown, never fully investigated
Unknown, despite investigation

Examples of long term conditions Information to sit beside section A6 and section B Q28
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
E140z Infantile autism NOS
Repeat medicines review

Adults with Incapacity (Scotland) Act 2000 Information to sit beside section A Q10, section B Q2bv, section B Q3, and sections B Q7 and B Q8. 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. Capacity to consent is specific to the treatment/investigation: a person

may have capacity to consent to some treatments, but not for other treatment that require more complex decision-making.

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

Assessment of capacity should cover the following areas Information to sit beside section A Q10 and Sections B Q7 and B8.

- 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?

A different pattern of health needs Information to sit beside section B Q2bi, and section B Q6, and section B Q17

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

- Much more commonly experienced are: risk of choking, aspiration, epilepsy, gastro-oesophageal reflux disorder, constipation, sensory impairments, osteoporosis, mental ill-health, schizophrenia, dementia, autism, dysphagia, dental disease, musculoskeletal problems, accidents, obesity, nutritional problems, visual impairment, hearing impairment, impacted cerumen, and behaviours that challenge others.
- Health problems related to smoking, alcohol, and use of illegal drugs are less common.
- Some behaviours that challenge others , e.g. self injury and pica, are specific to learning disabilities and may be associated with specific genetic syndromes.
- The commonest problems detected at health checks that aren't already known about are impacted cerumen, gastro-oesophageal reflux disorder, mental ill-health, obesity, xerosis cutis, visual impairment, constipation, then tinea. Problems are detected across the full range of bodily systems.
- GPs have developed a list of more common LTCs which could be used as a reference.

Specifically consider if the person has any of the health needs and disabilities which are commonly experienced by persons with learning disabilities, or any long-term conditions, including:

Physical disorders and disabilities that occur commonly in persons with learning disabilities Information to sit beside section B Q2 and section B Q6, and section B Q17
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 Information to sit beside section B Q2bi and section B Q6, and section B Q17
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)

The commonest causes of death also differ compared with the general population Information to sit beside section B Q2bi, and B Q6, and B Q17

- For adults with learning disabilities without Down syndrome, aspiration/reflux/choking, and respiratory infection are the

commonest underlying causes of mortality; for Down syndrome adults dementia is the most common underlying cause of mortality.
- 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 gastro-intestinal cancer and leukaemia.
- Swallowing problems are a significant risk factor for choking in this population, and is amenable to good care; as is reflux.

COVID Information to sit beside section B Q2iv and section B Q36
Data from wave 1 of the pandemic on 17,203 adults with learning disabilities in Scotland shows they had more COVID infection, severe infection, mortality, and case-fatality when compared with people without learning disabilities. After standardising for age and sex, compared with people without learning disabilities, they were 2.6 times more likely to have severe infection, and 3.3 times more likely to die. Over the age of 55, they were 7.4 times more likely to have severe infection, and 19.1 times more likely to die compared with people without learning disabilities. The Scottish Government included people with intellectual disabilities as a priority group for vaccination.

Health needs Information to sit beside section B Q5 and section B Q6
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.

Reactive rather than proactive models of care particularly disadvantage persons with learning disabilities Information to sit beside section B Q5 and section B Q6
- 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 recognising 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.

Psychotropic drug side effects Information to sit beside section B Q8
Dry mouth or thirst
Sleepiness of lethargy
Dizziness
Felling faint when getting up/standing up
Fast or irregular heart beat
Blurred vision
Altered taste
Weak limbs
Insomnia
Confusion
Agitation
Problems passing urine
Nausea and/or vomiting
Abdominal pain
Constipation
Diarrhoea
Tremor
Stiff arms and legs
Restlessness
Abnormal movements of mouth/tongue
Distorted painful muscles e.g. neck
Increased salivation
Increased sweating
Itchy skin
Jaundice
Sunburn
Skin rash
Onset of/increase in seizures
Weight gain
Oedema
Menstrual disturbance
Breast milk production

Antiepileptic drug side effects Information to sit beside section B Q8
Nausea and/or vomiting
Dizziness
Drowsiness
Headache
Clumsiness
Tremor
Unsteadiness
Confusion
Impaired concentration

Agitation
Nystagmus
Double vision
Blurred vision
Abdominal pain
Constipation
Diarrhoea
Loss of appetite
Skin rash
Acne
Bruising
Jaundice
Loss of hair
Oedema
Weak limbs
Menstrual disturbance

Epilepsy Information to sit beside section B Q10

- Epilepsy is common in people with learning disabilities.
- It can be a cause of death, and of injury.
- If is often sub-optimally controlled.
- If the person has seizures, check when their medication was last reviewed, increased or changed – if there has been no recent attempt to improve seizure control, this needs reviewing by the GP in the first instance and may need onward referral.
- Rescue medication should be prescribed for people with epilepsy if clinically appropriate, for example if seizures are prolonged, if they cluster or if they have been difficult to control in the past. This should be accompanied by a written protocol which is reviewed annually.
- People with epilepsy should have a risk assessment including of their environment and support. The professional who undertakes this may differ in different Health Boards. Check if the person has had a risk assessment and if not, contact your community learning disabilities service to refer for this.
- "Excellence in care" outcomes for epilepsy include that persons with learning disabilities and epilepsy should have an "epilepsy plan of care" developed and annually reviewed. The epilepsy plan of care should include each of person/carer involvement, seizure description, risk assessment, and treatment review. A learning disabilities nurse is likely to lead on this, and if it is not in place or has not been reviewed within the year, a referral to the learning disabilities team should be made.

SIGN 143: (2018) to the documentation

https://www.sign.ac.uk/media/1079/sign143_2018.pdf

PATIENTS WITH RECURRENT PROLONGED OR SERIAL SEIZURES IN THE COMMUNITY

In some patients, epilepsy is so severe that the occurrence of severe or prolonged seizures is likely to be frequent. In such cases, carers of patients with recurrent prolonged or serial seizure episodes in the community may be able to terminate the seizure episode, prevent the development of status epilepticus and avoid unnecessary hospital admission by the administration of buccal or intranasal midazolam 10 mg, or rectal diazepam 10–20 mg close to seizure onset. Buccal/intranasal midazolam is not, however, currently licensed for use in adults and evidence for its use by carers is derived from studies in children and adolescents. An agreed and individual written administration protocol set by the specialist team should be followed. The protocol should be a clear written instruction that includes the indications for administering rescue medication, the maximum dose in 24 hours, the drug name, strength, dose and frequency, the route of administration, and when to call for emergency help and transfer to hospital. The protocol should be reviewed regularly for efficacy and appropriate usage.

Risk of choking Information to sit beside section B Q12

- 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. Rett syndrome.
- These are significant risk factors for choking and death.
- Indicators include regurgitation, trouble swallowing, aspiration problems, cough or dyspnoea, recurrent chest infection, spluttering, previous episode of choking, cyanosis after eating, slow to eat a meal.
- Multidisciplinary assessment of swallowing/feeding problems/postural care (protection of body shape) can reduce dehydration, aspiration and respiratory infections.
- If suspected, refer for assessment, and/or seek advice/support from your local community learning disabilities service or dysphagia service. Speech and language therapists (swallowing assessment), dieticians (food consistency), and physiotherapists (posture/positioning when feeding) can all help.

Gastro-oesophageal reflux disorder Information to sit beside section B Q13

- 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, this needs reviewing by the GP to consider a treatment trial of a proton-pump inhibitor, then reassessment.

Vision and hearing test Information to sit beside section B Q14 and section B Q16 and section C Q7 and section C Q9
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. Some opticians/high street providers now also provide hearing tests.

Indicators of possible visual impairment Information to sit beside section B Q14 and section C Q7

- 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 Information to sit beside section B Q15

- 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.

Impacted cerumen Information to sit beside section B Q16 and section C Q8

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.

Pain Information to sit beside section B Q21

Pain may be harder to assess in people with learning disabilities, and can present atypically e.g. by problem behaviours/challenging behaviour. There are some instruments to assess pain in people with disabilities e.g. the Disability Distress Assessment Tool (DisDAT). If the person requires an assessment for pain, consider seeking support from your community learning disabilities nurse to undertake this.

Osteoporosis Information to sit beside section B Q24

- 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.
- Your Health Board may have a bone health protocol for adults with learning disabilities. Refer to the local community learning disabilities service if further advice/support is needed.

Vulnerable adult Information to sit beside section B Q26

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'.

Ability levels Information to sit beside section B Q30
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 be 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 refers to IQ=50-70, or mental age of 9-12 years
- Moderate learning disabilities refers to IQ=35-49, or mental age of 6-9 years
- Severe learning disabilities indicates IQ=20-34, or mental age of 3-6 years
- Profound learning disabilities indicates IQ=20, or mental age less than 3 years

E30.. Mild learning disabilities, IQ in range 50-70
E310. Moderate learning disabilities, 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 Information to sit beside section B Q30. Further information will be available on NHS NES TURAS

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 lower it e.g. cerebral palsy, stroke, blind, schizophrenia and dementia – so make allowances for these conditions.
Your community learning disabilities team can provide further help if needed.

Oral health Information to sit beside section B Q31 and section C Q6

- 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 regarding alternatives.

Health promotion initiatives for the general population Information to sit beside section B Q31, section B Q32, section B Q33, section B Q34, and section B Q35

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 community learning disabilities service regarding alternatives.

Vaccination Information to sit beside section B Q36, section B Q37, and section B Q38, and section BQ39

- Persons with learning disabilities are less likely to be vaccinated against influenza.
- Respiratory infections are common and can cause premature death from pneumonia, so influenza vaccination 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 vaccination.
- People with learning disabilities are at higher risk of COVID infection, severe infection, and mortality than are other people. The Scottish government included them as a high priority group for vaccination.
- People with learning disabilities are at risk of HPV infection through sexual activity of their choice, and through sexual abuse. The same HPV vaccination rules should be followed as for other people.

Health Screening Programmes Information to sit beside section B Q40, section B Q41, section B Q42, and section B Q43 B Q44

- 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, so do need cervical screening.
- Breast awareness measures are probably lower, and may pass unnoticed.
- Bowell cancer is at least as common as, and may be more common in people with learning disabilities than in the general population.
- Men with learning disabilities may not check their testicles and may need referring to a sexual health clinic.
- Refer to your local learning disabilities service if the person may benefit from preparatory explanatory work in advance of a smear, mammography, bowel screening, eye screening or abdominal aortic aneurysm screening.

Contractures Information to sit beside section C Q12

- 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.
- Consider also if pain management is needed.

Down syndrome and thyroid disease Information to sit beside section C Q18

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