The following are excerpted from the NHS Primary Health Facilitators for People with Learning Disabilities' 'Resource Pack for Primary Care Teams: Access to Primary Care for People with Learning Disabilities', with thanks to Dr R.G. Jones & South Birmingham PCT, who developed the 'Learning Disability Support Package', from which the 'Resource Pack' has been adapted.

How an Individual with a Learning Disability may communicate

Verbal

- Individuals who have a learning disability may be able to comprehend (understand) more than they can articulate.
- They may be repetitive.
- If they are anxious or upset, their speech may become quicker or louder.
- They may use inappropriate language or speak out of context.
- Some individuals may have developed their own words to express themselves.

Non- Verbal

- The individual may avoid or overuse eye-contact.
- They may not understand the social boundaries relating to personal space or touch.
- They may use different sounds or gestures to convey their needs.
- They may use signs, but may have their own way of signing.
- Individuals may use pointing as an indication of their needs.
- It is important to consider the environment, as many factors, such as noise and distractions, can impair communication.
- Waiting is often difficult when a person is anxious about something – fear may build up, causing uncooperative or difficult to manage behaviour.

Thomas et al. (2002)

- Highlight those patients who cannot tolerate waiting in the waiting area. If possible, wait somewhere else or in the car and phone the carer when you know the GP is ready.

- Is the surgery easy to get around? Have you pictures on the doors, of the doctor, nurse, and W.C.? Can the patient understand when the next appointment is due, can they tell the time, and would an appointment at O'clock be easier than 9.45am?

- Requests for home visits, particularly from learning disability community homes, can be avoided if you can be flexible with appointment times. Sometimes limited staff and the demands of other residents make it difficulty to attend during routine times.

- If in doubt, ask your healthcare facilitator for advice or to liaise with the person and/or carer.

- Think about the person's capacity to consent to any proposed intervention. Try to evaluate if you need to obtain the person's capacity to consent or if you are proceeding in the 'best interests' of the person.

- Try to obtain as much accurate information about the condition as possible, always ask the person first using simple words and sentences: don't talk about the plumbing and water works when you need to ask about their wee! If there is difficulty then ask the carer if they can clarify the details.

- Try to remember health promotion advices that you would give out routinely, include special leaflets for people with a learning disability, e.g., going for a smear test.

- Include people with a learning disability in all your quality outcomes initiatives, e.g., Diabetes/CHD/asthma. These are often undiagnosed and not monitored in people who have a learning disability.

With thanks to:-Abbottswood Rd Surgery

Health Issues and Additional Health Needs Of People with Learning Disabilities

Research has demonstrated that many people with a Learning Disability have a range of undiagnosed and untreated health problems. Often they themselves don't recognise the symptoms of illnesses or that they are in fact unwell; if they do recognise they are ill, they are often unaware what help is available or what to do about it. Prevention and early detection of illness is something we all value. Regular health screening would recognise and help to prevent or treat conditions. Early intervention would increase the success rate of treatment if needed. Inviting people with a Learning Disability for health screening would increase early detection and treatment of health problems and also increase their awareness of services available. This in return will help primary care services to meet their government targets. It is acknowledged that people with a learning disability are likely to experience 2 times more health problems than the average person in the general population. Research by Elliot, Hatton and Emerson (2003), identify that the main health problems for people with a learning disability are:

- Respiratory disease – the leading cause of death (46% - 52%) this is much higher than the general population (15% - 17%).
- Coronary heart disease – second most common cause of death (14% - 20%) – nearly 50% of people with Down's syndrome are affected by congenital heart defect.
- Stomach disorders and proportionally higher rates of gastrointestinal cancer.
- Epilepsy is much more prevalent with 22% compared with less that 1% in the general population.
- Hypothyroidism – people with Down's syndrome have a greater risk of hypothyroidism, with risk increasing with age.
- Osteoporosis – people with a learning disability have substantially lower bone density.

Other Health Problems May Include: -

- Mental health problems
- Hearing or visual impairment
- Speech difficulties
- Obesity
- Hypertension
- Skin disorders
- Dental problems

In addition to this, people with learning disabilities are less likely to access advice and help with other issues. For example, in young adults, target areas may include:- drinking, smoking, contraception, STI'S and weight management.

Routine Screening has also been overlooked. Target areas for women include: - breast screening, smear test, menstruation and well women clinics. For men, this includes testicular and well man clinics.

Regular medication reviews should be undertaken and vaccination status identified.

15 Health Targets

Agreed by international consensus as highly prevalent, easily detected, and amenable to readily available treatments

1. **Monitor nutritional status by regular height and weight checks**
2. **Prevent and treat chronic constipation**
3. **Update epilepsy treatment, seizure review**
4. **Screen for thyroid deficiency, especially Down Syndrome**
5. **Identify and treat mental health problems**
6. **Identify and treat gastro-oesophageal disease**
7. **Identify and treat osteoporosis, take preventative measures, where possible**
8. **Review medication frequently, possibly three monthly**
9. **Ensure vaccinations are updated, including flu/hepatitis**
10. **Provide exercise opportunities**
11. **Offer physical assessment by medical practitioner**
12. **Refer to a genetic clinic those without an aetiological diagnosis**
13. **Arrange mammogram / smear tests as in general population**
14. **Regular access to dental checks**
15. **Hearing and vision**

Beange, Lennox, and Parmenter, (1999)

SYNDROME SPECIFIC CHECKLIST

(Of recognised potential medical complications)

For other syndromes please see: Syndrome Reference Book

	DOWN SYNDROME	PRADER WILLI	FRAGILE X
Audiovisual	Visual Impairment (Multifactorial) (Annual Ophthalmic Assessment Recommended) Hearing Impairment (Multifactorial) (Annual Audio logical Assessment Recommended.)		Visual Impairment (Multifactorial) Hearing Impairment
Endocrine	Thyroid Disorder (Annual TFT Recommended)	Non-Insulin Dependant Diabetes Mellitus (secondary to obesity)	
Psychiatric / Psychological	Alzheimer's type dementia. (Clinical onset uncommon before 40 years)	Hyperphagia Impulse control difficulties Self injury	Attention Deficit Hyperactivity. Disabilities in social functioning
C.N.S.	Epilepsy		Epilepsy
Cardiovascular	Congenital Heart Disease Mitral valve prolapse		Aortic dilation Mitral valve prolapse (related to connective tissue dysphasia)
Muscular / Skeletal	Atlanto occipital+ Atlanto axial instability	Hypotonia	Connective tissue dysplasia Scoliosis
Other	Blood Dyscrasia Skin disorders Obesity Sleep apnoea (Hypoplastic Pharynx) Increased susceptibility to infectious disease	Severe Obesity Undescended testes	Hernia (CT related) Abnormalities of speech and language.
Inheritance	Most cases are sporadic. 2% due to translocation involving chromosome 21 or rarely parental mosaicism.	Atypical (Most sporadic)	Atypical X linked

SYNDROME SPECIFIC CHECKLIST

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	STURGE WEBER	(CLASSICAL) PHENYLKETONURIA	NEUROFIBROMATOSIS	TUBEROUS SCLEROSIS
Audiovisual	Glaucoma		Hearing impairment (Glioma affecting auditory nerve.)	Retinal Tumours
Endocrine				
Psychiatric / Psychological	Variable intellectual capacity	Variable intellectual capacity Disabilities in social functioning.	Variable intellectual capacity	Variable intellectual capacity
C.N.S.	Epilepsy Variable clinical phenomena depending on site of angioma.	Epilepsy Hyperactivity	Variable clinical phenomena depending on the site of the tumours.	Cerebral astrocytomas Epilepsy
Cardiovascular		Poor peripheral circulation		Cardiac Rhabdomydomas
Muscular / Skeletal		Hypotonia	Skeletal abnormalities especially Kyphoscoliosis Hernia (CT related)	
Other	Haemangioma (mainly skin and meninges)	Eczema	Variable clinical phenomena depending on the location of neurofibroma. Tumours are susceptible to malignant change. Other varieties of tumours may be associated.	Kidney and Lung Hamartomas Polycycstic Kidneys
Inheritance		Autosomal recessive	Autosomal dominant	Autosomal Dominant