



# Learning Disability CQUIN - Learning Disability Community Nurse (Learning Disability Primary Care Liaison Nurse)

## Role Outline and Practice Engagement

### 1. Role

#### General Description:

The practice must have a Clinical Lead for Learning Disability who will liaise with the Learning Disability Community Nurse and be prepared to allow access to the system to help perform searches etc.

The Learning Disability Community Nurse will provide assistance to practices signed up to the ES (Enhanced Service) in the development of fully comprehensive registers of patients with learning disabilities using standardised read code searches.

The records of identified patients will be flagged on the system to alert all members of staff to the possible additional needs of the individuals on the register.

The Learning Disability Community Nurse will provide assistance in development of easy read invitations for health checks and generally increase access to easy read health information (see reasonable adjustments)

The Learning Disability Community Nurse will aid the implementation of standardised e-templates for health checks and the production of health action plans.

The Learning Disability Community Nurse will assist the practice in improving the use of reasonable adjustments\* and support and advice around health check appointments to increase the uptake of primary care services by learning disability patients.

\*Reasonable adjustments may include the following;

- offering appointments at the beginning or end of surgery to avoid long waits
- longer duration of appointments
- offering easy read information

In addition the use of emails and text messages etc may not be appropriate. Ensuring that people with a learning disability often have impairments of vision, hearing and mobility. When unwell the client may not behave as they usually do so may require more time and patience to access the service. This may alter their usual behavioural presentation which may require further reasonable adjustments.



The Learning Disability Community Nurse will provide advice and signposting to other allied services where appropriate in support of primary care.

1

- introduction letter
- initial meeting with practice
- pre questionnaire
- goal setting

2

- review the current process including offering and recording health checks and health action plans
- review of current register

3

- run searches using recommended read codes to identify people to include or exclude from the register

4

- arrange an interim meeting to discuss the above and suggest possible changes and reasonable adjustments
- confirm new register and and changes to practice
- Observe and monitor progress

5

- arrange a review meeting to discuss changes and plan for the future
- review of goal setting
- provide a feed back report

2. Protocol for the identification of patients with Intellectual/Learning Disability.

This has been developed in line with the GMS contract 2014/15 guidance for the Enhanced Service-Learning Disability (LD) Health Check Scheme. The ES requires the establishment and maintenance of a practice register of patients with LD, now to include patients between the ages of 14 and 17 years old.



Within each practice area required to invite the patients on this register to an annual health check, using a suitable accredited protocol and produce a health action plan to meet the individual's needs. A modified version of the Cardiff Health Check template has been made available to all practices (alterations have been made to incorporate the requirements of the ES). Practices will currently be at different stages of development of their own registers and due to a number of mostly historical issues, registers may not be as comprehensive as they could be. This protocol sets out a step wise approach to developing a register, ensuring the delivery of care to the correct population, thereby making a start towards closing the inequality in health provision that exists for people with learning disabilities.

Learning Disability is very different from Learning Difficulty and only patients with a Learning Disability are included in this scheme. Learning Disability is defined as; "a significantly reduced ability to understand new or complex information, to learn new skills, with reduced ability to cope independently, starting before adulthood (18 years) with a lasting effect on development. It encompasses a triad of intellectual disability i.e. impaired intelligence, impaired social functioning and impaired communication."

Approximately 2% of the population have LD, 25% of whom will have severe or profound learning disability. An average GP practice will have 40 patients per 2000 of list size, though there will be variation depending on socioeconomic factors within each practice area.

## **2.1 Practice Register Development**

There should be a named Clinical Lead for each practice who will liaise with the Learning Disability Community Nurse and who will ensure the appropriate inclusion of patients to the register and its maintenance. Practices which already have an adult register in place should review it to ensure it is up to date and has the expected number of patients per practice population before moving onto the searches for younger patients for inclusion to the register. The introduction of a register for 14-17 year olds is a new requirement for the ES for this year.

This CQUIN is based on adult services but a section on a suggested approach for 14-17 year olds has been included in order to facilitate this process.



## ADULTS

Initially the register will include patients already known to the practice and through each stage will become more comprehensive by searching in more depth for those not known by other means.

### Stage 1

- Those living in accommodation for adults with Intellectual/learning disability using address or post code searches.
- Search using read codes which give a definite indication of LD
- **E3...** Mental retardation
- **E3z..** Mental retardation NOS
- **Xa0ER** Educationally subnormal
- **XaREt** Mild learning disability
- **XaQZ3** Moderate learning disability
- **XaQZ4** Severe learning disability
- **XE1MZ** Down's syndrome
- **PJyy2** Fragile X syndrome
- **X0058** Rett syndrome
- **X78Ek** Down's syndrome NOS
- **PJ2..** Edwards Syndrome
- **XalwZ** Smith Magenis Syndrome
- **PKyz5** Angelman's syndrome
- **XaKY5** On learning disability register

(It may be noted here that most patients with these syndromes other than Downs and Fragile X die before adulthood.)



## Stage 2

A computer based search for codes which give a possible indication of LD and which need verification by the lead clinician or the patient's own GP.

- **I3Z4E** Learning difficulties
- **PJ70.** Klinefelters syndrome
- **XM1Pu** Congenital cerebral palsy
- **F23z.** Congenital cerebral palsy NOS
- **X00TP** Aspergers syndrome
- **PK5..** Tuberos sclerosis
- **PK61.** Sturge Weber
- **E140z** Infantile Autism
- **Eu84z** Pervasive development dis
- **XaluT** Suspected Autism
- **XE1Mi** Multiple system cong anom NEC
- **E2723** Giles de la Tourette's disorder
- **E273z** Stereotyped repetitive movements NOS
- **Ua14s** Global developmental delay
- **Ub0gW** Special educational needs
- **B927.** Neurofibromatosis type 1
- **F593.** Deaf mutism NEC
- **XE17P** Deafness NOS
- **P1...** Spina Bifida
- **PKy93** Prader Willi syndrome
- **X00Ti** Developmental disorder
- **XaJmc** Referral to learning disability team
- **I3Z3.** Low IQ
- **PKy80** Noonan Syndrome

## Stage 3

Involve the whole practice and brainstorm all members of the team including practice staff, attached staff, speciality nurses, local services, DWP correspondence and anyone else.



## Stage 4

The practice lead clinician should ensure those patients on the register are correctly identified as having a recognised Learning Disability and code them as such. The read code for “on the learning disability register” is XaKY5. Terms such as “appears”, “suggests” or “is indicative of” should be avoided as these do not support a conclusive diagnosis.

PATIENTS AGED 14-17

(Adapted from work kindly shared by Dr Peter Lindsay and his team at Aireborough Family Practice)

## Stage 1

Perform a search for all patients aged between 14 and 17 and 11 months

## Stage 2

From the search above, perform a search using the codes below:

- **E3...** Mental retardation
- **E3z..** Mental retardation NOS
- **6664** Mental handicap problem
- **XaQZ4** Severe learning disability
- **XaQZ3** Moderate learning disability
- **XaREt** Mild learning disability
- **Xa0ER** Educationally subnormal
- **PJ...** Chromosomal abnormality
- **XE1MZ** Down’s syndrome
- **PJyy2** Fragile X syndrome
- **X00058** Rett syndrome
- **X78Ek** Downs syndrome NOS
- **PJ2..** Edwards syndrome
- **XalwZ** Smith Magenis syndrome
- **PKyz5** Angelmans syndrome
- **C301.** Phenylketonuria
- **PK5..** Tuberous sclerosis
- **Eu81z** Dev Dis Scholas Skill Unsp or LD
- **Ub0gV** Child with special educational needs
- **Ub0gW** Special educational needs
- **Ua14s** Global developmental delay
- **E140** Infantile autism
- **X00TP** Asperger syndrome



The lead clinician will review this list and ensure that patients to be included on the register have evidence of intellectual/learning disability. These patients should then be coded as having a learning disability/being on the learning disability register. **The read code for “on the learning disability register” is XaKY5.**

### **Stage 3**

For a truly comprehensive register the records of patients from the initial search of 14-17 and 11 month old patients, excluding those now on the LD register. This information should be manually reviewed looking for any communication from the community paediatrician, CAMHS or educational psychologist. The lead clinician will then review these records and add patients who have evidence of LD to the register.

### **Stage 4**

The remaining patients from the list created in stage 3, not included in the register, should then be circulated to all practice members asking if there are any concerns about behaviour/development or an awareness of possible learning disability. Parents/carers of patients who are identified should be then sent the letter in the resources section of the easy “on the i” get checked out website. Patients will be included in the LD register if there are responses confirming being under the care of the Community Learning Disability Team or for attending an establishment for young people with intellectual/learning disability.

### **ADULTS AND PATIENTS AGED 14-17.**

The register should be maintained and the lead clinician should ensure new patients are added when appropriate and that there is an annual review of the registers. As awareness around this issue increases, it is hoped that community paediatric services, CAMHS and LD services will regularly report to practices, though it will still be necessary to repeat this process annually to keep the register up to date.

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Appendix 1  
**HEALTH CARE OF PATIENTS IN THE TEENAGE YEARS**

Re        NAME        DOB

Dear

As our patients move from childhood to adulthood, we want to continue to offer them the best care we can. In childhood medical care is sometimes given in the school setting and it would be very helpful if you could complete the following short questionnaire and post it back to us in the SAE enclosed.

Which school does        *name*        now attend?

.....  
.....

Which clinics does        *name*        attend regularly?

(cross out the words that are not needed)

None.

These .....

.....  
.....

Other than doctors at the practice, which doctors does        *name*        see regularly? (cross out the words that are not needed)

None.

These .....

.....  
.....

Thank you for your help and for posting this back to us.

Kindest regards,

Yours sincerely,

Dr