



» DIRECTED ENHANCED SERVICE MEETING THE PRIMARY CARE NEEDS OF PEOPLE WITH LEARNING DISABILITIES

TRAINING FOR PRIMARY CARE STAFF 2009 – 2010

Mark Bradley – Health Facilitation Co-ordinator

improving lives

Oxleas **NHS**
NHS Foundation Trust

Welcome

- This training does not purely focus on meeting the requirements of the Directed Enhanced Service.
- We also hope to develop and maintain the relationship between specialist Learning Disability Services, Primary Care, people with learning disabilities and their carers.
- The ultimate aim is to recognise the health needs of our local learning disabled population, accurately record these needs and work together in a systematic way to ensure they are continually met.

improving lives

What today's training will include:

- Understanding of learning disabilities & associated health needs
- Barriers faced by people with learning disabilities
- Identification of people with learning disabilities and clinical coding
- Health action planning and Health Facilitation
- Experiences and Expectations of pwld
- Comprehensive and effective health checks
- Communication and Learning Disability
- Mental Capacity, Disability Duty & the Law
- Collaborative working
- Fun, Coffee & Support!

improving lives

How much do you understand about learning disability?

- We are interested to know how useful this training is. To do this, it's helpful for us to know how much you understand about people with a learning disability before we begin.
- Please allow 5 - 10 minutes to complete the Questionnaire - Form 1 and return to trainer.
- We will also ask some questions at the end of the training as part of our evaluation.

improving lives

Oxleas 
NHS Foundation Trust

What is a Learning Disability?

The Department of Health defines a Learning Disability as including the Presence of:

- A significantly reduced ability to understand new or complex information, or learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development.

improving lives

Causes of Learning Disability

- Prenatal – chromosome, genetics, toxins
- Perinatal – birth complications, infections
- Post natal – infections or trauma
- Remember – it must have started before adulthood

improving lives

Prevalence of Learning Disability

- National Prevalence estimated at 2-3 %
- 210,000 with Severe & profound LD
 - 65,000 children
 - 120,000 adults of working age
 - 25,000 older people
- Mild to moderate 25 per 1,000 population (1.2 million)
- Per GP practice of 2,000 patients – average of 40 pwld

improving lives

World Health Organisation (WHO, 1992) ICD-10

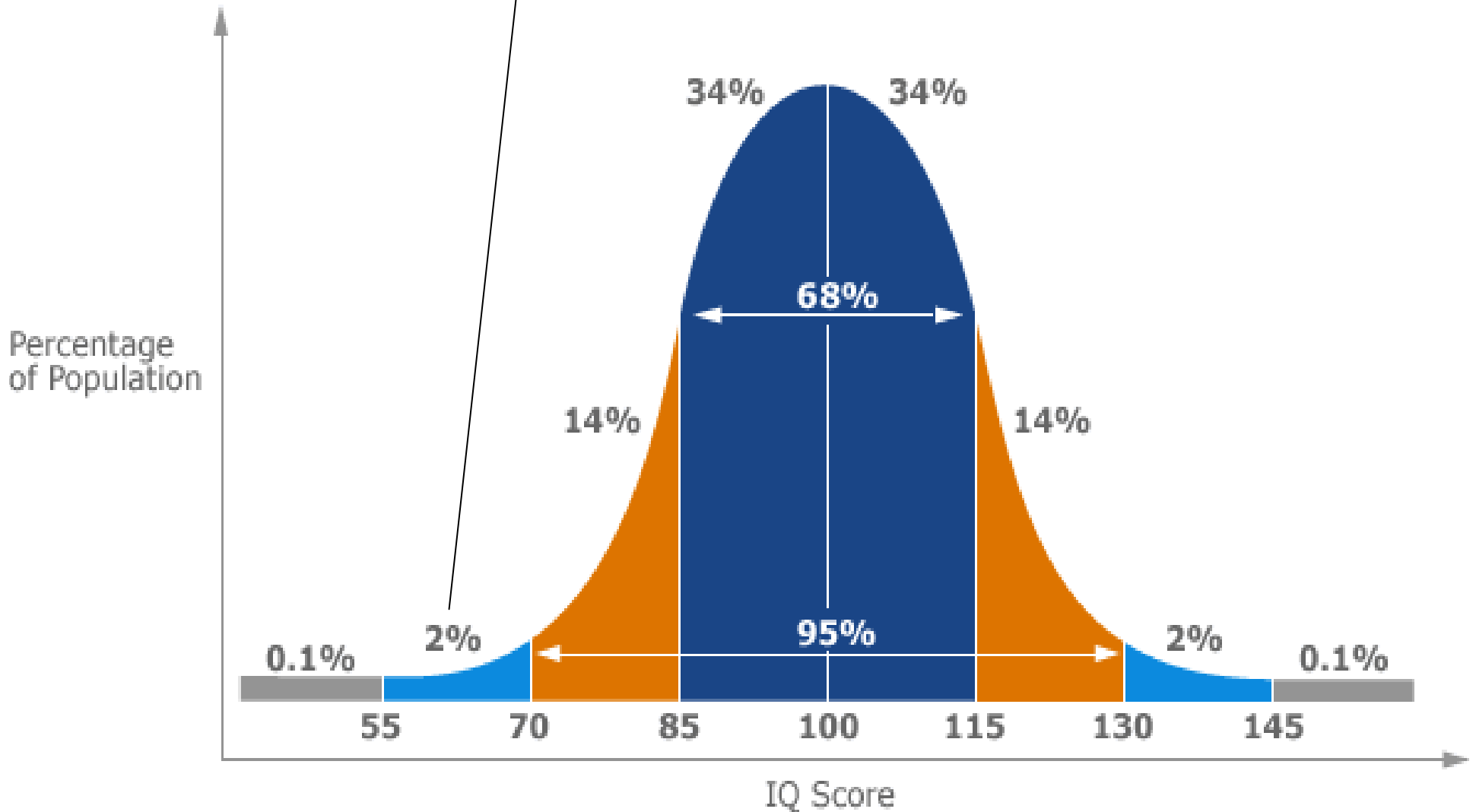
- Mild – IQ between 50 and 70
- Moderate IQ between 35 and 50
- Severe and Profound Learning Disability IQ = below 35

improving lives

Oxleas **NHS**
NHS Foundation Trust

Learning Disabilities
IQ below 70 = 2- 3% of
general population

IQ Score Distribution



Learning Disability described

Mild Learning Disability:

- Able to hold a conversation,
 - Independent in social care,
 - Basic or limited reading and writing skills
 - Able to maintain social relationships and employment.
- For this group, primary care teams will provide much of their health care with little need for intervention from specialist teams

Moderate learning disability:

- Enjoy a level of independence requiring additional support in some aspects of life.

improving lives

Severe or profound Learning Disability

- Very limited or specialised communication skills
- Additional physical and mobility problems.
- Require a greater level of support in most or all aspects of life including identifying health related problems.

improving lives

Oxleas **NHS**
NHS Foundation Trust

What a learning disability is NOT

- Problems with reading, writing or numeracy only.
- Emotional difficulties that may have sufficiently disrupted schooling, influencing achievement.
- Conditions like Attention Deficit Hyperactivity Disorder (A.D.H.D.) or hyperactive disorder.
- Asperger's syndrome and some individuals with Autism.
- However you can have a **learning difficulty as well as a learning disability.**

improving lives

Identifying Learning Disability

- **There is no true or false answer**
 - Someone may wrongly present as having a learning disability.
 - Some conditions or disabilities may affect or mask the diagnosis of a learning disability, these include:

Physical disability e.g. cerebral palsy	Mental Health – this can effect adaptive functioning
Sensory disability e.g. hearing difficulties	Challenging behaviour – e.g. ADHD
Epilepsy e.g. drugs impairing intellectual functioning	Personality disorder

improving lives

HEALTH QUIZ!

People with Learning Disabilities experience a different pattern of ill-health when compared with the general population.

Designing services purely to meet the needs of the general population will fail to meet the needs of people with learning disabilities.

So.... what are these differences?

improving lives

Oxleas **NHS**
NHS Foundation Trust

Learning Disability Health Quiz

Compared to the rest of the population, people with learning disabilities are 58 times more likely to die before the age of:

- 25?
- 50?
- 60?

improving lives

Oxleas 
NHS Foundation Trust

Learning Disability Quiz

15% - 17% of the general population die of respiratory diseases. What is the percentage in people with learning disabilities?

- 23 – 29%
- 31 – 37%
- 46 – 52%

improving lives

Learning Disability Quiz

22% of people with a learning disability have epilepsy – what is the percentage of people with epilepsy in the general population?

- 1%
- 10%
- 17%

improving lives

Learning Disability Quiz

Preventable deaths for people with a learning disability are? times higher than the general population

- 2
- 3
- 4?

improving lives

Learning Disability Quiz

For adults in the general population aged 65 and over, the percentage of people with dementia is 5.7%. What is the percentage for adults aged 65 and over with a learning disability?

- 14.7%
- 21.6%
- 37.5%

improving lives

Oxleas 
NHS Foundation Trust

Learning Disability Quiz

In the general population 77% of women have cervical smear tests, for women with learning disabilities the percentage is

- 7%
- 11%
- 19%

improving lives

How did you do?

The following slides provide more information relating to the **different pattern of ill-health in LD** when compared to the general population

improving lives

Oxleas 
NHS Foundation Trust

26% of people with LD are admitted to general hospitals each year compared to 14% of the general population

These are unacceptable health inequalities



improving lives

Oxleas **NHS**
NHS Foundation Trust

Health Issues in LD

- **Mortality** – People with learning disabilities are 58 times more likely to die before the age of fifty
- **Cancer** – The pattern of cancer is different in LD with lower rates of lung, prostate, and urinary tract cancers, and higher rates of oesophageal, stomach, and gall bladder cancer and leukaemia.
- **Helicobacter Pylori Infection:** endemic in LD population – postulated that high prevalence of this infection leads to a higher prevalence of gastric carcinoma.

improving lives

Health Issues in LD

- **CHD** – 2nd most common cause of death in LD - nearly 50% of people with Down's Syndrome have congenital heart defects.
- **Respiratory Disease** – Most common cause of death – rates 3 times higher than general population at **46 – 52%**.
- **Sensory Impairments** – Common visual impairments and 40% hearing Impaired.
- **Epilepsy** – At **22% of the LD population** it's over 20 times more common than in the general population (=1%)
- **SUDEP** (Sudden Unexplained death in epilepsy) – 5 times more common in LD than in others with epilepsy

Hollins S, Attard M T, von Fraunhofer N, McGuigan S and Sedgwick P (1998): Mortality in people with learning disability: Risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology*, 40:127-132

improving lives

Health Issues in LD

- **Dementia** – rates **4 times greater** and early onset in Down's Syndrome
- **Thyroid Function** – Greater risk of hypothyroidism
- **Mental Health** – Schizophrenia is 3 times more common
- **Osteoporosis** – substantially less bone density
- **Importance of Postural Care!!!**
- **See:** www.posturalcareskills.com

improving lives

Dysphagia

The following slides have been put together by Lesley Brown - Senior Speech and Language Therapist, Bexley Learning Disability Team.

National Patient Safety Agency Report:

“Understanding the patient safety issues for people with learning disabilities” (2004)

“Swallowing difficulties are more common in people with learning disabilities. If not managed safely they can lead to respiratory tract infections, a leading cause of early death”.

- Poor nutrition and hydration
- Carers lack of awareness of the symptoms of aspiration
- Problems of implementing health guidelines in social care settings

PEOPLE WITH LEARNING DISABILITIES

36% of individuals in long-stay hospital had chewing and/or swallowing problems

Hickman J (1997): ALD and Dysphagia: issues and practice. *Speech and Language Therapy in Practice Autumn:8-11*

60% people with Cerebral Palsy have difficulties with chewing and/or swallowing

Del Giudice E, Staiano A, Capano G, Romano A, Florimonte L, Miele E, Ciarla C, Campanozzi A and Crisanti A F (1999): Gastrointestinal manifestations in children with cerebral palsy. *Brain & Development Jul;21(5):307-11*

People with CP show a deterioration in oral motor skills and dysphagia in their early 30's

Sheppard J J (2002): Swallowing and feeding in older people with lifelong disability. *Advances in Speech Language Pathology Sept; 4(2):119-21*

**As many as a
quarter of the
respiratory
disease deaths of
PLD can be
directly linked to
aspiration
pneumonia**

**Community Services Commission (2001): Disability, death and the responsibility of care.
Sydney: New South Wales Community Services Commission**

It's about Safety!

- National Patient Safety Agency Report 2004
- ***“People with learning disabilities are more at risk of things going wrong than the general population, leading to varying degrees of harm being caused while in hospital “.*** (Especially for those with higher support needs)

improving lives

Oxleas 
NHS Foundation Trust

What about our locality?

- The following slides refer to the prevalence of learning disability in our locality



improving lives

Primary Care Trust

- Total Population = ???,000
(PCT's Annual Report 07/08)
- Expected LD population based on national stats (2-3%) = from ?,000 to ?,000 pwld
- Current Qof figures = ?
- Council LD register = ?
- Those in out of borough placements = ?

improving lives

The DES requirements for identifying people with LD

The pre-requisites for taking part in the DES are as follows:

- ‘practices will have liaised with the LA to share and collate information, in order to identify the people on their practice LD register with moderate to severe learning disabilities’

improving lives

Oxleas **NHS**
NHS Foundation Trust

How are we identifying people with LD?

- The Health Facilitation Co-ordinator is supporting practices with their LD registers re: QOF and DES requirements.
- The LD Team is a joint Oxleas and Social Care service and as a result, maintains 2 separate service user information systems (CF21 & RIO)

improving lives

Oxleas **NHS**
NHS Foundation Trust

Comparing Registers

The LDT register data is currently being sorted by GP practice

However, this information is often out of date.

1. Practices will be provided with an initial list for confirmation
2. Practices can then contact the LD Team to confirm whether their patients are 'known to social services' as per DES requirements.

improving lives

What READ CODE to use?

- Those commonly used include E3, Eu7, Eu81z or 918e, but the key requirement is to come to a local agreement across the PCT to meet the existing quality outcomes framework (QOF) indicator and identify the target population – We recommend 918e.
- A full list of LD related read codes can be provided.

improving lives

Some read codes that may help to identify your patients with LD

Conditions

Description	4 byte	5 byte
[X]Rett's syndrome		Eu842
Gilles de la Tourette's disorder		E2723
Stereotyped repetitive movements	E4D3	E273.
Congenital cerebral palsy		F23..
Cerebral palsy, not congenital or infantile, acute		G669.
Deaf mutism, NEC	F684	F593.
Deafness NOS	F68.	F59z.
Spina bifida	N12.	P1...
Down's syndrome	N721	P10..
Down's syndrome NOS		P10z.
Fragile X syndrome	N725	P1yy4
Edward's syndrome	N724	P12..
Edward's syndrome NOS		P12z.

improving lives

Oxleas **NHS**
NHS Foundation Trust

Remember where your patients live!

GPs may be providing health care to people with learning disabilities from different boroughs.

As a result, it is important to be aware that a Local Authority Register will only reflect the LD population in that borough.

It is possible for GPs to have people registered in neighbouring boroughs

Make sure you have considered this in your DES applications

improving lives

COFFEE BREAK 20mins



improving lives

Oxleas **NHS**
NHS Foundation Trust

What local people with Learning Disabilities think...



improving lives

Oxleas **NHS**
NHS Foundation Trust

Insert Advocacy Presentation
20 slides from Respect - Bexley
Slides to come from Bexley & Bromley
Advocacy



improving lives

Oxleas **NHS**
NHS Foundation Trust

Barriers to Health Care

The following was taken from:

<http://www.gptom.com/page26.html>

A list of barriers to primary care was compiled after a multidisciplinary meeting with people with learning disabilities.

improving lives

Oxleas 
NHS Foundation Trust

Barriers to healthcare:

- Having difficulty when ringing the practice with the automated multi-choice systems.
- Having difficulty with touch screen systems for booking in when you get to the surgery.
- If you go with a carer, not being spoken to directly. Doctors or nurses sometimes just talk to the carer.
- Not understanding what medication is for and the reason why it changes.
- Not understanding why you need to be examined. For example, what the nurse or doctor is doing when they take your blood pressure and what it means when it is high or low.

improving lives

Barriers to healthcare:

- Not having copies of letters that are written about you. Also, understanding what is written in letters.
- Doctors and Nurses using medical terms which we do not understand.
- Being referred for tests and not understanding what they are for.
- Not understanding how to get results when tests have been carried out or understanding what the results mean.

improving lives

Barriers to healthcare:

- Assuming what the medical problem is because of past history, instead of taking a full history and carrying out appropriate examinations.
- The doctor or nurse asking the carer what they believe to be the diagnosis rather than taking into account objective evidence from history and examination.
- Lack of facilities for hoisting, therefore thorough examinations difficult.
- Not enough time for appointments.
- Inappropriate doorways in some surgeries.
- No changing room available for personal care.

improving lives

Barriers to healthcare:

- Assuming what the medical problem is because of past history, instead of taking a full history and carrying out appropriate examinations.
- The doctor or nurse asking the carer what they believe

improving lives

Oxleas **NHS**
NHS Foundation Trust

Local GPs views (2001) from the Personal Health Profiles Research on barriers to healthcare :



57 Bexley and Greenwich GPs told us the greatest barriers were:

Communication	47%
Time and resources	44%
Getting a good history	42%

improving lives

Oxleas **NHS**
NHS Foundation Trust

Health Action Planning & Health Facilitation

The following slides explain what we are doing in Bexley, Greenwich or Bromley

In line with the DES requirements and Valuing People Now.



improving lives

Oxleas **NHS**
NHS Foundation Trust

Health Action Planning

A health action plan (HAP) details:

- ‘the actions needed to maintain and improve the health of an individual and any help needed to accomplish these. It is a mechanism to link the range of services and supports they need, if they are to have better health..... The plan is primarily for the person with learning disabilities and is usually co-produced with them.

improving lives

Oxleas 
NHS Foundation Trust

Health Facilitation

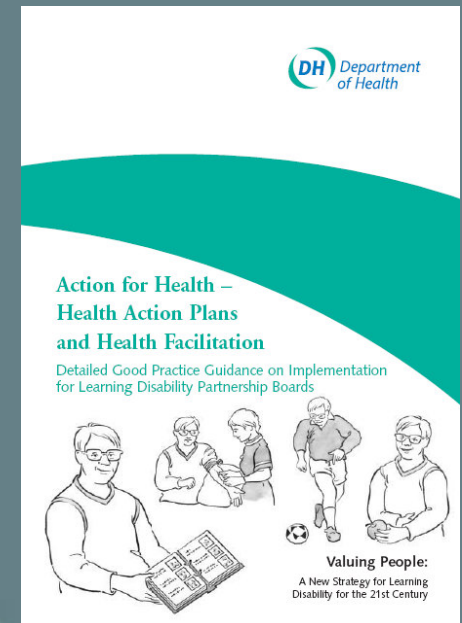
Health Facilitation is described as;
'the process of enabling people to understand health issues and to access mainstream health services'.

(Bernal 2006)

The DH divide this into 2 levels:

Level 1 = Service development work, informing, planning and commissioning

Level 2 = Person to person work with people with learning disabilities



improving lives

Oxleas **NHS**
NHS Foundation Trust

Health Checks and Health Facilitation

- The aim is that Health Checks will be the **1st point of contact** for the Health Action Plan and Personal Health Profile.
- Carers or those offering 1:1 support will be directed to the Health Facilitation Lead for information, support and training relating to the PHPs and Health Action Plans.



improving lives

Health Checks for People with LD - DVD

- We recently commissioned a short film about Annual Health Checks.
- The film is produced by people with learning disabilities with support from a local Day Service.
- It explains the use of Personal Health Profiles and Health Action Plans (This model is in line with DES Requirements) – Enjoy.

improving lives

The Health Check Model

- We have a Vision and Emis based guideline for the annual health check (Isoft Premier available on www.pcc.nhs.uk/204 but yet to be tested).
- An 'accessible' health check invitation and 'pre-health check questionnaire is also available freely.

improving lives

Oxleas 
NHS Foundation Trust

The Health Check - Screen Shot

The screenshot shows a software window titled "Reception (3)" with a menu bar containing "Filtered List", "Patient Details", "Problems", "Journal", "Tests", "Therapy", "Elderly", "Guidelines", "Next Patient", "Prevention", and "Consultations". The main content area is titled "Learning Disabilities Quality Indicators v12.0.01" and includes a note: "NB: Sections marked with an asterisk must be updated to be included for QOF." Below this, a list of indicators is displayed, with the first item, "*Learning Disabilities Register", highlighted in green. Other items include "LD Management", "Co-Morbidity", "Behaviour Change", "Marital Status", "Carer Details", "BP / Pulse", "Alcohol", "Immunisations", "BMI", "Examination", "Dental", "Hearing", "Sight", "Mobility", "Speech", "Contraception", "Cytology", "Mammography", "Health Action Plan", "Smoking Status and Cessation Advice", "Current Smoking Status", "Smoking Exception (expiring)", and "Smoking Cessation Advice".

improving lives

Completing Health Checks

1. Practices confirm eligible patients with moderate to severe LD known to Bexley LDT (& Mild LD with complex needs).
2. Practices contact those patients with LD using the letter provided, attaching the pre-health check questionnaire
3. Patients book an appointment and return with the completed questionnaire.

improving lives

Oxleas 
NHS Foundation Trust

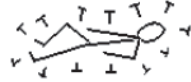
Completing Health Checks

4. Practices will have a supply of Personal Health Profiles and a list of who is entitled to one.
5. Practices complete the health check (observing patient's consent and best interests) using the guideline provided and introduce the patient to the personal health profile. A copy of the DVD will be made available to each practice.

improving lives

Completing Health Checks

6. The Health Action plan pages can be completed after the health check, once health needs have been identified.
7. Any support needed to understand health action planning or personal health profiles can be provided by the health facilitation co-ordinator.

HEALTH ACTION PLAN - Epilepsy 

Person's Name: _____ Date: _____

Action (What is needed?):	Who is responsible? (Who does it?):	Details in P.H.P (Yes/No):	Date for Review (When you come back):

improving lives

Reasons for annual health checks

- Provides an opportunity to ensure health needs are identified and met.
- Provides an opportunity to check & review patients Health Action Plan.
- Provides an opportunity to offer health promotion advice.
- Provides an opportunity to build relationship & desensitise any fears.

improving lives

Oxleas **NHS**
NHS Foundation Trust

COMMUNICATION AND LEARNING DISABILITY

The following slides by: Lesley Brown
Senior Speech and Language Therapist
Bexley Learning Disability Team

improving lives

Oxleas **NHS**
NHS Foundation Trust

Communication

80% of people with learning disabilities will have difficulties communicating.



- ✓ Two way
- ✓ Understanding
- ✓ Expression
- ✓ Variety of methods

*There are always ways of increasing service users' understanding and facilitating their expression -
IT'S UP TO US TO MAKE THE CHANGES*



What slows down or stops communication for people with LD?



Factors relating to the person with LD

Factors relating to the conversational partner

Factors relating the environment

Factors relating to the person with LD

Sensory Problems

Concentration and memory difficulties

Verbal comprehension - limited or literal

Speech - not used or poor intelligibility

Expressive language

Response time

Limited literacy skills

Limited experience of decision making



Other problems along the way

Suggestibility

'Yielding to leading questions' and 'shifting' initial response to negative feedback

Acquiescence

Tendency to say 'yes' whether or not they agree

Automatic 'No' or 'Don't know'

Often indicates lack of understanding

Learned Helplessness

Passivity resulting from perceived lack of control

Factors relating to the conversational partner (i.e. you!)

Lack of familiarity with person and their individual communication methods

Limited experience using specific communication methods

Overestimation of level of comprehension

Using spoken and written language that is too complex

Not allowing sufficient time

Top tips for effective communication



Adapt your language

- Use short, simple sentences of common everyday words – avoid jargon;
- Use the person's own vocabulary;
- Try using open questions or changing the question around to check response.
- Avoid analogies as these may be taken literally.

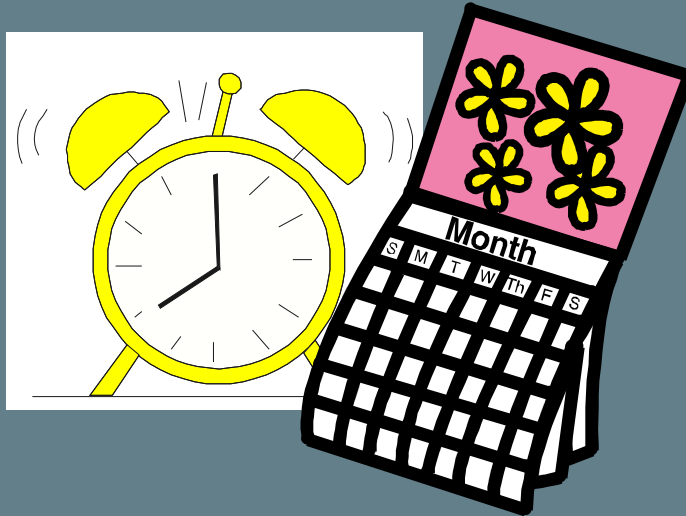
Top tips for effective communication



Be prepared for the person to use alternative methods of communication such as signing, charts or books.

Ask if the person has a **COMMUNICATION PASSPORT**

Top tips for effective communication



Allow time

- During a conversation some people will need lots of time to understand and express themselves - consider double appointments
- For some people you will need to go over ideas on a number of occasions - understanding may be a gradual process.

Top tips for effective communication



**Link time
concepts to
familiar events**

Many people with learning disabilities have little or no understanding of time. You may need to explain things in a different way. For example, instead of "twice a day" use "with breakfast and at bedtime" and use a visual schedule.

Top tips for effective communication



Danger!

Never assume understanding

Many people with learning disabilities will appear as if they have understood and may be able to repeat back what you've said.

Always be cautious and check this out. Ask them to explain it in their own words.


Top tips for effective communication



Do not assume the person will understand the link between an event and their illness.

People with learning disabilities may not make the connection between something that has happened and them feeling ill.

Diagnostic Overshadowing, The Disability Discrimination Act & Consent



improving lives

Oxleas **NHS**
NHS Foundation Trust

Diagnostic Overshadowing

- Described as: The presenting symptoms put down to the 'learning disability', rather than seeking another, potentially treatable cause.
- When a person presents with a new behaviour or existing ones escalate, you should consider:
- Physical problems - pain or discomfort, e.g. from ear infection, toothache, constipation, reflux oesophagitis, deterioration in vision or hearing.
- Psychiatric causes - depression, anxiety, psychosis, dementia.
- Social cause - change in carers, bereavement or abuse.

improving lives

Disability Discrimination Act 1995

- Legal requirement not to treat disabled people less favourably.
- Legal requirement to make reasonable adjustments.
- To bring about equality it can be necessary to treat some people differently.
- Reasonable adjustments are often about practices and procedures rather than physical access, and often cost nothing.

improving lives

Consent

The Mental Capacity Act (2005):

5 Key Principles:

1. Every adult has the right to make their own decisions & must be assumed capable of doing so until proved otherwise
2. Everyone should be given all the support they need to make their own decisions before conclusions are made that they cannot
3. People should be able to make unwise or eccentric decisions - it is capacity to make decisions, that is the issue.
4. Any decisions or anything done for or on behalf of a person who lacks capacity must be made or done in their best interests.
5. Anything done for or on behalf of people without capacity should restrict their rights & freedoms as little as possible

improving lives

Mental Health – Green Light

The Mental Capacity Act (2005):



improving lives

Oxleas **NHS**
NHS Foundation Trust



improving lives

Oxleas **NHS**
NHS Foundation Trust

Collaborative Working

Do you know your local Learning Disability Team?

- Your local LD Team is a joint service with health and social care professionals
- It is a multi-disciplinary team
- You can refer to this team if you have any concerns relating to unmet health or social care issues
- Eligibility Criteria applies as described earlier re: understanding learning disability



improving lives

The Learning Disability Team includes

- Administration & Team Support
- Physiotherapy
- Community Nursing
- Psychiatry
- Occupational Therapy

- Psychology
- Speech & Language Therapy
- Social Work & CLASS
- Person Centred Planning/Life Planning
- Health Facilitation

improving lives

What the Team does:

- Provides health interventions and specialist therapies to support independence.
- Shares expertise including training, advice and practical support to people with learning disabilities, their families, carers and other agencies.



improving lives

Oxleas **NHS**
NHS Foundation Trust

What the Team does:

- Support people with learning disabilities to stay healthy and safe, for example, health promotion.
- Support the communication needs of people with learning disabilities and help other health services to communicate effectively.
- Develop new ways of working with others to deliver better services for people with learning disabilities.

improving lives

What you can do – moving forward:

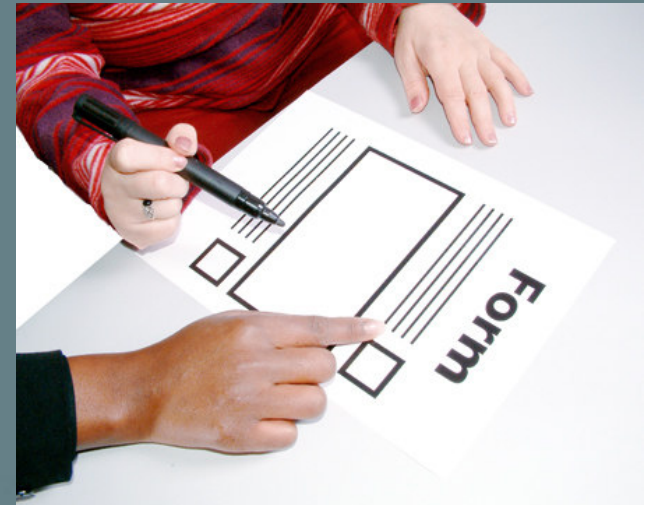
- Have a brief discussion about practical ways to support patients with learning disabilities in primary care.
- What support do you think you'll need?
- What do you think will work well?
- What do you think the difficulties will be?
- Top 10 tips hand out



improving lives

Final Evaluation!

- Your training has now ended.
- Please complete the Post Training Evaluation Form (2)
- Remember your names will only be used to let us know if we've helped you learn more about learning disabilities than you did before attending this training.



improving lives

Thank You

- For further support and information on learning disabilities, read coding and Health Checks, please contact your local Health Facilitation Lead
- Further resource and contact information is available in your training packs

improving lives

Oxleas 
NHS Foundation Trust

Acknowledgements

- To the following people/organisations that have supported the development of this training pack and associated materials:
- Laura Summers - Leicester PCT
- Stephan Bruschi - NHS Westminster
- Natalie Winterton - Brighton & Hove PCT
- Daniel Marsden - East Kent Hospitals Trust
- Dr Tom Howesman
- Cornwall Partnership Trust
- Portsmouth City Teaching PCT
- Health & Social Care Colleagues from Bexley, Bromley and Greenwich
- Respect in Bexley
- Bexley and Bromley Advocacy

Thank you,
Mark Bradley
Health Facilitation Co-ordinator
Oxleas NHS Foundation Trust

improving lives

Oxleas **NHS**
NHS Foundation Trust