Improving Health and Lives
Learning Disabilities Observatory

NHS England

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Reducing premature mortality in people with Learning Disabilities: Effective interventions and reasonable adjustments

Background: Premature mortality and avoidable deaths

There is consistent evidence that people with learning disabilities (LD) in England die much earlier than the rest of the population, and that a large proportion of these deaths are preventable:

- The median age of death for people with learning disabilities is considerably younger than the general population[1-4], e.g. 16 years younger in the recent Confidential Inquiry into premature deaths of people with learning disabilities[1 2].
- People with learning disabilities are much more likely than the general population to experience premature deaths that are avoidable[1 2 5]. The Confidential Inquiry reported that 42% of the deaths of people with learning disabilities were premature and that 48% of deaths were avoidable, either by public health interventions (12%), good quality healthcare (28%) or both (9%)[1 2]. On the basis of these figures, the deaths of at least 1,200 people with learning disabilities per year in England could be avoided by good quality healthcare.
- An Independent Inquiry for the Department of Health has concluded that 'there is evidence of a significant level of avoidable suffering and a high likelihood that there are deaths occurring which could be avoided' in people with learning disabilities[6].

NHS England is firmly committed to reducing health inequalities and delivering year on year improvements in outcomes for people with a learning disability. The NHS Mandate sets a clear expectation that NHS England will deliver improved outcomes for people with a learning disability. Domain 1- Indicator 1.7 specifically relates to reducing premature mortality in adults with learning disabilities and we are held to account for delivery of the mandate indicators.

More generally, the experiences and outcomes from services for potentially vulnerable groups of people in society, such as people with a learning disability can provide an important barometer for quality throughout the NHS. NHS England has therefore made learning disability a corporate priority for 2014/15.

How many people have learning disabilities?

Comprehensive national data on the number of people with learning disabilities across the lifespan in England are unavailable. Latest estimates from Public Health England[7] suggest:

- In England in 2013, there are 1,068,000 people with learning disabilities, including:
    - 224,930 children (identified at School Action Plus or Statemented as having either a primary or secondary Special Educational Need associated with learning disabilities);
    - 900,900 adults, of whom 206,132 (23%) are known to GPs as people with learning disabilities. Adults with learning disabilities not identified as such within health and social care are likely to be adults ineligible for social care support but at high risk of experiencing social determinants of poor health[8].

Effective Interventions and Reasonable Adjustments

Much of the web resource presents evidence for the effectiveness or cost-effectiveness of a range of health interventions for specific health conditions. This section of the web resource for people with learning disabilities is not structured in terms of specific health interventions for people with learning disabilities, for the following reasons:

- People with learning disabilities have been largely excluded from mainstream medical research[9] and the bulk of research focusing on health issues with people with learning disabilities has not been directed to those health problems identified as major causes of death amongst people with learning disabilities[10]. This has resulted in a paucity of evidence concerning the effectiveness of health interventions specifically for people with learning disabilities.
- There is no principled reason to assume that effective health interventions for the general population would not also be effective for people with learning disabilities.
- The Confidential Inquiry reported that the two major factors contributing towards avoidable deaths in people with learning disabilities were diagnoses of health problems being delayed or not made at all, and effective treatments being delayed or not being made at all[1 2].
- Increasing evidence suggests that the inequalities in healthcare experienced by people with learning disabilities could be substantially alleviated by making reasonable adjustments to healthcare practices to ensure that people with learning disabilities can make effective use of existing healthcare programmes and interventions[1 2 5 6 8 11 12].

Under the Equality Act 2010, all public bodies are required to make anticipatory 'reasonable adjustments' to their policies and practices in order to provide fair access and treatment to disabled people, including people with learning disabilities[13]. Joint guidance for CCGs on improving the health and wellbeing of people with learning disabilities from Public Health England, the Royal College of General Practitioners and the Royal College of Psychiatrists was updated in November 2013[14].

This web resource will briefly outline some systemic reasonable adjustments in primary care and acute health services, then outline a small number of priority interventions for health conditions that may be particularly important in reducing premature mortality amongst people with learning disabilities. Our intention is to regularly update this resource as better evidence becomes available.

Systemic reasonable adjustments to primary care and acute health services

Although CCGs do not currently commission primary care services, reasonable adjustments to primary care services are vital[1 2 5 6 13 14] as people with learning disabilities are not accessing GP services to the extent that their health needs require[8], are 70% more likely to be admitted to hospital as an emergency with an ambulatory care sensitive condition[15], and are less likely to access a broad range of screening programmes[8 16 17].

The most far reaching reasonable adjustment to primary care services is annual health checks for people with learning disabilities, supported by a Directed Enhanced Service. Annual health checks for people with learning disabilities are effective at detecting unmet health needs and triggering further health investigations and treatment[18], although coverage is currently running at approximately 50% of eligible people with learning disabilities[19].

There is a growing evidence base concerning the reasonable adjustments required to make acute hospital services effective for people with learning disabilities and the consequences of not making such reasonable adjustments[1 2 6 8 11 12 13 14]. All NHS Foundation Trusts currently self-certify quarterly to Monitor whether they are compliant with six standards concerning reasonable adjustments for people with learning disabilities[20].

The table below lists some commonly recommended systemic reasonable adjustments for people with learning disabilities within primary care services and acute hospitals (and that facilitate linkage between services)[1 2 11 12 13 14 20 21]. Below this table are some examples of good practice in making reasonable adjustments to health services.

Reasonable adjustment	**Primary care**	**Acute care**	**Linking services**
Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems	√	√	√
Patient-held records for all people with learning disabilities with multiple health conditions	√	√	√
Named healthcare coordinator for people with complex or multiple health needs		√	
Accessible information for people with learning disabilities and carers, universally available	√	√	
Accessible processes for people with learning disabilities to make appointments	√	√	
Appointments: longer appointment times and planned appointments at beginning/end of day to reduce waiting time within the health care setting	√	√	
Working in partnership with families and paid carers: providing information, inclusion in decision-making, adjusted visiting hours, facilities for overnight stay	√	√	
Proactive access to learning disability liaison specialist staff (typically nurses) to remove barriers and facilitate access to effective health services	√	√	√
Comprehensive annual health check	√		
Clear health action plan following from annual health check	√	√	√
Risk assessment and associated linked reasonable adjustments action plan for people with learning disabilities entering acute care		√	
Advocacy for people with learning disabilities	√	√	
Annual audits of scale, type and effectiveness of reasonable adjustments	√	√	
Training for all staff to promote effective reasonable adjustments for people with learning disabilities	√	√	

Good practice examples:

Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems

Risk of Admission Patient Alerts (RAPA) - How this flagging system works for people with learning disabilities in Derriford Hospital.

- Plymouth ICT Shared Service has developed an alerting system that automatically notifies community patient (all patients) services via NHS mail when one of their patients is admitted to hospital.
- This software system identifies any attendance at outpatients or emergency department and sends an immediate alert to the CLDT, GP, and Liaison nurse. Information is immediately displayed in the office of the Learning Disability Liaison team.
- Real-time information allows the Learning Disability Liaison team to respond and ensure all people with learning disabilities get appropriate reasonable adjustments and support.
- This also links to other hospital systems, for example waiting lists and outpatient bookings.
- The result is faster and more efficient information sharing between hospital departments and the Learning Disability Liaison team and community staff, which is key to better planning of patient care and shorter hospital stays.

From Confidential Inquiry one year on conference
www.bristol.ac.uk/sps/media/cipold_presentations/workshop1presentation2-saoirse-read.pdf

Patient-held records for all people with learning disabilities with multiple health conditions

The Complex Health Intervention Pack (CHIP) in Sussex

- The Complex health Intervention Pack (CHIP) has been introduced for people on the complex health pathway. The aim was to offer people with learning disabilities and complex needs an information pack that is personal to them, incorporating accessible information that supports carers and primary health care agencies to ensure that their health needs are properly met.
- They wanted to avoid misdiagnosis and over/under treatment in the primary healthcare setting.
- The continued evaluation and review of the CHIP is conducted by a multiagency group with family and carer engagement.
- It has led to improved co-ordination of multi-agency work.
- Each person has a CHIP co-ordinator but individual clinicians have a responsibility to keep guidelines up to date. Currently there are two hard copies for everybody (one at base and one with the person).

From Confidential Inquiry one year on conference
www.bristol.ac.uk/sps/media/cipold_presentations/workshop4presentation2-david-warner.pdf

Named healthcare coordinator for people with complex or multiple health needs and Working in partnership with families and paid carers

Example from the Confidential Inquiry[23]

Susan had profound and multiple learning disabilities and lived in a care home near her family who were closely involved with supporting her. Susan had a number of co-morbidities and had frequent admissions to two hospitals. There was fragmentation of her care, a lack of coordination and information sharing, and her parents submitted formal complaints about her care on two occasions.

After a particularly problematic two years, a new Care Coordinator took over. A Best Interest meeting was convened by the Care Coordinator, which hospital and community health and social

care staff and Susan's parents all attended. The meeting focused on ways to improve Susan's care, shorten any hospital admissions, identify the reasonable adjustments that Susan required to be able to access health services effectively, and to plan for Susan's future care and end of life needs.

Clear decisions were made at the meeting and Susan's family and the professionals involved in her care agreed a way forward. The care coordinator worked with the newly appointed Learning Disability Liaison Nurses at the hospital to arrange the additional funding that Susan required to meet her needs when she was an inpatient, and to alert staff of an impending admission so that any delays in Susan's care could be avoided. Susan's agreed care plan worked well during a subsequent hospital admission.

Accessible processes for people with learning disabilities to make appointments

Choose and Book in Cornwall

- All GP referrals to the Referral Management System in Cornwall for outpatient appointments in hospitals which identify a person as having a learning disability are referred directly to the hospital acute learning disability liaison nurse team.
- This enables the acute liaison nurses to work with the person needing the outpatient appointment, carers, and hospital staff in advance to determine which reasonable adjustments are require to ensure the person can attend their appointment and get the healthcare they need.
- The reasonable adjustments required were highly individual, but included:
- Easy read information and reminders in advance of the appointment
- Arranging appointments (and car parking facilities) to minimise waiting times on the day
- Arranging pre-appointment visits to the hospital to help the person familiarise themselves with the hospital and the staff
- Working with hospital staff to ensure an understanding of the Mental Capacity Act and Best Interest Decision-making

More details are available on the IHaL reasonable adjustments database here www.ihal.org.uk/adjustments/index.php?adjustment=249

Clear health action plan following from annual health check

Example from Coventry and Warwickshire[26]

Coventry and Warwickshire Partnership NHS Trust has developed a resource pack for all their GP practices. The pack is given to GPs at events and is designed to raise awareness of health issues for people with learning disabilities. The nominated learning disability lead in the practice also receives electronic copies of the documents and the folder can be updated as necessary.

The folder contains information on what a learning disability is and a screening tool to help determine if someone has a learning disability. There is advice about read codes (all GP practices in the area now use standardised read codes) and a practice protocol for delivering health checks, including an easy read invitation letter. There is information on the Mental Capacity Act and consent, tips on communication and signs and symbols, information on the associated health needs of people with learning disabilities, epilepsy management plans and other useful information. The folder includes information on referring to the Community Adult Learning Disability Service. All referrals to the team go through a central booking service, making it easier for GPs and others to refer.

The Trust has been encouraging GPs to use the Health Check template developed in the North East of England. All practices in Solihull are using the template, and some GP practices in other areas are beginning to pilot the template. The template enables better local data collection, and produces a health action check list following the health check.

The document can be accessed at:
www.covwarkpt.nhs.uk/professionals/Documents/Learning%20Disabilities%20Resource%20Pack%20for%20General%20Practice.pdf

Advocacy for people with learning disabilities

Confidential Inquiry case study[1]

Stanley had a number of health conditions, and had progressive frailty and significant weight loss. Eating had become an ordeal and it was exhausting him. An IMCA was appointed to be involved in the decision making process regarding an investigatory procedure to investigate his weight loss, and the insertion of gastrostomy tube through which he could be fed. The IMCA convened a series of Best Interest meetings, communicated and liaised with Stanley's primary and secondary care agencies and ensured that all the relevant information was being considered in clinical decisions.

It was agreed that it would be in Stanley's best interests to insert a gastrostomy tube for feeding him, although one consultant felt that the procedure would be futile and would not consider authorising it. The IMCA was confident to challenge this, and Stanley was referred to another consultant who was, despite the risks that it involved, fully supportive of the procedure. Following the procedure the IMCA convened a further Best Interest meeting regarding its replacement. The gastrostomy significantly contributed to Stanley having a further 12 months of better quality life.

Annual audits of scale, type and effectiveness of reasonable adjustments

The Gloucestershire Reasonable Adjustment Tool

The Gloucestershire Reasonable Adjustment tool provides a way of monitoring reasonable adjustments in order to facilitate improved access to all types of mainstream service for people with learning disabilities. The tool can be utilised in a range of settings and provides a simple record of the work carried out by learning disability workers to facilitate access to mainstream services along with a record of the outcome. The tool is applicable to approaches based around an individual or to approaches based on influencing wider systems.

More details are available on the IHaL reasonable adjustments database
www.ihal.org.uk/adjustments/index.php?adjustment=133

Training for all staff to promote effective reasonable adjustments for people with learning disabilities

Confidential Inquiry case study[1]

Kathleen had inoperable cancer and was dying. The staff at her residential care home made every effort to allow to Kathleen live out her life in what had become her home. They were prepared to acquire equipment and take on new skills to allow this to happen. The palliative care consultant provided a teaching session for the care home staff to explain about the process of dying of cancer, pain control, syringe drivers, and other aspects of terminal care. Kathleen was successfully cared for at home by the care home staff with support from the Macmillan service and her GP, with good symptom control.

Priority interventions for major causes of premature mortality in people with learning disabilities

The Confidential Inquiry and other evidence[1 2 3 4] is consistent in reporting some major causes of avoidable premature mortality in people with learning disabilities that are amenable to the application of effective healthcare interventions. Priorities for CCGs to pay particular attention in terms of priority health conditions are in the table below, with recommendations for interventions.

Examples of good practice for each of these priority health conditions are provided in the table below. References alongside each health intervention in the table contain more detailed guidance and examples of good practice for each intervention – further examples of reasonable adjustments are also available in an online searchable database here www.ihal.org.uk/adjustments/

Priority health condition	**Intervention**
Respiratory disease	1) Annual influenza and pneumonia vaccinations for all people with learning disabilities[1 2 14] 2) Proactive and assertive treatment of gastro-oesophageal reflux[14] 3) Expert postural care support[14] 4) Reducing dysphagia through expert swallowing assessments, clear clinical pathways for gastrostomy insertion, and regular review[14 22]
Cancer	1) Proactive support for people with learning disabilities to access cancer screening[23]
Epilepsy	1) Reasonable adjustments to ensure that epilepsy diagnosis, treatment and seizure control management for people with learning disabilities conforms to NICE guidelines[14 24]
Heart and circulatory disorders	1) Reasonable adjustments to ensure access to effective weight management and exercise programmes by people with learning disabilities[14] 2) Effective diabetes management[14 25]

Good practice examples: Respiratory disease

Confidential Inquiry case study[1]

Sarah had input from the speech and language therapist to help her with communication and her feeding regimen and swallowing. Drinking became more difficult in the last 2-3 years. She was reassessed, prescribed thickeners for her drinks and supplied with a special cup to drink from. Sarah had eating and drinking guidelines drawn up by the dietician, speech and language therapist and Sarah's family. A film was made to demonstrate the guidelines, which was transferred onto DVD for training those who may be required to feed Sarah. A poster was also made to highlight the guidelines. In addition, Sarah had an 'All about me' document to share important information about her care with her carers.

Sarah continued to receive regular support from the dietician and her weight was monitored. She had a target weight of between 6 and 7 stone which she maintained fairly well. Her weight started to fall during her last year and it was taking longer and longer to feed her so the dietician advised dietary supplements to increase her calorie intake – these were then prescribed by her GP. The

dietician also discussed with Sarah's mother possibility of a gastrostomy and what this might entail for Sarah.

Postural Care in Wakefield

The Postural Care Service in Wakefield has developed over 10 years, and includes the following components:

- Strong support from commissioners, with an emphasis on prevention and early intervention
- Measuring clinics for all children at risk of developing body asymmetry
- Physiotherapists responsible for hip surveillance (e.g. ordering X-rays) and regular audits
- Wheelchair clinics to ensure individually designed, maximally effective wheelchairs for postural care from a very early age
- An integrated paediatric equipment budget
- Strong relationships between the postural care team and special education services
- An orthopaedic consultant who holds regular joint clinics with the postural care team in a variety of locations convenient for family members (e.g. special schools)
- Extensive training for families in providing postural care to their family members
- A postural care team lead within each overnight short break service to ensure continuity of postural care while the person is in the short break service
- A multidisciplinary postural care interest group meeting regularly

Good practice examples: Cancer

Example of Breast awareness sessions – Knowsley[23]

In Knowsley, the Learning Disability Nurse Health Facilitator worked in partnership with Breast Cancer Care UK and Knowsley Being Involved Advocacy Group to develop and deliver accessible/easy to understand breast awareness sessions for women with disabilities and their carers. The sessions include a woman with learning disabilities sharing her experiences of screening and peer group discussion. A variety of resources are used as part of the session including photographs, a power point presentation, easy read/picture leaflets and parts of a video 'Your guide to breast screening.' The video is in a format suitable for people with disabilities and was developed by Merseyside and Cheshire Cancer Network funded by Knowsley PCT Public Health Team and neighbouring PCT's. The video is available from: http://www.mccn.nhs.uk/index.php/videos

Feedback from sessions to date: After attending a session a woman disclosed to her support worker that she had some symptoms that she had seen in the session (discharge from her nipple). The support worker went with the woman to see her GP, who referred her to the breast clinic. She had a mammogram and was diagnosed with a benign tumour which she is going to have removed. A GP reported that a patient told him that she had recently attended a breast cancer awareness session and she is now 'breast aware'. She explained to him what she needs to do and her mum confirmed she has observed her examining her breasts in front of the mirror in her bedroom. A parent reported that her daughter who is not of age yet for breast screening informed her she attended the session and is now 'breast aware' examining her breasts, and asked to attend her mum's breast screening

appointment. She did this and at the session asked the radiographer lots of questions. She enjoyed the experience of seeing what the mobile unit looked like.

Example of reasonable adjustments regarding cervical screening from Devon[23]

The primary care liaison nurse in Mid-Devon worked with a sample group of 21 women who were known to social services, and who had not attended a cervical screening appointment for five years or more. She visited all the women to talk to them about why they had not attended. Ten were clear that they did not want a smear, one had had a total hysterectomy, and some did not have the capacity to consent and so required a best interest decision. However five women decided to have a smear test, and were supported to have one by the nurse.

The project demonstrated that a letter alone is not enough. The women would have continued to ignore the letters without support, encouragement and guidance. The nurse used a range of aids to help the women understand about cervical screening including the 'keeping healthy down below' guide, and the equipment used when taking a smear. Checking what sort of sanitary protection women use can be helpful, as women generally find it easier to have a smear test if they use tampons rather than towels. It is helpful to operate the speculum so that women get used to the noise it makes, and get women to assume the position they will be in when they have the smear taken, as this can make women feel vulnerable, and it is better to rehearse this prior to the appointment. Visiting the GP surgery and meeting the nurse before the appointment itself can also be helpful.

Good practice example: Epilepsy

Matthew's book

This project, commissioned by the Humber NHS Trust, is centred around Mr Matthew Prosser. Matthew has profound and complex needs. Matthew's parents, Tony and Tricia, planned the project together with Ken Pugh who has been really important in developing and collating the material.

Together with key professionals, they prepared a multi-media, interactive, iPad-based guide to Matthew and his care needs. The book includes Matthew's epilepsy management plan and three short videos that show some seizure activity to illustrate when further intervention is required.

The book will follow him wherever he goes, including hospital, to ensure that all staff working with him can quickly find out about the essential aspects of his care and what good practice means for him.

The photographs, videos and audio interviews, together with relevant text have been collated using Apple's iBooks Author software. The book, if necessary, could be shared with another person or a service that has an iPad or an Apple computer. There is no limit to how many books like this may be held on an iPad so, conceivably, a hospital ward could have an iPad with books about the needs of many people with complex needs or communication difficulties.

To view screenshots of Matthew's book, please visit
http://designforcare.wordpress.com/projects/matthews-book-2/

Good practice example: Heart and circulatory disorders

In Nottingham City and the Broxtowe, Rushcliffe and Gedling areas of Nottinghamshire County, there is a four week educational training programme called Juggle, for people with type 2 diabetes who don't take insulin. Juggle is a structured diabetes education programme that meets the requirements set down by NICE and the Department of Health for the education of adults with diabetes. The curriculum has been adapted to meet the needs of people with a learning disability, and the service runs programmes specifically for people with learning disabilities and their carers. A health facilitator supports the programme by meeting the participants before the programme, attending the sessions and following up any issues that are highlighted with individuals.[25]

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