

commissioning brief healthy living

Health inequalities and
people with learning
disabilities in Gloucestershire

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1. What is the issue?

Despite the publication in 2001 of the White Paper 'Valuing People', progress has remained disappointing in terms of access to good quality healthcare, with persisting health inequalities for people with learning disabilities (PWLD).

Definition of learning disability

Learning disability (LD) includes the presence of:

- a significantly reduced ability to understand new or complex information, to 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

DH 2001. *Valuing People*



Key health inequality issues

PWLD (adults and children) are 58 times more likely than the rest of the population to die before the age of 50¹, with the main cause of death being respiratory disease, followed by coronary heart disease which is increasing. Life expectancy is shortest for those with the greatest support needs² and the most complex and/or multiple conditions.

Factors contributing to these higher mortality rates include:

- non-identification and non-investigation of physical health problems.
- more vulnerability to certain illnesses and conditions than the general population (e.g. physical disabilities, epilepsy, mental illness, sensory impairment, behavioural disorders, obesity) in addition to experiencing the same range of health concerns as the general public.
- significant association of cerebral palsy, incontinence, mobility problems, and residence in hospital with PWLD dying at a younger age.
- poorer access to needed healthcare.
- difficulty in identifying and describing symptoms of illness.

PWLD also experience geographical access issues as a result of:

- poverty – a significant number are dependent on benefits.
- limited choice of transport.
- dependence on others to attend clinics.

In January 2009, following consultations in late 2008, a new strategy was published 'Valuing People Now'³ which takes forward the vision of 'Valuing People'. This strategy which has better health for PWLD as a key priority highlights the central issues for the NHS:

- achieving full inclusion of people with learning disabilities in its mainstream work on reducing health inequalities
- ensuring high-quality evidence-based specialist health services.



1 Valuing People Support Team (2005). *The story so far....Valuing People A New Strategy for Learning Disability for the 21st Century*

2 Bittles, A.H. et al. *The influence of intellectual disability on life expectancy. Journal of Gerontology Series A. Biological and Medical Sciences.* 2002; 57(7):470-472

3 HM Government (2009). *Valuing People Now: a new three-year strategy for people with learning disabilities. 'Making it happen for everyone'.*

4 Department of Health (2001). *Valuing People. A New Strategy for Learning Disability for the 21st Century.*

What else do we know about people with learning disabilities in general?

- There is no precise information on the number of PWLD in the general population.
- Mild/moderate learning disability is linked with poverty, with higher rates in deprived and urban areas⁴.
- Prevalence has an ethnic dimension: it is three times higher in South Asians⁵, with a possible high prevalence in the African Caribbean community.
- Morbidity and mortality is higher in PWLD from a minority ethnic group⁶.
- LD registers are likely to contain information on people with more severe learning disabilities.
- PWLD whose behaviour presents a challenge to services are an extremely diverse group, which includes individuals with all levels of learning disability, and many different sensory or physical impairments, who present different kinds of challenges. Such challenging behaviour is a common reason for 'out-of-area placements'. These take people away from their families and communities.
- People placed out of area may actually experience worse services^{7, 8}, but these may be expensive services.
- The demographic profile of adults with learning disabilities is expected to change in coming years due to the ageing demographic profile of the population in general, the effects of reduced mortality in PWLD, as well as the increase in prevalence of children with disabilities who will mature into adulthood.

5 Azmi S, Emerson, E. Caine, A. Hatton, C. (1996). *Improving Services for Asians with Learning Disabilities and their Families*. Manchester: Hester Adrian Research Centre/Mental health Foundation.

6 Mig, G, Nocon, A. Ahmad, W. Jones, L. (2004) *Learning Difficulties and Ethnicity*. Report to the Department of Health.

7 Beadle-Brown, J.; Mansell, J. Whelton, B.; Hutchinson, A.; Skidmore, C. People with learning disabilities in 'out-of-area' residential placements: 2. Reasons for and effects of placement. *Journal of Intellectual Disability Research* 2006; 50(II): 845-856

8 Cambridge, P.; Beadle-Brown, J.; Milne, A.; Mansell, J.; Whelton, B.; Exploring the incidence, risk factors, nature and monitoring of adult protection alerts. Canterbury: Tizard Centre, 2006.

What do we know about People with Learning Disabilities in Gloucestershire?

Although there is a lot more we should know about PWLD in Gloucestershire, we do know the following:

- There are currently 1,951 people aged 15 years and over on the county's Service Users Register; 59 to 103 of whom are placed out of county⁹. This 'captures' PWLD who access adult social services.
- 2,207 people aged 18 years and over are on GP registers¹⁰. These registers 'capture' PWLD who access GP services, and may include PWLD who are from outside the county but in residential institutions in Gloucestershire.
- 0.28% of service users on the county's register are from South Asian backgrounds compared with 1.2% South Asian within our population.
- 'White Other' is the commonest minority ethnic group represented on the county's register, followed by 'Black Caribbean'.
- 2gether NHS Foundation Trust currently has a total of 1,560 clients from Gloucestershire on their caseload. Of these, 72% with ethnicity recorded are White British clients with 0.2% from South Asian backgrounds.
- The three registers (County, GP and 2gether) overlap in terms of coverage of PWLD, but are not by themselves complete.

By applying national prevalence rates to our population figures, we also know the following:

- an estimated 11,975 people have learning disabilities; of them, 10,777 are aged 15 years and over¹¹.
- an estimated 2,696 people should be known to services; 2,311 aged 15 years and over.
- between 1,748 and 2,330 people may have severe learning disabilities.
- About 347 people aged 15 years and over can be expected to have behaviour that challenges services.

9 A review of the register is currently underway and figures may change.

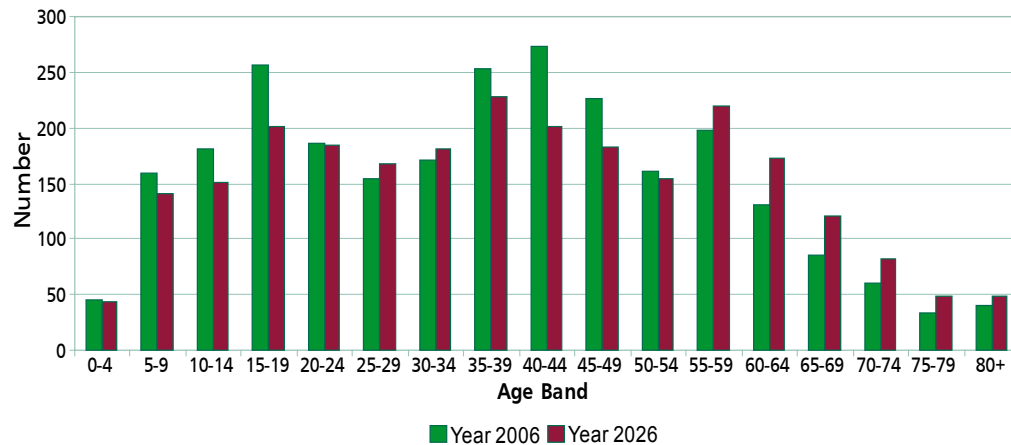
10 Derived from Quality and Outcomes Framework (QoF) data for 2006-07.

11 Applying estimates from Emerson and Hatton's 'Estimating the current need/demand for supports for people with learning disabilities in England, 2004' to the mid-2007 resident population estimates for Gloucestershire.

- an increase of about 50% can be expected in the number of PWLD aged 65 years and over that would be known to services by 2026. More PWLD will be needing social care.



Figure 1: Changes expected in numbers of people with learning disabilities known to services in Gloucestershire 2006 to 2026¹²



Access to primary care for people with learning disabilities

Primary care represents the single point of access to not only health promotion and the prevention of ill health, but also to most healthcare and treatment. Yet PWLD find it much harder to access assessments and treatment for general health problems that have nothing directly to do with their disability. They also receive lower levels of health promotion and preventive care. This is exacerbated by a striking lack of awareness in primary care of the health needs of PWLD¹³.

¹² Applying estimates from Emerson and Hatton's 'Estimating current need/demand for supports for people with learning disabilities in England, 2004' to the Gloucestershire trend based population estimates.

¹³ Michael, J. (2008) *Healthcare for all. Report of the independent inquiry into access to healthcare for people with learning disabilities.*

A GP practice with a list of 2,000 can expect to have around six patients with severe, and around 44 with mild/moderate learning disabilities, though these rates may vary between different practices¹⁴. In Gloucestershire, the Quality and Outcomes Framework (QoF) Registers¹⁵ show that the proportion of different practice populations recorded as having a learning disability varies from 0% to 4.3%. For these registers to be a useful tool in meeting the health needs of PWLD, they should not only identify everyone registered with the practice who has a learning disability, but should also be able to define their levels of learning disability, as well as associated co-morbidities and support needs. This would enable the identification of what 'reasonable adjustments' need to be put in place, as well as the appropriate targeting of support needs e.g. for those with mobility problems, incontinence and cerebral palsy who are at higher risk of premature death.

There is evidence to show that regular health checks in primary care for PWLD do identify unknown and unmet needs¹⁶. The recent special services for PWLD (Directed Enhanced Services for Learning Disabilities)¹⁷ negotiated nationally, to be provided by GPs, provide an opportunity to address these needs.

'Unmet needs' may include previously unrecognised, or poorly managed, medical conditions such as hypertension, obesity, heart disease, abdominal pain, respiratory disease, cancer, gastrointestinal disorder, diabetes, chronic urinary tract infection, oral disease, osteoporosis, thyroid disease and visual and hearing impairments¹⁸. Some of these shortcomings may be as a result of 'diagnostic overshadowing' – a tendency to attribute symptoms and behaviour associated with illness to the learning disability, and for the illness to be overlooked.

¹⁴ Michael, J. (2008) *Healthcare for all. Report of the independent inquiry into access to healthcare for people with learning disabilities.*

¹⁵ QoF is a voluntary annual reward and incentive programme for all GP surgeries in England, detailing practice achievement results. It is not about performance management but resourcing and then rewarding good practice.

¹⁶ Alborz, A.; Kalmouka, A.; McNally, R.; Parkinson, G. (2006). *Literature Review on the Effectiveness of Interventions to Improve Physical Health of People with Learning Disabilities.* London: Disability Rights Commission.

¹⁷ NHS Employers, British Medical Association (2008). *Clinical directed enhanced services (DES) guidance for GMS contract 2008/09. Delivering investment in general care.*

Even when health needs are recognised, there is evidence to suggest that PWLD may receive less effective treatment for them¹⁹. This highlights the need to ensure that PWLD do receive appropriate and standard investigations and treatment.

What do PWLD think?

Focus groups by All Wales People First to support the inquiry 'Equal treatment: Closing the gap' provide some valuable insight into the views of PWLD about accessing primary care services.

- They would like a simple straightforward way to make appointments.
- They appreciate practice systems that make it clear to clients when to go in to see the doctor.
- They appreciate doctors being able to do home visits.
- They would like staff to be polite, helpful, know what they are doing, smile and be welcoming, know them by name and say hello with their name.
- Clear communication was valued – enough explanations in simple language, with greater use of non-verbal and non reading-based means of communication to aid understanding.
- They expressed concerns about privacy.

They generally had relevant information about healthy lifestyles, but would like more structured support to help them do this especially in terms of maintaining a healthier diet and exercise.

Hospital admissions

There is evidence nationally to suggest that PWLD have a higher number of hospital admissions – 26% versus 14% for general population – and a greater average length of stay.

In Gloucestershire, admissions of PWLD²⁰ to Gloucestershire Hospitals NHS Foundation Trust (GHNHSFT) were 103 in 2005/06, 203 in 2006/07 and 229 in 2007/08 (using 'First Finished Consultant Episodes' [FFCEs] as a

¹⁸ Disability Rights Commission (2006). *Equal Treatment: Closing the Gap. Background evidence for the DRC's formal investigation into health inequalities experienced by people with learning disabilities or mental health problems.*

¹⁹ Michael, J. (2008). *Healthcare for all. Report of the independent inquiry into access to healthcare for people with learning disabilities. 20 ICD10 codes F7* were used in all 14 diagnostic positions to enable identification of any diagnosis of Learning Disability.*

proxy). Over a third of the admissions in 2007/8 were to general medicine (especially for epilepsy) and almost a fifth were for oral surgery, mainly for dental caries.

The average length of stay (LOS) for general medicine was 1.5 days, while the average LOS for oral surgery was zero days (day cases). Admissions for epilepsy, pneumonia and pleural effusions had relatively longer lengths of stay compared to other diagnoses. Given the relatively high number of admissions and very short LOS for dental related problems, there is a need to review the availability of appropriate oral health promotion services to PWLD, especially to those living in family homes who tend to have higher rates of untreated dental decay. We also need to ensure this is a central part of the health check. The management of epilepsy and respiratory problems at primary care level may also need to be enhanced.

All the admissions of PWLD to 2gether NHS Foundation Trust (2FT) in 2007/08 were attributable to the treatment category of 'Learning Disabilities', with an average LOS of 202 days. There were no admissions of PWLD in the 'Adult Mental Health' category, while the highest LOS (569 days) was for the treatment of 'Specific Personality Disorders'.

Table 1: Average length of stay in 2gether NHSFT using Last Finished Consultant Episodes by primary diagnosis

Primary diagnosis	Average LOS (Days)
Mild mental retardation	135
Moderate mental retardation	211
Pervasive developmental disorders	101
Severe mental retardation	332
Specific personality disorders	569
Turner's syndrome	16

Source: Gloucestershire PCT Secondary Users Service (SUS) Commissioning Dataset

Further exploration of these lengths of stay will be necessary to enable better understanding of the appropriateness of these admissions in PWLD.

Admission into hospital can be a painful and devastating experience for PWLD as documented in *Death by Indifference*²¹ and the Health Facilitation Team²² has documented similar cases in Gloucestershire in the past. Vulnerability in hospital is one of five patient safety priorities identified for PWLD by the National Patient Safety Agency.

²¹ Mencap *Death by indifference. Following up the Treat me right! Report*

The issues with this are:

- it is harder for PWLD to ask for help if in pain, feeling ill etc.
- staff may not be appropriately trained and may overlook health concerns
- additional health concerns (e.g. epilepsy) are not recognised by hospital staff
- learning disability staff and carers are often expected to provide full nursing care
- issues of consent are more complex.

Care coordination, such as organising referrals, maintaining and communicating medical record information and assisting and supporting patients to access healthcare services appropriately, have been found to reduce length of stay in hospital, re-admission rates and hospital charges. An 'acute liaison nurse' role may provide such coordination. The impact of such a role should, however, be monitored in order to add to the evidence base on its effectiveness.

The limited training and education of clinical staff in primary care and hospital services about learning disabilities contribute significantly to the failure to deliver 'equal' treatment to PWLD, as well as treat them with respect and dignity. Fulfilling the requirements of the Disability Discrimination Act 2005 through making 'reasonable adjustments' that include addressing the communication needs of PWLD and enabling an enhanced awareness and identification of their health needs by health professionals, would help improve access.

22 Based in 2gether NHS FT, the Team work with PWLD, carers, support staff, health professionals and organisations to advocate and facilitate access to primary and secondary health services for P'WLD.

2 What are we doing about it now?

The Learning Disability Health Facilitation Team continue to make concerted efforts to support Gloucestershire GPs in ensuring that practice registers for PWLD are in place and up to date, mainly by sharing with GPs information on PWLD that are known to them.

NHS Gloucestershire and the Learning Disability Strategic Unit of 2FT have been collaborating on the implementation of the recently published Directed Enhanced Service (DES) for Learning Disabilities²³, which focuses on annual health checks. An SLA which provides details of this is to be agreed with GP practices in this regard.

One of the health targets in *Valuing People* was for all PWLD to have a Health Action Plan (HAP) by June 2005, but this was not fully met. The use of HAPs can support annual health checks and the subsequent delivery of effective care and treatment, especially at transition points or at points when needs change. The Health Facilitation Team has recently updated the HAP packs, and these have been sent to all community learning disability teams and inpatient units in the county, in order to ensure that PWLD have a HAP. All GP practices have also received a HAP DVD.

The Health Facilitation Team has made concerted efforts to address vulnerability in hospital with initiatives which include the following:

- Gloucestershire's hospital assessment book, which is based on a traffic light system and has been recognised nationally as a very useful tool in meeting the needs of PWLD when hospitalised.
- easy read leaflets (*Going to Hospital*) and photographic patient journey booklets.
- a 'link nurse' system where a nurse from each ward/department acts as a champion for learning disabilities. A total of 41 link nurses have been trained across Gloucestershire Royal Hospital (16), Cheltenham General Hospital (24) and Delancey Hospital (1).
- micro-teach sessions on wards and in departments to raise awareness of learning disability.
- development of pictorial menus.

The team has also worked with Public Health, GP practices and the Breast Screening Unit to improve access to breast and cervical screening for women with learning disabilities.



23 British Medical Association, NHS Employers (2008). *Clinical directed enhanced services (DES) guidance for GMS contract 2008/09.*

3 What do we need to do next?

Providing PWLD in Gloucestershire with full and equal access to quality healthcare would require the following:

- improvement in data collection (including ethnicity data) and sharing to enable better identification and monitoring of healthcare needs and treatment. Aligning data held by social services with those held by specialist LD services and GP practices to build a county-wide comprehensive register that documents the level of learning disability, as well as associated co-morbidities and individual support needs.
- training of primary care and hospital staff on the health needs of PWLD and issues of consent.
- enhancement of primary healthcare services for PWLD with consideration of the use of the Primary Care Service Framework in commissioning services.
- engagement of primary care in health action planning and health facilitation as part of person-centred planning.
- appropriate investment in well developed community-based services for people whose behaviour presents a challenge.
- improvement in, and better management of continuity and coordination of care at transitions between primary and secondary healthcare, as well as between adults' and older people's services especially for those with the greatest support needs e.g. people with cerebral palsy, incontinence, mobility problems. The consideration of an acute liaison nurse will support this.
- investment in enhancing the capacity of the Health Facilitation Team to enable them to function more effectively
- reviewing the appropriateness of admissions and lengths of stay in 2gether NHS Foundation Trust.
- ensuring that all healthcare staff understand the law relating to disability equality for PWLD, especially through training and provision of support.
- provision of optimal opportunities for oral health promotion, screening, physical activity and healthy eating for PWLD.

4 Next steps

This briefing will be shared with the Gloucestershire Supporting People Board, the Learning Disabilities Partnership Board and the Joint Commissioning Group to act on the findings and recommendations.

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