



## Primary Care Contracting

### Primary Care Service Framework: Management of Health for People with Learning Disabilities in Primary Care

- This 'enhanced service' framework should be read in conjunction with the **supportive statements for commissioning** on the Primary Care Contracting website – [www.pcc.nhs.uk](http://www.pcc.nhs.uk) – and the **additional supportive notes** at the end of this document. A **complementary suite of practical 'health check' resources** is also available on this website to help commissioners, providers and other stakeholders with contextual planning and local service design and development. These additional implementation tools or pointers have been developed in conjunction with the Valuing People Support Team and the Foundation for People with Learning Disabilities and with the help of those currently commissioning or providing primary care services.
- The document itself can be adapted and used as a basis for an enhanced service via a primary care contract or Service Level Agreement. This will hopefully avoid duplication of effort and speed up the commissioning process. It would be appropriate to adapt or include local information in the relevant sections. Legal advice or support for local contractual arrangements may need to be considered.
- NHS Primary Care Contracting kindly requests feedback from PCTs or Practice Based Commissioners following implementation of this Framework via the brief feedback questionnaire on their website – [www.pcc.nhs.uk](http://www.pcc.nhs.uk). This will assist in its on-going development and sharing of good practice across the NHS.
- The Department of Health and NHS Primary Care Contracting would like to thank all those individuals, departments and organisations who have contributed to the development of this Primary Care Service Framework as well as Steering Group members. Thanks also go to Dr Jeff Anderson of Primary Care Unlimited – [www.primarycareunlimited.com](http://www.primarycareunlimited.com) – for coordinating the development of each Framework.

## Primary Care Service Framework: Management of Health for People with Learning Disabilities in Primary Care

- 1. Purpose of this Primary Care Service Framework**

The purpose of this Primary Care Service Framework is

  - to equip commissioners, providers and practitioners with the necessary background knowledge, service and implementation details to safely commission and deliver a high quality, integrated service for the management of health for people with learning disabilities in primary care.
  - as a means of improving health and quality of life for people with learning disabilities by providing patient-centred, systematic and integrated support.
  
- 2. Period of Service**

This service will run for a period of twelve months from [INSERT DATE] (with extensions subject to satisfactory annual review).
  
- 3. Scope and Definition of service**

The service is open to male and female adult patients aged 16 and over so as to include those in the transition period. It is directed at those with a diagnosis of **mild, moderate or severe learning disabilities**. It can be provided either at individual practice level, or on a locality or PCT basis.

It is open to all types of providers with an interest in primary, acute and tertiary learning disability services for example, GP practices, Community Pharmacists, community and specialist nurse-led services, voluntary and third sector, Local Authority and other education support services, the independent sector or other alternative providers. This will depend on the ability of the provider to ensure the appropriate health services are delivered by appropriately qualified practitioners. This Framework may achieve more success through an integrated and community based model, making best use of joint commissioning approaches and networks of provision.

The service is about primary care and access to mainstream health services for people with learning disabilities. It currently does not include, but may also be relevant to, those individuals with other needs but who do not have a learning disability. For example, those with diagnosed autistic spectrum disorders or Asperger syndrome.

This primary care service should not be confused with (and sits outside of) essential and additional GMS or PMS services already provided, current Quality and Outcomes (QOF) indicators.
  
- 4. Parties to the agreement**

*Insert names of any accountable individuals and organisation details.*
  
- 5. Background**

There are an estimated 210,000 people with severe learning disabilities in England, with 1.2 million people with mild to moderate learning disabilities (Department of Health, Valuing People, 2001). This means that for every 1000 patients there will be about 4 patients with severe learning disabilities and about 20 with mild to

moderate learning disabilities. These figures also correspond with the latest QOF prevalence data for 2006-07.

People with learning disabilities typically do not seek out health care and a system of organised health checks is therefore required. Also many people with learning disabilities have difficulty in accessing health care and are less likely to access routine screening such as cervical screening, mammography (Healthcare Commission, 2005) or screening for bowel cancer. Additionally, people with learning disabilities experience 'diagnostic overshadowing': that is, reports of physical ill health being viewed as part of their learning disability and so not investigated or treated. This could mean that levels of ill health are even higher than data suggests.

People with learning disabilities have greater health needs than the general population. They are more likely to experience mental illness and more prone to chronic health problems such as epilepsy, cerebral palsy and other physical disabilities. People with learning disabilities are also at higher risk of premature death. They are 58 times more likely to die before the age of 50 than the general population and 4 times more likely to have a preventable cause of death (Hollins et al. 1998). People with learning disabilities are more likely to have a vision impairment compared to the general population and around 40% are reported to have a hearing impairment (Carvill, 2001). There are also increased numbers of people with learning disabilities surviving into old age and increased numbers of children surviving into adulthood with complex health needs.

In 2001, the *Valuing People: A new strategy for learning disabilities for the 21<sup>st</sup> Century* White Paper published by the Department of Health ([www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)) emphasised the requirement to introduce Health Action Plans for all people with learning disabilities and the *Choosing Health: Making healthier choice easier* White Paper (DH, 2004) stated the target to introduce health checks for disabled people to help address the wider intentions to reduce health inequalities and improve ill health. The Quality and Outcomes Framework in general practice also has indicators relating to the development of a learning disability patient register.

The *Our Health, Our Care, Our Say: A new direction for community services* White Paper in 2006 reaffirmed the Department of Health's commitment to introduce regular comprehensive health checks for people with learning disabilities and placed a stronger emphasis on health and well-being, prevention of ill health and early intervention as well as providing more care at home, or as close as possible to home, and outside formal hospital settings. The PEARL study (2002) carried out by the Welsh Centre for Learning Disabilities investigated the impact and effectiveness of providing personalised health checks for people with learning disabilities. The study found that health checks result in previously unrecognised health needs being identified earlier for people with a learning disability and on-going audits are required to sustain any health improvements.

There are important national targets to achieve in this area which include the Public Service Agreement

(PSA) target to improve health outcomes for people with long term conditions by offering a personalised care plan for vulnerable people most at risk – [www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Longtermconditions/index.htm](http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Longtermconditions/index.htm). Similarly, there is a national inequalities target to reduce the life expectancy gap by 10% by 2010 between people in the fifth deprived (Spearhead) areas and the average for England. Furthermore, the Operating Framework priorities for 2007-08 underpin how local organisations will work to deliver the commitments in their Local Delivery Plans this year, including better overall financial health. Included in these is the priority to reduce health inequalities and promote health and well-being, providing the impetus and incentive for local organisations in partnership with the NHS, such as local authorities, to work together to deliver these benefits to the local population.

The Public Sector Disability Equality Duty (DED) which came into effect from December 2006 and the Disability Discrimination Act (2005) places a legal duty on public bodies to promote equality of opportunities for disabled people. Equal access to services is also a priority within Standards for Better Health (Healthcare Commission, 2006).

In 2007, the Disability Rights Commission (DRC) report ‘Equal Treatment: Closing the Gap’ – [www.drc.org.uk/library/health\\_investigation.aspx](http://www.drc.org.uk/library/health_investigation.aspx) - identified a number of recommendations for the NHS to address the health inequalities experienced by people with learning disabilities. The Department of Health produced a response to the DRC recommendations in ‘Promoting Equality’ which reinforces what the NHS is currently doing to promote equality of services for people with learning disabilities and also what the Department of Health expects of NHS and other statutory organisations in relation to this issue in the future.

Both the National Patient Safety Agency and the Mencap ‘Treat Me Right’ Campaign (2004) highlighted concerns about the identification of people with learning disabilities and their safety and treatment within the health care system. Furthermore, the Mencap report ‘Death by Indifference’ suggested that information transfer and communication with GP practices was a significant factor in improving primary care services for people with learning disabilities.

## **6. Summary of Local Need**

*Commissioners should outline or reinforce a summary of local health and social care or service need drawn from a Joint Strategic Needs Assessment, done with Local Authority partners. Suggested options to include here can be found in the additional notes below.*

## **7. Service Objectives and Intended Health Outcomes**

Joint working between service providers is critical to achieving the following list of service objectives and intended health outcomes for the local population:

- To improve equality of access for all people with learning disabilities (including those in transitional stage) providing better coordinated access to primary medical, community and specialist services, including palliative care.

- To provide regular, comprehensive and individualised health checks for people with learning disabilities and provide appropriate treatment and follow up in an appropriate environment
- To provide individualised health action plans which help people with learning disabilities become more involved in taking care of themselves and which also involves their family carers or supporters enabling them to take better care of their needs
- To promote better health outcomes, and better involvement in health care, for people with learning disabilities by improving access to health promotion and improvement programmes such as national health screening, physical activity, weight management, and smoking cessation
- To reduce the need for hospitalisation or length of stay in hospital by providing better and more coordinated care for people with learning disabilities across different sectors
- To improve the support for, information sharing and understanding of the needs of people with learning disabilities and their family carers.

## 8. Service Outline

Note - The following service specification should be individualised to take account of the appropriate level of learning disability and not make assumptions about an individual's capabilities or level of need.

Providers should consider all or the majority of the following:

1. Develop, and share with other key stakeholders, a local strategy for delivering the service, including gaining input from service users and family carers or supporters into the content of the strategy. This strategy should be developed in association with local Learning Disability Partnership Boards.
2. Nominate a lead clinician in general practice who may be supported by a health facilitator or other primary care professional.
3. Building on the patient registers held at practice level and other databases held by PCTs or Local Authorities, develop a systematic process for recalling patients with frequency according to individual's needs. This should be communicated to family carers and support workers.
4. Provide routine, comprehensive and individualised health checks and follow up for people with learning disabilities, on an annual basis as a minimum, including specifically for people in their 18<sup>th</sup> year. These checks should be delivered by and through GPs and Practice Nurses. More frequent checks may be necessary at transition stages or as indicated by specific guidance or NSFs depending on the individual's medical condition or need. Additional advice and support for the delivery health checks should be sought from local community learning disability teams.
5. Work with individual patients, family carers and supporters to develop a patient-held individualised care management plan (Health Action Plan) for each registered patient identified as having a learning

disability. This should include information, advice and support to family carers and supporters to facilitate access to more coordinated services and improving and maintaining health.

***More information on the steps to delivery of health checks can be found in the additional supportive notes below and a suite of practical materials is available to download alongside this document at [www.primarycarecontracting.nhs.uk/204.php](http://www.primarycarecontracting.nhs.uk/204.php)***

6. Promote and ensure access to regular health screening where appropriate and according to national guidelines.
7. Following any timely and appropriate referral to other community service providers (such as specialist learning disability teams, mental health teams, local authority support, the voluntary sector and other primary care services – for example, podiatry, optometry, dentistry), work to develop effective partnerships across agencies to promote good health, treat any cause of ill health and prevent further deterioration. Improving communication links across services may also include reasonable adjustments to referral protocols such as including flags to indicate a person has a learning disability.
8. Provide pro-active health educational support and training to other individuals or agencies linked with the care of people with learning disabilities (for example family carers, volunteers, or other unqualified support) to help improve knowledge and understanding of the individual's health needs and access to the full range of appropriate services.
9. Refer patients and their family carers to local or national peer support groups, for example the Expert Patient Programme for patient with learning disabilities [www.expertpatients.nhs.uk](http://www.expertpatients.nhs.uk) or self-advocacy organisations with details obtained through the local authority.

## **9. Support for Self Care**

Providers should be in a position to identify those individuals who would benefit from additional support for self care and enable these individuals to access the four main areas of self care - Skills and Education; Information; Tools and Devices; Self Care support networks. Additional detail around support for self care can be found in a parallel Primary Care Service Framework which can be found at [www.pcc.nhs.uk/204.php](http://www.pcc.nhs.uk/204.php) and [www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Longtermconditions/DH\\_4128529](http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Longtermconditions/DH_4128529) on the Department of Health website.

## **10. Location of Service**

*Commissioners will need to re-assure themselves that any service is provided from premises that are fit for purpose in a modern way and address issues of service user needs and uptake, particularly in communities with poor health outcomes. Details should be included here.*

## **11. Integrated Governance**

Any commissioned service must meet all national standards of service quality and clinical governance including those set out in Standards for Better Health (updated April 2006 [www.dh.gov.uk](http://www.dh.gov.uk)). These core and

developmental standards of provision are designed to cover the full spectrum of health care as defined in the Health and Social Care (Community Health and Standards) Act 2003. The seven domains are safety, clinical and cost effectiveness, governance, patient focus, accessible and responsive care, the care environment and public health. Compliance with relevant NICE guidance such as for the diagnosis and management of epilepsies in adults and children in primary and secondary care ([www.nice.org.uk](http://www.nice.org.uk)) is also required.

Clinical Governance arrangements must be proportionate to the service provided and comply with any local expectations or requirements of the commissioner.

**Professional competency, education and training** – All healthcare professions delivering the service will be required to demonstrate their professional eligibility, competence, and continuing professional development in order to remain up-to-date and deliver an effective service which is culturally appropriate. Staff appraisal on an annual basis and at an appropriate level will also be required. Commissioners will need to be reassured that practitioners have the required competencies at an appropriate level.

Commissioners should be satisfied that providers of services for people with learning disabilities have a planned, regular programme of education, training and support for their staff, extended team and community networks in matters related to their programme(s).

Training and educational opportunities should be available within the local health and social care community and may even be user-led. These are often delivered or facilitated by local specialist learning disability teams and may be overseen by the Learning Disability Partnership Board - the local statutory learning disability network led by the Local Authority. Training providers would be advised to have links to this Board as a quality assurance mechanism. Other opportunities may be available from the following:

- Regulatory bodies such as the BMA or NMC – [www.bma.org.uk](http://www.bma.org.uk) or [www.nmc-uk.org](http://www.nmc-uk.org)
- AMSPAR – Association of Medical Secretaries, Practice Managers, Administrators and Receptionists – [www.amspar.co.uk](http://www.amspar.co.uk)
- Skills for Health – [www.skillsforhealth.org.uk](http://www.skillsforhealth.org.uk)
- Skills for Care – [www.skillsforcareanddevelopment.org.uk](http://www.skillsforcareanddevelopment.org.uk)
- BILD – British Institute of Learning Disabilities – [www.bild.org.uk](http://www.bild.org.uk)
- Valuing People Support Team – [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk)

Additionally, guidance for frontline staff in promoting access to healthcare for people with a learning disability is available (from Scotland) in 'Getting it Right Together' - [www.nhshealthquality.org/nhsqis/2959.140.680.html](http://www.nhshealthquality.org/nhsqis/2959.140.680.html)

Providers should ensure safe staffing capacity at all times and staff should be able to demonstrate that they have participated in organisational mandatory and update training, for example infection control, manual

handling, risk assessment as required.

**Patient, public and staff safety** – Providers will be required to demonstrate that evidence based clinical guidelines are being used. Providers should have in place appropriate health and safety and risk management systems and that premises are safe and young person friendly. They should also ensure that any risk assessments and significant events are both documented and audited regularly and outcomes of these implemented. Services should comply with national requirements for recording, reporting, investigation and implementation of learning from incidents. Further details can be found on the National Patient Safety Agency website [www.npsa.nhs.uk](http://www.npsa.nhs.uk) with their 2004 report ‘ Understanding the Patient Safety Issues for People with Learning Disabilities’ available at [www.npsa.nhs.uk/press/display?contentId=2793](http://www.npsa.nhs.uk/press/display?contentId=2793) Furthermore, under the Disability Discrimination Act (1995), reasonable adjustments should be made to the care environment and process to ensure people with learning disabilities are accommodated safely and appropriately in the course of their care or treatment. For example, introducing longer appointment times, reminding patients of appointments they may have, or providing assistance in or around primary care premises.

**Clinical audit and review** – Providers will be required to demonstrate their coordination of and involvement in regular inter-professional and inter-agency meetings and regular clinical audit of the service interventions and outcomes such as drug therapies or well-being and behaviour changes.

**Information management** – Any communications strategy or provision should be coherent with and follow local policies and the Department of Health Code of Confidentiality, local child and adult protection procedures, and should outline the mechanisms to safeguard patient information when shared within an integrated service. Furthermore, accurate clinical coding is vitally important to capture enough information about a person with learning disabilities to ensure better planning and monitoring of health inequalities.

People with learning disabilities often find it difficult to communicate and therefore there may be difficulties in gaining patient consent for both treatment and for sharing of any personalised data. The principles and legal requirements outlined in the Mental Capacity Act (2005) should therefore apply to ensure people with learning disabilities are not otherwise denied care or treatment. These include i) a starting assumption that people have capacity to consent ii) putting in place a range of techniques to listen and obtain consent iii) that incapacity to consent only applies to specific situations and occasions and cannot be a general judgement iv) listening to family carers and supporters in obtaining a ‘best interests’ judgement. More information can be found at [www.dca.org.uk/legal-policy/mental-capacity](http://www.dca.org.uk/legal-policy/mental-capacity)

**Patient and public involvement** – Providers will be required to demonstrate active engagement with patients and local communities in commissioning and developing services, self care plans or in supporting patients to utilise self care opportunities. Providers should demonstrate how systematic patient feedback is being used to shape and improve services. Involving family carers and supporters will help deliver the components within this service specification, especially for people with more severe learning disabilities.

Local Involvement Networks (LINks), the voluntary sector and patient advocacy organisations, and the Care Services Improvement Partnership (CSIP) 'Having a Voice' programme - [www.neyh.csip.org.uk/silo/files/brochure.doc](http://www.neyh.csip.org.uk/silo/files/brochure.doc) - are all further mechanisms to seek active involvement in service planning, delivery and monitoring.

**Equality and human rights** - Delivering good quality care will require organisations to demonstrate competence in identifying and taking action on inequality and also needing to engage with communities that have not found accessing public services easy. Undertaking Equality Impact Assessments (EQIAs) is a specific legal obligation, and conducting EQIAs and using the evidence to create a meaningful dialogue with communities (especially seldom heard from groups) is central to effective commissioning and service provision. This will create an evidence-based approach. As a minimum, core standard C7e of *Standards for Better Health* stipulates "healthcare organisations should enable all members of the population to access services equally and offer choice in access to services and treatment equitably". To assist this process, organisations may wish to refer to 'Creating a Disability Equality Scheme: a Practical Guide for the NHS' - [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4139666](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4139666). As supplementary guide on the Disability Equality Duty focusing on people with learning disabilities will shortly be published by the Department of Health.

**Managing complaints** – Responsive protocols and procedures should be in place for managing patient complaints. These should be available in 'easy read' format so they are accessible to people with limited communication skills. Complaints should be reviewed at regular intervals and learning from these shared and applied as appropriate to ensure that services are continually improved.

**Continuous quality improvement** – a set of indicators should be selected or developed and then agreed which defines the key quality requirements of the service. The service should also identify how it uses these measures and others to ensure that the quality of the service is continuously improved.

## 12. Information management/requirements

Information needs may be different depending on the scale of service provision at PCT-wide, locality or individual practice level. The following describe a selection of key quality requirements and measurable indicators which will be used to demonstrate service effectiveness and provider performance.

Providers should consider the following:

- The number and percentage of patients recorded as diagnosed with a mild or moderate learning disability as a proportion of the practice(s) population in the last 12 months

Of this, the number and percentage of patients in each category:

- Who have been offered a comprehensive health check in the last 12 months

- Who are in their 18<sup>th</sup> year and have been offered a comprehensive health check in the last 12 months
- Who have been helped to develop an individual health action plan in consultation with the user
- Who have had a medication review
- Who have improved their health and well being by
  - improvements in co-morbidities such as Epilepsy or Mental Health
  - improvements in chronic diseases such as for Coronary Artery Disease, Diabetes, Hypertension, Cancer
  - improvements in lifestyle behaviours such as smoking, alcohol consumption, diet, and physical activity
  - improved quality of life
- Who have been offered a longer than average appointment time which is convenient to the patient
- Whose family carers have made separate contact with the primary health care team
- Whose family carers have been diagnosed with depression or other mental health condition and whose condition has improved in the last 12 months
- Improved rates of uptake to routine health screening services
- Number of people with learning disabilities who have been admitted to specialist learning disability or mental health facilities.

Further information to demonstrate the value of the service, or for planning purposes, may also be required by commissioners such as:

- The publication 'Better Metrics' in 2006, supported by the Office of the Strategic Health Authorities, provides a description and rationale for a range of clinically relevant service equality measures to set alongside managerial targets in the NHS. These measures will support this Primary Care Service Framework –  
[www.healthcarecommission.org.uk/db/documents/Learning\\_disabilities\\_metrics\\_master11Dec06.pdf](http://www.healthcarecommission.org.uk/db/documents/Learning_disabilities_metrics_master11Dec06.pdf)  
 These metrics show what data sources are currently available, currently possible to collect, or currently unavailable.
- Access to comprehensive databases held by Local Authorities, such as carer assessments, to identify changing health need, recognising future needs, and changes in demographics within this population. Data may inform planning and utilisation of future primary care resources.

- Review of the learning disability strategy and modifications/developments following patient feedback and action points for the next years plan.
- Demonstrate how the multi-professional team works by demonstrating shared goals in treatment, shared patient health records and evaluation of the activities of the team within the learning disability integrated service.
- Clinical audit of the learning disability service and patient outcomes, demonstrating follow up of results.
- Providers should also be aware of the Department of Health policy around handling and disclosing patient information. 'Confidentiality – NHS Code of Practice' can be found at [www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf](http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf). There is also a specific confidentiality code of practice for GMS, PMS and APMS providers at [www.dh.gov.uk/assetRoot/04/10/73/04/04107304.pdf](http://www.dh.gov.uk/assetRoot/04/10/73/04/04107304.pdf).
- A local basket of indicators also exists for health inequalities and can be found at the London Health Observatory [www.lho.org.uk](http://www.lho.org.uk)

It is also essential that providers **revisit** the indicators measured and are able to **repeatedly** provide comparable data over time to demonstrate that health outcomes and service quality have been improved within the timeframes agreed.

### 13. Service Monitoring and Evaluation

Service providers will need to demonstrate the effectiveness of the service to commissioners possibly at regular times during the year and, at the least, on an annual basis. This will need to be provided to the commissioners in an annual report, which will inform any annual review process or meeting. The process by which this evaluation is achieved can also be used to show the outcomes of the service to other key stakeholders such as patients and family carers. Service evaluation should cover, as a minimum, the following areas:

**Service Activity** – Volume of work against any agreed activity levels and distance from profile, capacity, needs and demand analyses, workforce arrangements, real time referral data to other care pathways or appropriate agencies

**Clinical Outcomes** – Regular analysis and interpretation of clinical outcomes data as well as regular analysis and interpretation of PPA data for prescribing.

**Quality and Governance** – Quality criteria will need to be established (in agreement with commissioners) and measured with standards needing to be met on a continual basis. Results of clinical audits will be used to inform service provision during the year. EQIA data should be used to underpin local integrated service provision.

**Patient Experience** – Patients views on their experiences and satisfaction levels will need to be measured

through an on-going, systematic process to test whether the service is engaging with patients, family carers and supporters in a way that supports them. Different approaches to obtaining these views and experiences will be necessary because traditional survey techniques tend to exclude people with learning disabilities because they are less likely to be in contact with mainstream services and are unlikely to be able to engage with traditional survey techniques for reasons of literacy, comprehension and communication. These processes should also be stratified where possible to show any differential impact on disadvantaged groups (e.g. Black and Minority Ethnic groups, deprived groups, males, females etc) and any resultant service changes (planned or achieved) should be highlighted.

Separate analysis and interpretation of national and local patient satisfaction surveys for those people with learning disabilities may also be necessary. Additionally, demonstration of effective engagement with people with learning disabilities and the voluntary sector will be essential, for example adaptation of health information into 'easy read' formats. The Care Services Improvement Partnership (CSIP) programme 'Having a Voice' is a useful resource to support local engagement with services users.

**Value for Money** – Cost effectiveness or 'best value' analyses of the primary service outcomes in relation to comparative costs of hospital activity or those services providing equivalent quality of care. Such measures could include attendance rates, waiting times, length of stay. Other possible analyses include: - Prescribing costs; benefits of increase in social capital and active citizenship; Staff and non-staff costs of running the service; Capital costs etc.

Many people with learning disabilities do not currently work and many receive support from statutory services, so there is less emphasis on 'time off work' and more on value for money of independent living in terms of cost savings to other statutory services and investing to save on preventative measures.

#### 14. Funding

There will be no fixed or nationally agreed price for this service. Commissioners and providers may wish to access alternative funding mechanisms, such as local programme budgeting along the whole patient pathway, and should agree funding which is reflective of the level of service to be delivered locally and could include:

- Basic funding for achieving minimum requirements within the service specification
- Additional funding or financial incentive for delivering specific local patient outcomes
- Indication of national benchmark prices if available

#### 15. Contract Management

*The name and contact point of the contract manager of both the commissioner and provider should be given here. Any specific local arrangements for contract management should also be stated.*

**16. Review, variation and re-commissioning process**

A number of important contractual design and management issues will be followed throughout the period of the contract. In particular:

- Formal review of the service will be on-going and will inform the end of year service review process which will be used to determine if service is to be extended or de-commissioned.
- Any in-year contract variations will be discussed and agreed by both parties and will be included as additions to this Primary Care Service Framework.
- Following the review the commissioner will decide whether the service has been effective, including whether it is addressing the needs of disadvantaged groups with high needs. If not, the commissioner will discuss with the provider any formal escalation or recovery plan with realistic timeframes for delivery.
- Appropriate notice periods and termination procedures will be agreed by both parties.

Both parties may wish to seek legal advice before agreeing any formal contractual arrangements resulting from this Primary Care Service Framework.

**17. Signatories**

*Signatures from all parties as those accountable for the agreement*

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## Additional supportive notes to assist the implementation of the Primary Care Service Framework: Management of Health for People with Learning Disabilities in Primary Care

### *Commissioning 'business case' and Value for Money*

- PCTs are accountable locally to the population whose health services they commission. It is therefore the responsibility of the PCT to reflect all members of their local population when commissioning services, and to monitor trends in health, healthcare quality and access, and to respond appropriately. It is likely PCTs will need to collect data locally to meet this responsibility, as well as auditing service utilisation and responding robustly where problems are identified.
- Despite the limited information available about user satisfaction and improved health outcomes, NHS and social services expenditure on services for adults with learning disabilities stands at around £3 billion (Valuing People, 2001) and has doubled over the last ten years. This does not include expenditure on mainstream health care received by people with learning disabilities. The recent report 'Getting to grips with the money' - [www.socialcare.csip.org.uk/index.cfm?pid=80](http://www.socialcare.csip.org.uk/index.cfm?pid=80), highlights the problem of significant cost pressures for the NHS and Councils in the future. This is mainly due to the increasing complexity of need, and rising demand for high quality services as a result of local and national demographic changes. A more detailed report is available at [www.adss.org.uk/publications/guidance/learning.pdf](http://www.adss.org.uk/publications/guidance/learning.pdf)
- Commissioning budget pressures for learning disability services exist for a number of reasons including expensive, long term contractual commitments with residential, nursing and day care services as well as high unit costs such as residential care beds. There may be further pressures locally on individual agencies if social service budgets are used to commission specific health services for people with learning disabilities, particularly those individuals moving from childhood into adulthood. Well-commissioned mainstream primary care services will ease the pressure on more specialised services further along the pathway.
- Through implementation of this Primary Care Service Framework, commissioners may experience a decrease in overall prescribing costs due to less inappropriate repeat prescriptions and an increase in medication compliance. Giving correct information about medication and checking understanding are key elements of the health check process.
- In the wider context of commissioning services for people with learning disabilities, there are areas where local services are not adequate or appropriate for some individuals in dealing with their seriously complex needs. As a result, there is evidence of some very high cost individual 'out of area' placements to consider within the overall budget and single person services may need to be commissioned. Where local specialist services can be developed to meet these needs, there may well be opportunities for significant savings to be made, as well as satisfying the general principle of care closer to home. However, the issues of shared risk or economies of scale opportunities across localities or PCTs should also be considered.
- Local specialist commissioning resources may be enhanced with the possibility of tightening eligibility criteria, benchmarking costs for residential care across a number of providers, or transferring in-house services to the private or voluntary sector. Furthermore, there is growing evidence that the use of individual budgets has not added to costs yet has improved satisfaction among service users. The 'In Control' project has more detailed evidence on this issue – [www.in-control.org.uk](http://www.in-control.org.uk)
- A commissioning note on some of the major issues has been developed by the Foundation for people with Learning Disabilities – [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk). It suggests the need for a recognised 'strategic health facilitator' whose role it would be to work proactively with local services and ensure access for people with learning disabilities to mainstream services is equitable. See 'Skill mix and partnership opportunities' section below.

- Commissioners should also be aware of the wider savings which would be realised through support for self care as described in a complementary Primary Care Service Framework. This can be found on the NHS Primary Care Contracting website [www.primarycarecontracting.nhs.uk/204.php](http://www.primarycarecontracting.nhs.uk/204.php)

#### *Practice Based Commissioning (PBC) sign off*

- Currently, the commissioning of and support to services for people with learning disabilities is not seen as a universal priority under Practice Based Commissioning. As the implementation of PBC develops, it will be vital to raise awareness of the issues and give specific attention to ensuring that access to mainstream services are properly considered.
- PCTs and Practice Based Commissioners should be aware that business case proposals for the provision of this Primary Care Service will need to meet the full requirements of any local service delivery plan and authorisation process. This may well be at PCT Board level or any delegated panel. For proposals that pertain to the provision of services for a wider population, consideration as to further engagement and sign off with the SHA may be necessary.
- The Commissioning Framework (Department of Health, July 2006) highlights how commissioners should follow EU best practice principles when considering competitive procurement of local services. This does not necessarily mean open tendering processes should be adopted in every case. The Department of Health would not normally expect tendering where practices currently under GMS/PMS contracts could provide services as a means of extending patient choice.
- The Commissioning Framework for Health and Well Being consultation document (Department of Health, March 2007) emphasises the key role practice based commissioners play in more effective commissioning by shifting to more personalised services, promoting health as well as preventing the causes of ill health and working with key partners to achieve improved health outcomes overall. For more information visit [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_072604](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_072604)
- PBC resources can also be obtained from the Department of Health [www.dh.gov.uk](http://www.dh.gov.uk) and NHS Primary Care Contracting [www.pcc.nhs.uk](http://www.pcc.nhs.uk). PBC guidance can be found at [www.dh.gov.uk/assetRoot/04/14/15/64/04141564.pdf](http://www.dh.gov.uk/assetRoot/04/14/15/64/04141564.pdf)

#### *Contracting for the service*

- This service should be considered as a 'locally enhanced service'. As such, the full range of providers and primary care contracting flexibilities should be considered, including GMS, PMS, PCTMS, APMS, and community and voluntary organisations. Once an appropriate provider has been selected, the appropriate contracting route should be adopted. Additionally, providers may wish to sub-contract part or all of the service provision. This should be made clear throughout the contract implementation process.
- NHS Primary Care Contracting has developed a simple guide for potential providers of services such as this Primary Care Service [www.pcc.nhs.uk/3.php](http://www.pcc.nhs.uk/3.php)

#### *Incentivising provision*

- The Commissioning Framework in July 2006 [www.dh.gov.uk/assetRoot/04/13/72/30/04137230.pdf](http://www.dh.gov.uk/assetRoot/04/13/72/30/04137230.pdf) emphasised the options open to commissioners to support new local providers of services by offering additional quality incentives or use of local primary care premises or

pump-priming loans. However, the Kings Fund has described some of the considerations when developing local incentives. For instance, introducing new providers into the local health economy may improve service quality and efficiency but this may be at the expense of service responsiveness, provider collaboration and sustainability of services. Also care must be taken to develop better access to services without generating extra demand within the local health economy which increases pressure on other services, including user-led services and the voluntary sector.

### *Summary of local need*

- Local demographic information along with a broad public health profile may need to be considered and made explicit. Specific details of morbidity and mortality levels, other health and well being data and condition-specific data, health inequality data and ethnicity profile are also important and should be included if available. It is essential to clarify that this service is a priority identified in the Local Delivery Plan for either the PCT or the local PBC group as well as being compatible with the wishes of patients and family carers.
- Additional relevant information should also be considered for inclusion such as recent service user feedback, current service staffing levels and competencies, local partnership arrangements, and any expected changes to local need. It is worth re-emphasising that people with a learning disability find it difficult to access mainstream services or the threshold level of learning disability in relation to contact with specialist learning disability teams is quite high which tends to result in an underestimation of the scale and sensitivity of the problem. Furthermore, local data analysis (when extrapolated to national level) suggests a significant change in demographics with many people with learning disabilities living much longer. This puts added pressure on local services available and future service demand and makes preventative community based services more cost-effective.

### *Involving patients and the public*

- The White Paper 'Our Health, Our Care, Our Say' made it clear that patients and the public would be firmly placed at the centre of NHS and social care services, with a stronger local voice. Following this, the Department of Health has published a framework for creating stronger public engagement in the development of health and social care services [www.dh.gov.uk/assetRoot/04/13/70/41/04137041.pdf](http://www.dh.gov.uk/assetRoot/04/13/70/41/04137041.pdf). This will develop with patients and the public having more involvement in service planning processes where possible including design of individualised care plans and choice of services as well as involvement in decision-making processes and service evaluation mechanisms at both provider and commissioner level.
- Local Involvement Networks (LINKs) are new ways for people who use health and social care services to have their say in how they are planned and run. LINKs replace Patient and Public Involvement Forums. There will be a LINK in every local authority area and are closely linked to Overview and Scrutiny Committees. They will be a network of people, organisations or groups representing a diverse range of views and ideas and a host organisation will be responsible for setting up a LINK and giving practice support. There is now a regular LINKs Bulletin produced in 'easy read' format on the Department of Health website – [www.dh.gov.uk](http://www.dh.gov.uk). Further details about LINKs can also be found on the newly developed National Centre for Involvement – [www.nhscentreforinvolvement.nhs.uk](http://www.nhscentreforinvolvement.nhs.uk)

### *Skill mix and partnership opportunities*

- As well as the support provided by local specialist learning disability teams to individuals and their family carers, there is a need to support the pro-active education and coordination of other strategic partners who have input into the care of people with learning disabilities. Whilst specialist community nurses may have more of a role supporting the individual, the 'Strategic Health Facilitator' role is critical to the effectiveness of local health and social care services in a community. It is not necessarily a clinical role but offers an interface between strategic, operational and the individual level. A clearly defined role, endorsed by the Department of Health, could offer vital support by:

<ul style="list-style-type: none"> <li>Providing direct clinical leadership to community specialist nursing teams and other primary care practitioners</li> <li>Interpreting national policy and supporting its implementation</li> <li>Developing partnerships among key stakeholders</li> <li>Developing support systems and tools for service providers</li> <li>Linking GPs with Public Health programmes</li> <li>Overseeing health promotion projects</li> <li>Working with care homes</li> <li>Developing and supporting Health Action Plans</li> </ul>	<ul style="list-style-type: none"> <li>Identifying training requirements for staff, providing education and training and giving advice on training to other stakeholders</li> <li>Working with data repositories, such as Local Authorities or Universities, and information sharing at all levels</li> <li>Facilitating joint assessment processes and care pathway development</li> <li>Liaison with service users, family carers, supporters and other mainstream services.</li> </ul>
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- An example Job Description and detailed KSF profile of a Strategic Health Facilitator is provided in the suite of practical materials available to download alongside this document at [www.primarycarecontracting.nhs.uk/204.php](http://www.primarycarecontracting.nhs.uk/204.php).**
- Where there is a need to develop the GP or Practitioner with Special Interest role, it is important to be aware of new guidance and regulation procedures published by the Department of Health. This will mean greater adherence to any new special interest competency framework and more formal special interest accreditation of new practitioners. For more details visit [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH\\_074792](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_074792)

### *Definitions*

- The term 'Learning Disabilities' is used to describe a significant, lifelong experience that has three components:
  - Reduced ability to understand new or complex information or to learn new skills (in global rather than specific areas)
  - Reduced ability to cope independently
  - Onset before adulthood with lasting effect on the individual's development

- Many people with learning disabilities have no formal diagnosis of the cause of their learning disability. However, some of the causes will include: Down's Syndrome; Tuberous Sclerosis; Eclampsia / ante-partum haemorrhage / complications of pregnancy; Fetal Alcohol Syndrome; Birth Injury; Meningitis / encephalitis; Fragile X syndrome; Head injury; Brain tumour; Hydrocephalus; Microcephaly; Phenylketonuria (PKU); Prader Willi syndrome; Smith-Magenis syndrome; Congenital rubella; Rett syndrome; Williams syndrome.
- People with learning disabilities will have various levels of learning disability. As a guide, these are described as:
  - **Mild:** *Good understanding and language use. Mostly independent in self care and practical / domestic skills although new learning is slower than average. May have limitations in reading and counting skills. Many achieve independent living and establish intimate relationships*
  - **Moderate:** *Slow to develop speech and understanding, requiring support throughout life. Few persons with moderate learning disabilities can read, write or count well. Independent living is rare without support. Most people are fully mobile, physically active and have social skills*
  - **Severe:** *Limited understanding and language use, may be able to communicate needs and make simple choices. Limited self care skills requiring practical daily support. Motor impairment, epilepsy and physical disorders are common*
  - **Profound:** *Severely limited in ability to understand and use language. Little or no self care skills requiring considerable daily support. The person may be able to take part in simple practical tasks. Severe neurological, physical disorders and epilepsy are common. Most are non-ambulant, incontinent and have severely restricted mobility.*

#### Health Checks

- **Detailed information on the steps to delivery of health checks can be found in the suite of practical materials available to download alongside this document at [www.primarycarecontracting.nhs.uk/204.php](http://www.primarycarecontracting.nhs.uk/204.php)**
- An individual health check for people with learning disabilities is an integral part of the Health Action Plan and is supported by a review of support availability and other information on coordination and access arrangements with other services such as secondary care. The PEARL study shows that for the health checks to be effective, it is essential for them to be followed up with regular audits which results in timely treatment and improvement in health outcomes. In 2005, a study into the role of health check programmes by the National Primary Care Research and Development Centre showed there was an improvement in access to health services following health checks and that fewer referrals were made as health checks were made more regular and routine.
- An individual health check should cover the following essential elements:

<ul style="list-style-type: none"> <li>▪ Family history and risk factors</li> <li>▪ Immunisation record</li> <li>▪ Health Screening and Health Promotion</li> <li>▪ Vision and Hearing</li> <li>▪ Chronic illnesses including Epilepsy</li> </ul>	<ul style="list-style-type: none"> <li>▪ Physical examination including fitness, mobility and posture</li> <li>▪ Review of Mental Health and emotional needs</li> <li>▪ Syndrome specific check</li> <li>▪ Medication review</li> <li>▪ Oral Health</li> </ul>
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<ul style="list-style-type: none"> <li>▪ Sexual Health</li> <li>▪ Drug and Alcohol use</li> <li>▪ Continence</li> <li>▪ Behavioural disturbance</li> </ul>	<ul style="list-style-type: none"> <li>▪ Carer details and constraints</li> <li>▪ Referrals made and subsequent follow up</li> <li>▪ Identified areas of risk and actions to be taken</li> </ul>
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### Health Action Plans

- A Health Action Plan should be developed for all people with a learning disability and this should be reviewed regularly. The Health Action Plan is a personal plan, in context, about what a person with learning disabilities can do to be more healthy and should offer an integrated approach to the care of the individual, including the contribution of family carers and supporters. It should contain details of healthy living support and access arrangements to the range of services available. The Health Action Plan should be prepared in consultation with the user. It helps to make sure people get the services and support they need to be healthy, and can offer a powerful means of reducing health inequalities. [www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Learningdisabilities/DH\\_4001807](http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Learningdisabilities/DH_4001807) provides further information and guidance for partnership boards.
- The 'Do Once and Share' project describes the components and development of a Health Action Plan, providing both interactive and text version tools to help primary care practitioners, health facilitators, and other agencies navigate through an integrated care pathway and provide support to enable patients and family carers to make informed decisions about the health and health care of someone with a learning disability. More information on the project can be found at [www.informatics.nhs.uk/doas/action\\_team\\_2005/learning\\_disabilities](http://www.informatics.nhs.uk/doas/action_team_2005/learning_disabilities)
- The following Read codes have been designed to assist basic recording within general practice. They can be used alongside other Read codes that record specific conditions and are not intended to be used instead. The important message is that Read codes are agreed locally to meet the existing QOF indicator and identify the target population.

Health Assessment	9HB3	Learning Difficulties Health Assessment
Health Action Plan Offered	9HB2	Learning Difficulties Health Action Plan Offered
Health Action Plan Reviewed	9HB1	Learning Difficulties Health Action Plan Reviewed
Health Action Plan Declined	9HB0	Learning Difficulties Health Action Plan Declined
Commonly used <b>version 2</b> Read codes for people with learning disabilities	E3, Eu7, Eu81z, 918e	
Commonly used <b>CTV3</b> Read codes for people with learning disabilities	E3, XaKyb, X00TL%	

***An example paper-based and electronic template which is compatible with a range of GP IT systems along with details of how to download the templates is provided in the suite of practical materials available to download alongside this document at [www.primarycarecontracting.nhs.uk/204.php](http://www.primarycarecontracting.nhs.uk/204.php).***

### *Health Inequalities*

- Reducing the gap in infant mortality across social groups, and raising life expectancy in the most disadvantaged areas (the Spearhead areas) faster than elsewhere are the focus for the 2010 health inequalities Public Service Agreement target. Effective, pro-active action to tackle health inequalities at local level by commissioners, providers, practitioners and other stakeholders will be key to meeting the target. To understand more about the Equalities and Human Rights agenda in the NHS, the Department of Health has recently published a useful guide for NHS Boards – [www.dh.gov.uk/assetRoot/04/14/13/71/04141371.pdf](http://www.dh.gov.uk/assetRoot/04/14/13/71/04141371.pdf).
  - With any provision of service, consideration must be given up front to the impact on inequalities in health which may result from service outcomes. This Primary Care Service provides an opportunity to narrow the inequalities gap by providing services not only to the mainstream population but also those in disadvantaged groups with poor health outcomes. Provision of this Primary Care Service should consider, where possible, outreach services by practitioners which offer a more flexible approach to ensure all groups in the population have good access to services. Twenty-two local pilot examples which reinforce this approach have recently been published by the Department of Health in 'Communities for Health: Learning from the Pilots' (February, 2007) – [www.dh.gov.uk/assetRoot/0414/32/25/04143225.pdf](http://www.dh.gov.uk/assetRoot/0414/32/25/04143225.pdf).
  - The Foundation for People with Learning Disabilities led a national pilot to test the metrics highlighted in the 'Better Metrics' report. The pilot demonstrated this it was possible to make real improvements in access to services, especially if action was co-ordinated and it was given sufficient time for implementation. More details can be found on the Foundation's website at [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)
  - The first Local Authority Health Profiles covering the whole of England have been produced by Public Health Observatories and will be updated every year. These profiles, which can be used by both local authorities and the health service, are designed to show where there are important problems with health or health inequalities to help target action to improve the health of local people. The profiles can be accessed at [www.communityhealthprofiles.info/](http://www.communityhealthprofiles.info/)
  - Commissioners may also wish to consider looking at the profile of their local population against the Health Poverty Index [www.hpi-org](http://www.hpi-org) or the inequalities reports compiled by the London Health Observatory [www.lho.org](http://www.lho.org) to help them understand the impact this service may have on local population health.
  - Further help in this area can be obtained from the National Support Team for Health Inequalities at the Department of Health.
  - Links to Health Literacy through support for self care and using health as a useful means of educating local people.
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