Health Data sets

Learning Disability and Obesity focus
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Report Dated: October 2011
Health Data sets

Learning Disability and Obesity focus

1.0 Introduction

In 2009/10 The Department of Health West Midlands and its partners undertook an equality impact assessment or regional and local obesity work programmes and identified that it was necessary to develop a focus on the needs of people with learning difficulties regarding maintaining a healthy weight, participating in physical activity and making healthy food choices.

The initial stages of this focus included:

- Gaining an understanding of the agendas, policies and challenges effecting people with learning disabilities
- Developing an understanding of the relationship between obesity and learning disabilities
- Understanding the challenges of maintaining a healthy weight for people with learning disabilities
- Developing knowledge of the programmes of work happening already to tackle obesity within this specific group in the community.

The initial data trawl regarding learning disabilities and obesity undertaken by the DHWM/WMPHO Public Health Analyst highlighted the lack of available data regarding the number of people with disabilities who were overweight or obese at a national, regional and local level.

The West Midlands Learning Disability and Obesity Framework for Action recognise the importance of improving data collection regarding prevalence and also on the services available to support people with learning disabilities to manage their weight effectively. Improving data and research is a core strand within the framework and focuses on:

1. Develop a better understanding of what is happening to prevent/tackle obesity for people with learning disabilities
2. Develop a better understanding of healthy eating and physical activity needs of people with learning disabilities and their carers.

This report aims to provide an overview of the various datasets and metrics that relate to Learning Disability and Obesity, to support these objectives to be delivered.
The report includes information on various health related frameworks, equality frameworks; metrics reports in the West Midlands, QOF related read codes, reviews undertaken by the Public Health Observatory for Learning Disabilities and locally derived health check reports.

It is hoped that this literature review will highlight the opportunities available to us to improve data collection and use to aid the development and delivery of weight management services for people with Learning Disabilities. A series of recommendations are made at the end of the report for consideration by the partners in the West Midlands Learning Disability and Obesity Network.

2.0 Current and Future Data sources and Reviews relating to Learning Disability and Obesity

2.1 Public Health Outcomes Framework

The consultation document on the Public Health Outcomes Framework sets out the proposals for the indicators and outcomes that will govern the forthcoming new Public Health System for England. The framework looks to develop meaningful indicators with evidence based interventions that support the delivery of the outcomes. It will reflect the major causes of premature mortality or avoidable ill health and impacts of health inequalities. The framework contains a focus on reducing inequalities in health and takes a life course approach. The data will be collected at a National level to reduce the burden on Local Authority’s. It is expected that the data will be appropriate at local spatial levels, timely in release (<1 year) with quarterly reporting to determine progress.

The outcomes framework has 5 domains

1) Health protection and resilience
2) Tackling wider determinants of health
3) Health improvement
4) Prevention of ill health
5) Healthy life expectancy and preventable mortality

The framework should be used alongside the Joint Strategic Needs Assessment to determine local priorities.

2.2 NHS Outcomes Framework 2011/2012

Following a consultation phase the NHS Outcome Framework for 2011/2012 has been published. It will;
• Provide a national level overview of how well the NHS is performing.

• Provide a mechanism for accountability between the Government and the NHS Commissioning Board.

• Act as a catalyst to drive improvement and focus the NHS on tackling inequalities.

The framework will continue to evolve, starting as a tool for setting the direction of travel for the NHS in 2011/2012 and developing into a toll with which the Government can hold the NHS to account regarding the ambitions that have been agreed.

The levels of the ambitions will determine the;

• Trajectory baselines

• Cost effectiveness of the required improvements

• Timelines of the impact of NHS on Outcomes

• Achievability and inequalities

• Potential impact on behaviour and incentives.

The promotion of equality and reducing health inequalities is at the heart of the framework and the outcome indicators. The document recognises that the current data capture does not provide data outcomes for particular groups, including those with disabilities and learning disabilities. It states that the framework and the data sources will be refined to provide measures for these groups.

The framework will be refined annually with a full external review completed every 5 years.

The NHS Commissioning Board will translate national outcomes into meaningful outcomes and indicators at a local level. This will be linked to the Commissioning Outcomes Framework and is linked to financial incentive payments to Clinical Commissioning Groups, see the diagram overleaf for how the documents are data sets are linked.

The framework is set out in 5 domains;

1) Preventing People from dying prematurely

2) Enhancing quality of life for people with long term conditions

3) Helping people to recover from episodes of ill health or following injury.

4) Ensuring that people have a positive experience of care.
5) Treating and caring for people in a safe environment and protecting them from avoidable harm.

**Diagram 1: The quality improvement system in the NHS**

The outcomes consist of:

- 10 overarching indicators
- 31 improvement areas
- A suite of 51 supporting NICE quality standards.

The NICE quality standards linked to the obesity and learning disability agenda are diabetes in adults and children, a standard for long term conditions/people with co-morbidities/complex needs is currently in development. There does not appear to be a quality standard for obesity at present.

At present none of the data sets for the NHS Outcomes Framework have data that determines disability or learning disability as part of the demographic data.
2.3 The Adult Social Care Outcomes Framework

The consultation document “A vision for adult social care; capable communities and active citizens” sets out a new strategy for Adult Social Care comprising of 3 interdependent themes; transparency, quality and outcomes in adult social care.

The strategy focuses on quality services and commissioning that;

- Get it right the first time
- A positive experience of care and support
- Protecting vulnerable people
- Ensuring value for money

The strategy is linked to increasing the uptake of personalised budgets and the individual choice agenda. The goals of the framework are to;

- To empower local citizens and support transparency
- To improve outcomes for those with care and support needs
- To improve the quality of social care services

The strategy is framed around five core elements;

- Building the evidence base
- Demonstrating progress
- Supporting transparency
- Rewarding and incentivising
- Securing the foundations of quality and safety to protect the most vulnerable

NICE quality standards will be developed to give 5 – 10 specific quality statements and measures for services based on the most up to date knowledge. These are in addition to regulatory frameworks.

There will be no national performance management role from the government with councils leading the way to support their own benchmarking and improvement through a peer review process. This process will include user and carer led assessments to support transparency. They will also set their own priorities. This local accountability will replace the Care Quality Commission’s annual assessment of councils as commissioners from 2011/2012.
The framework has 2 key elements;

- A quality and outcomes data sets (QODS)
- A set of outcome focused measures.

The QODS will start with data already available and progress to include further robust and sustainable data. The measures will be published annually through a single information portal.

The framework incorporates;

- Overarching measures
- Outcome measures
- Supporting quality data and measures

The domains and outcomes can be seen in table 1 overleaf.
A new excellence rating for social care providers is being developed to act as an accredited marker of best practice. This will incorporate the NICE quality standards. The use of financial incentives for providers of services is being considered to reward quality improvements.

The timescales for the roll out of the framework are;

Late 2011 – March 2013 - Implementation

Diagram 2: The interactions between the 3 health related outcomes frameworks

Diagram 2 highlights the interactions between the NHS, Public health and Social Care frameworks, recognising that some outcomes are linked across the 3 areas of care.

Table 2, overleaf provides a detailed overview of the 3 Health and Social Care Outcomes Frameworks detailed in section 2.1, 2.2 and 2.3 in relation to Obesity and Learning Disability. It highlights the breadth of proposed indicators that relate to this topic and also where indicators are featured in more than one framework.
Table 2: An Overview of the 3 Health and Social Care Outcomes Frameworks in relation to Obesity and Learning Disability

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<tr>
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<tbody>
<tr>
<td>Proportion of People with mental illness and or disability in settled accommodation (Source TBC)</td>
<td>x</td>
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<tr>
<td>Access &amp; utilisation of green space (Engagement with Natural Environment Survey)</td>
<td>x</td>
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<tr>
<td>Cycling Participation (Active People)</td>
<td>x</td>
<td></td>
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<tr>
<td>Social connectedness (DCLG Citizenship Survey)</td>
<td>x</td>
<td></td>
<td></td>
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<tr>
<td>Prevalence of healthy weight in 4 – 5 &amp; 10 – 11 year olds (NCMP)</td>
<td>x</td>
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<tr>
<td>Prevalence of healthy weight in adults (Health Survey for England)</td>
<td>x</td>
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<tr>
<td>% of adults meeting recommended guidelines on physical activity (5 x 30) per week (Active People)</td>
<td>x</td>
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<td>Self reported wellbeing (TBC)</td>
<td>x</td>
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<tr>
<td>Prevalence of recorded Diabetes (GP Practice System)</td>
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<td>Mortality rate of people with mental illness (TBC)*</td>
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<td>(Reducing premature death in people with serious mental illness)</td>
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<td>Under 75 mortality rate CV disease</td>
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<td>X</td>
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<tr>
<td>Ensuring people supported to manage their condition; Proportion of people feeling supported to manage their condition</td>
<td></td>
<td>x</td>
<td>x</td>
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<tr>
<td>Enhancing Quality of Life for carers; Health related quality of life for carers</td>
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<td>X</td>
<td>x</td>
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<tr>
<td>Patient experience of Primary Care</td>
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<tr>
<td>Patient experience of Hospital Care</td>
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<tr>
<td>Overarching measure; Social care related quality of life (Adult Social Care Survey)</td>
<td></td>
<td></td>
<td>X</td>
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<tr>
<td>The proportion of people using Adult Social Care Services who have control over their daily life</td>
<td></td>
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<td>X</td>
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<tr>
<td>Promoting personalised services; proportion of people using social care who receive self directed support (Social</td>
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<td>Domain 2</td>
<td>Domain 3</td>
<td>Domain 4</td>
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<td>Care data collection)</td>
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<tr>
<td>Overall satisfaction with local adult social care services (Adult Social Care Survey)</td>
<td></td>
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<tr>
<td>Proportion of people using social care and carers who express difficulty in finding information and advice about local services (Adult Social Care Survey &amp; Carers Survey)</td>
<td></td>
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<tr>
<td>Treating carers as equal partners; The proportion of carers who report they have been included or consulted in discussions about the person they care for.</td>
<td></td>
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<tr>
<td>Ensuring a safe environment for people with LD; Proportion of adults with LD in settled accommodation (Adult Social Care combined activity return)</td>
<td></td>
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</tbody>
</table>

*Need to identify if this will include any of Learning Disability spectrum or not.
2.4 Joint Strategic Needs Assessment (JSNA)

JSNA is a continuous process that identifies the 'big picture' in terms of the health and wellbeing needs and inequalities of a local population. The issues identified by JSNA should inform the priorities and targets set by the Local Area Agreement and consequent commissioning strategies, and influence other strategies and plans e.g. PCT Local Delivery Plans, Children and Young People's Plans, PBC commissioning plans, Supporting People strategies, and Community Safety Strategies. JSNA should have an impact on commissioner priorities and actions, including practice-based commissioners, and government will look for evidence that commissioning decisions have been informed by the JSNA.

Minimum data sets for JSNA include the following:

- **Demography**: Population, migration, births, ethnicity

- **Social and environmental context**: Rural/urban and other characteristics, deprivation, employment and benefits, living arrangements

- **Current known health status**: Behaviours and lifestyle (smoking, alcohol, obesity, physical activity, sexual behaviour), teenage conceptions, illness, disability and mortality

- **Current met needs**: Number of social care clients, standards of service, primary care uptake

- **Service user**: Social care (user surveys), primary and community care (GPAQ, PALS, complaints), hospital (self-reported health outcomes, satisfaction surveys)

- **Public demands**: Local Authority (Annual Residents Surveys, Health Scrutiny Reports), NHS (petitions), National Patients Survey programme, LINKs, Citizen's Panels

However these data sets do not always include demographic breakdowns that identify people with learning disabilities within them. The JSNA will continue to play an important role in localities determining their priorities.

2.5 Learning Disability Health Check Data for obesity

The Learning Disability Health checks provide an opportunity for data collation for LD and Obesity.

GP Practices are required to use agreed read codes to meet existing QOF indicators and identify the target population. The GPs have standardised electronic templates from PCTs that need to be completed during the health check.

Learning Disability registers should be linked to disease registers.

Research has found that during the health check obesity is read coded as for the general population so the data on the number of people with LD who are obese is unlikely to be accessible in most PCT areas when doing a read code query.
2.6 Physical Health Care Needs Report from NHS West Midlands

This report provides an overview of the data collected through the Valuing People Now self-assessments that were undertaken across the West Midlands. The report found that;

- The PCT prevalence of LD ranges from 250 in Warwickshire to 470 per 100,000 in Stoke on Trent, averaging at 320 per 100,000 across the West Midlands.

- The overall impression is that ensuring appropriate access to physical health services for those with LD is problematic. There is a perceived lack of skill among clinicians providing mainstream services and appropriate adjustments to services to support equitable access are not made.

- Five of 17 PCTs are working to improve the lifestyles of those with LD. A further 5 PCTs were planning to implement programmes aimed at improving the physical health of those with either MH problems or LD, and as such all Public Health departments were either currently working with one or both of these client groups or had plans to do so.

- Services for those with LD are provided in a range of settings including day centres, in care homes or through MH Trusts. The majority of commissioners were of the view that contract specifications outlining the need to meet the general physical health needs of those with LD were under developed. Some however stated that a general clause requiring providers to respond to the physical care needs of individuals was included in specifications and one described a more detailed description of expectations in this area.

- A number of commissioners said that it was difficult to monitor standards, particularly in care homes. One PCT made reference to a programme of work being undertaken with care homes on meeting basic hygiene requirements deemed to be necessary because of a poor standard of personal care.

- A minority of interviewees made reference to health promoting activities such as healthy eating, cooking or walking being undertaken through day centres.

- In the main commissioners explained that their focus was on improving access to mainstream services for those with LD. However problems encountered were a lack of commitment and skill particularly in primary care and among hospital staff as well as a poor awareness among those with LD of what they should expect.
Potentially Promising Public Health Programmes

<table>
<thead>
<tr>
<th>PCT</th>
<th>Programme</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coventry*</td>
<td>One body, one mind</td>
<td>Nutritional advice and physical activity for those with MH problems</td>
</tr>
<tr>
<td>Sandwell</td>
<td>CVD risk screening</td>
<td>All MH inpatients screened for CVD risk. Approach being developed for patients managed in the community.</td>
</tr>
<tr>
<td>Shropshire*</td>
<td>Outdoors/indoors</td>
<td>Physical activity programmes specifically targeted at MH and LD clients</td>
</tr>
<tr>
<td>Stoke</td>
<td>MH Physical Care Pathway Exercise on prescription</td>
<td>Strategic approach to addressing physical health problems. Reported to have had a positive evaluation</td>
</tr>
<tr>
<td>Telford</td>
<td>Green gym</td>
<td>Running for 4 years. Reported to have had a positive evaluation.</td>
</tr>
<tr>
<td>Walsall</td>
<td>Health trainers</td>
<td>Service specification for targeted service for MH clients being developed.</td>
</tr>
</tbody>
</table>

2.7 The Improving Health and Lives Learning Disability Observatory

The Improving Health and Lives Learning Disabilities Observatory (www.ihal.org.uk) has been established by the Department of Health to:

1. Collate and disseminate information that will support the commissioning of services to reduce the health inequalities faced by people with learning disabilities in England;

2. Support those involved in commissioning and providing services to make better use of available information; and

3. Work toward improving the future scope and relevance of information on the health and well-being of people with learning disabilities.
2.7.1 The Use of Pooled Data from Learning Disabilities Registers: A Scoping Review

Learning disabilities registers are information systems that seek to collect and maintain information on the characteristics and needs people with learning disabilities within a defined administrative area. Typically, people identified by registers are either current or potential users of specialised health and/or social care services for people with learning disabilities. Current registers were designed in response to demands for better coordination and continuity of care and support a range of dispersed agencies across the community.

The primary functions of current learning disabilities registers are to support the local planning and delivery of health and social care services for people with learning disabilities. These primary functions include:

- Direct service functions such as direct referral or signposting of people with learning disabilities to specific services, raising awareness of services among users and carers, enabling online access to specific information on individual service users to relevant providers, dissemination of information to users and carers, confirming eligibility for bus passes, supporting people to self-identify as having learning disabilities when accessing health services or coming in contact with the police.

- Commissioning, management and planning functions such as the audit and evaluation of service provision, the validation of GP-held registers, recording existing need (including unmet need) and predicting growth in need for services over time.\(^i\),\(^ii\).

- Public health functions such as monitoring changes in the level and equity of distribution of need.

LD registers have also been used to investigate the specific needs of sub-groups of people with learning disabilities in relation to issues such as obesity, overweight and underweight.\(^iii\),\(^iv\).

Examples exist of the LD register’s including leisure/day time activities (Sefton & Harrow).

The report highlights that pooling data across separate registers (and operational databases) involves a number of challenges resulting from the inconsistency across registers in relation to such factors as:

- conceptual and operational definitions of learning disabilities;
- the coverage and process of identifying people with learning disabilities;
- the nature of information collected to describe the characteristics and needs of people;
• the process of information collection (e.g. interview, postal questionnaire);

• The geo-demographic characteristics of the population covered.

It is recommended that the Improving Health and Lives Learning Disabilities Observatory and the Special Interest Group (Learning Disabilities Registers) work together (and with interested other parties) in order to:

1. Develop a simple set of criteria that could provide a test of minimum acceptable data standards for the inclusion of registers (or operational databases) in any pooling exercise.

2. Undertake an annual data pooling exercises commencing in late 2010 in relation to estimating the:

a. age and gender specific administrative prevalence of learning disabilities;

b. age-specific mortality rates among adults with learning disabilities who are users or likely potential users of learning disabilities services.

3. Explore the possibility of pooling information from 2011 onwards on the situation and needs of particular groups of people with learning disabilities such as people who also have autism, people with more severe or profound learning disabilities and people with challenging behaviours or mental health difficulties.

2.8 Health Inequalities & People with Learning Disabilities in the UK: 2010

The report follows on from the 2002 comprehensive review of UK literature regarding Health Inequalities and people with Learning Disabilities, and was published in 2010 using the most up-to-date UK and International data.

The inequalities evident in access to health care are likely to place many NHS Trusts in England in contravention of their legal responsibilities defined in the Disability Discrimination Acts 1995 and 2005 and the Mental Capacity Act 2005. At a more general level, they are also likely to be in contravention of international obligations under the UN Convention on the Rights of Persons with Disabilities.

The literature review found that:

- People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population. All cause mortality rates among people with moderate to severe learning disabilities are three times higher than in the general population, with mortality being particularly high for young adults, women and people with Down’s syndrome.
• Life expectancy is increasing, in particular for people with Down’s syndrome, with some evidence to suggest that for people with mild learning disabilities it may be approaching that of the general population. viii

• Coronary heart disease is a leading cause of death amongst people with learning disabilities (14%-20%), ix with rates expected to increase due to increased longevity and lifestyle changes associated with community living. x

• Among adults with learning disabilities, 40% of people with dysphagia experience recurrent respiratory tract infections. Other negative health consequences of dysphagia include asphyxia, dehydration and poor nutritional status. xi

• Increased rates of diabetes among adults with learning disabilities have been reported in a population-based study undertaken in the Netherlands. 80 We are not aware of any UK-based data on the prevalence of diabetes among people with learning disabilities.

• Obesity is more prevalent among people with Prader-Willi syndrome, Cohen syndrome and Bardet-Biedl syndrome.

• The report found that people with learning disabilities experience a lack of knowledge and choice about healthy eating. xii

The Personal Health Risks and Behaviours section of the report details that:

**Diet**

• Less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient intake of fruit and vegetables. xiii Carers generally have a poor knowledge about public health recommendations on dietary intake. xiv

**Exercise**

• Over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health’s minimum recommended level, a much lower level of physical activity than the general population (53%-64%). xv xvi xvii People with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity xviii.

**Obesity & Underweight**

• People with learning disabilities are much more likely to be either underweight or obese than the general population. xix x xi xii xx xxi xxii Women, people with Down’s syndrome, people of higher ability and people living in less restrictive
environments are at increased risk of obesity. \textsuperscript{xi, xiii, xvii, xxiii} The high level of overweight status amongst persons with learning disabilities is likely to be associated with an increased risk of diabetes. \textsuperscript{xxiv}

The report identifies a range of organisational barriers to accessing healthcare services have been identified. \textsuperscript{xxv, xxvi, xxvii, xxviii, xxix, xxx} These include:

- scarcity of services
- physical barriers to access;
- failure to make ‘reasonable adjustments’ in light of the literacy and communication difficulties experienced by many people with learning disabilities
- variability in the availability of interpreters for people from minority ethnic communities;
- ‘diagnostic overshadowing’ (symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person’s learning disabilities);
- Disablist attitudes among healthcare staff.

The introduction of special health checks for people with learning disabilities has been shown to be effective in identifying unmet health needs, suggesting that health checks represent a ‘reasonable adjustment’ to the difficulties in identifying and/or communicating health need experienced by people with learning disabilities. While providing financial incentives to GPs may influence practice, incentives based on general population health need may be insufficient to improve the quality of care for people with learning disabilities. \textsuperscript{xxxi}

The report concludes that responding appropriately to the health inequalities faced by people with learning disabilities in England demands action on several fronts. These include:

- reducing the exposure of people with learning disabilities to common social determinants of (poorer) health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination;
- Improving the early identification of illness among people with learning disabilities by, for example, increasing uptake of annual health checks, and for women, cervical and breast screening. \textsuperscript{xxxii} Knowledge of the health risks associated with specific syndromes is of value in targeting the content of health checks;
• enhancing the health literacy of people with learning disabilities and of family carers and paid carers/supporters who play a critical role in promoting healthy lifestyles among many people with learning disabilities;

• making ‘reasonable adjustments’ in all areas of health promotion and healthcare in light of the specific needs of people with learning disabilities and acting within the legal framework of the Mental Capacity Act 2005 (e.g., through providing more accessible information and longer appointment times);

• Monitoring progress towards the elimination of health inequalities faced by people with learning disabilities.

2.9 Health Check Systematic Review

Background information

Following a Formal Investigation into the health inequalities experienced by people with learning disabilities, the Disability Rights Commission in 2006 recommended the introduction of annual health checks for people with learning disabilities in England and Wales as a ‘reasonable adjustment’ in primary health care services.\(^{xxxiii}\)

The introduction of annual health checks for people with learning disabilities in England was also recommended by the 2008 Independent Inquiry into Access to Healthcare for People with Learning Disabilities\(^{xxxiv}\). In September 2008 the NHS and the British Medical Association announced plans for a Direct Enhanced Service (DES) to deliver annual health checks in England.

In February 2009 directions were published by the Department of Health that required PCTs to offer GP practices in their area the opportunity to provide health checks for people with learning disabilities as part of a DES scheme. The DES, originally agreed for two years (2008-9 and 2009-10), has since been extended for at least another year (2010-11).

The report summarise the results of a systematic review of published scientific evidence concerning the impact of health checks on the health and well-being of people with learning disabilities.

The literature review found that lifestyle related checks for weight, BMI, diet, smoking, alcohol consumption and exercise were commonly reported within the Health Check studies\(^{xxxv,xxxvi,xxxvii,xxxviii,xxxix,xl,xi,xi,xi,xx,xxxvii,xxxviii,xxxix,xxli}\). Health education advice and referrals in relation to diet were also seen within the Health Check studies as actions from the original check up.

The evidence found during the literature review is clear in indicating that health checks are effective in identifying previously undetected health conditions in people with learning disabilities.
Levels of obesity ranged from 9% - 50% in the studies included in the review.

It appears that incentivised processes were well recorded and improved health check outcomes further.

The report found that there is a need for larger, longer term studies to establish the effects of the health checks on morbidity and mortality.

The review found examples of successful actions regarding weight management following dietary interventions.

Health Checks were a successful method of raising awareness in health professionals regarding the needs of people with learning disabilities. However some studies found that one potential barrier to people accessing effective health checks is the reluctance of GPs to undertake health checks for people with learning disabilities.

The report concludes that given the specific difficulties faced by people with learning disabilities (e.g., identifying and communicating symptoms of ill health, negotiating access within complex health systems), targeted health checks should be considered to constitute an effective and important adjustment to the operation of primary health care services in the UK as required by the Disability Discrimination Acts 1995 and 2005, the Equality Act 201087 and, more generally, in relation to international obligations under the UN Convention on the Rights of Persons with Disabilities xxxii.

2.10 Commissioning for Quality and Innovation (CQUIN) payment framework (NHS West Midlands)

The National CQUIN payment framework provides a national framework for locally agreed quality improvement schemes. The framework requires a proportion of provider contract value to be linked to the achievement of locally agreed ambitious quality improvement goals. The Department of Health addendum to the 2008 policy guidance on this states the following;

- Each provider of acute, ambulance, community, and mental health & learning disability services on a national standard contract is entitled to earn 1.5% of contract value subject to agreeing and achieving goals in the CQUIN scheme.

- Schemes are worth up to 1.5% of the contract with that provider. The goals should not duplicate specific minimum expectations of providers set out in existing commitments, tiers 1 & 2 of vital signs or in standard contracts.

- Local Commissioners and providers must discuss and agree how to translate the national goals into local actions.
• Commissioners can use schedule 5 of the acute contract to agree data collection to inform baselines on quality indicators which may feed into CQUIN schemes in future years. Schedule 3, part 4 can be used to monitor sustained performance against CQUIN goals achieved in previous years, reserving the CQUIN scheme itself for progressive improvements year on year.

The two national goals detailed in the 2010/11 guidance are;

i. Reduce avoidable death, disability and chronic ill health from Venous – Thrombelism (VTE)

ii. Improve responsiveness to personal needs of patients.

The second goal is monitored using results from the adult inpatient survey that is coordinated by the Care Quality Commission; it is a national data source, collected to common standards and definitions. The guidance recognises that Commissioners and providers may wish to extend the general approach to identify local patient experience baselines and indicators that are not covered by the inpatient survey that could be established through and with providers such as ambulances, mental health and learning disability services etc.

The CQC patient survey questions relating to measuring this goal are shown below and are combined to form a composite indicator, giving each acute organisation a score out of 100;

• Were you involved as much as you wanted to be in decisions about your care and treatment?

• Did you find someone on the hospital staff to talk to about your worries and fears?

• Were you given enough privacy when discussing your condition or treatment?

• Did a member of staff tell you about medication side effects to watch for when you went home?

• Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

It is unclear in the guidance whether a patient’s status as having a learning disability would be collated as part of this survey. The issue of coding and flagging learning disability status is recognised as being poor across the acute sector by the SHA. A CQUIN system has been put in place that will improve this and is explained in more detail below.

Payments can be split between a reward for improvement against a baseline and a separate a reward for exceeding an absolute value, with baselines being taken into account during this process.
NHS West Midlands have developed a CQUIN for improving the care and health outcomes for people with learning disabilities in acute hospital settings.

The goal description is to:

“Improve the care and health outcomes of people with learning disabilities by using ‘reasonable adjustments’ through the implementation of regional learning disability care pathways in acute hospital settings”

The indicator descriptions are;

- **Coding and Flagging Systems Indicator**
  Number of people who come into acute (emergency and planned), ambulance and community and have a pre-assessment.

  Metric Description: Proportion of Inpatient Admissions (elective & emergency) with following secondary diagnosis codes: Mental Retardation F70 – F79, Autism – F84.0; F84.1, F84.5 (Aspergers), Learning disabilities – F06.7, F70, F80.1

  Numerator: number of admissions (el & em) where secondary diagnosis code is; Mental Retardation F70 – F79, Autism – F84.0; F84.1, F84.5 (Aspergers), Learning disabilities – F06.7, F70, F80.1

  Denominator: Number of admissions (el & em)

- **Training on improving care pathway and outcomes indicator**
  Number of staff (administrative and clerical) who had received training on the following: coding and flagging, working with patients with a learning disability; Disability Equality Duty and Implementing reasonable adjustments within NHS and care settings.

  Audit process to be put in place.

- **Improved quality of patient care through “reasonable adjustments” to care systems indicator**
  Number of patients who have hospital stays over 48 hours, who have a completed risk assessment and necessary “reasonable adjustments” to the care identified in the care records.

The LD CIT has supported 7 care pathways and core principles to support these that provide resources and tools to acute staff to promote reasonable adjustments and support patients with LD in hospital settings.
It is hoped that this approach is likely to result in reduced hospital stays, effective implementation of reasonable adjustments and the avoidance of unnecessary admissions/readmissions.

The indicators for the CQUIN will build on information systems in place for recording admissions (elective and emergency) and will be collated quarterly and will be taken from the SUS inpatients data.

Reasonable adjustments are described as:

- Larger print
- Easier to understand words, pictures and symbols
- Clear and easy to understand information and signs
- More time to explain and listen
- First or last appointment
- A different place to wait
- Involve carers but talk to the person/patient
- Don’t use jargon or complex information
- Familiarisation visits, adjustments to visiting times
- Extended in patient stay
- Adjustment to procedures, e.g. walk to anaesthetic room, wear own clothes

2.11 Briefing Report: Update on the models of mental health care and equality metrics projects (October 2009) NHS West Midlands

The report covers the following areas;


2. The scoping of the equality metrics within the NHS Contract.

3. Equality impact assessment of the Models of Care projects and key outcomes.

4. Recommendations and next steps for mental health commissioners to consider in developing models of mental health care that are inclusive of the whole community.
The report provides details of several equality metrics including;

**Count me in: The National ethnicity and mental health census of inpatient care 2005 – 2010**


- The census covers mental health and learning disabilities.

- Findings can be viewed at [www.cqc.org.uk/guidanceforprofessionals/healthcare/allhealthcarestaff/countmein_census.cfm](http://www.cqc.org.uk/guidanceforprofessionals/healthcare/allhealthcarestaff/countmein_census.cfm)

- The data enables trusts to make comparisons between the trust population and the population of inpatients throughout England and Wales to support them in complying with national guidance and assist them to fulfil their commitments to providing non-discriminatory services.

The report scopes the Guidance on the standard NHS Contract for Mental Health and Learning Disabilities Services in England 2009/10. Areas relating to data collection detailed in the report are xliii;

- Commissioners and providers need to agree local approaches to assessing and recording outcomes including: service user defined outcomes, service user and carer satisfaction and engagement, employment status and settled accommodation.

- Each provider should agree an annual data quality improvement plan, as detailed in clause 29, including timescales and performance management mechanisms.

- Commissioners are expected to undertake their own local impact assessment of the agreement reached with providers, focusing particularly on the service specifications, care pathways and protocols and any other local requirements.

- Schedule 5 of the Contract introduces the requirement for a monthly equality monitoring report to be completed, to comply with statutory obligations and to support equality impact assessments.

- Commissioners and providers should agree additional quality requirements including service quality performance indicators with clear methods of measurements and defined consequences for failure to remedy performance problems.
2.12 Models of care project

The minimum data sets for outcome measures for the specifications for services for adults and children with learning disabilities detailed in the service specs developed under the models of care project include:

- People with learning disabilities are part of key clinical networks (including Mental Health, Coronary Heart Disease, Cancer, and Dementia).
- GP’s have systems in place to ensure patients with a learning disability have equal access to benefits in mainstream services, NSF’s and plans. (Better Metrics).
- People with learning disabilities are represented on all key clinical networks.
- PCT’s have evidence that any differential needs of the LD population are linked to the key health promotion targets (e.g. obesity, premature death etc.)
- Every person with a learning disability has a Health Action Plan (if they want one).
- GP practices have systems in place to ‘flag’ up people who have a learning disability.
- GP practices have in place systems to monitor the number of people with learning disabilities involved in practice and community-based health promotion activities (i.e. obesity and healthy eating activities).
- Screening and health promotion literature and information - for at least all of the areas identified in the evidence column – is provided in accessible and user-friendly formats.
- The PCT gathers data from providers to determine equity of access.
- Each GP Practice carries out an annual review of their learning disabled patients who have heart disease or diabetes.

The report recommends that:

- There is a need for better information and the intelligent use of the data available at a national, regional and local level.
- Commissioners capitalise on opportunities to ensure that appropriate monitoring and evaluation is undertaken on provider trusts to ensure compliance with equality metrics and data through the NHS Standard contract for Mental Health and Learning Disabilities Services in England.

The Equality and Human Rights Commission (EHRC) and the Government Equalities Office (GEO) have jointly developed an Equality Measurement Framework\textsuperscript{IV}, in consultation with the devolved administrations. The Commission has a legal duty under the Equality Act (2006) to monitor and evaluate progress towards equality and human rights, taking account of gender, ethnicity, disability, age, sexual orientation, transgender status, and religion or belief. The GEO has in addition a particular interest in inequality by social class.

The Equality Measurement Framework (EMF) is not a performance measurement tool but is intended to monitor social outcomes from an equality and human rights perspective. The Framework aims to provide a baseline of evidence to inform policy priorities and helping to identify inequalities that need further investigation.

The framework is set out in 10 domains that cover the international Human Rights framework

- Life
- Health
- Physical security
- Legal security
- Education and learning
- Standard of living
- Productive and valued activities
- Individual, family and social life
- Identity, expression and self-respect
- Participation, influence and voice.

The Shortlist of Indicators for Health includes;

Indicator 4: Healthy living

Measure 4.1 (E,S,W): Percentage who are living a healthy lifestyle, covering (a) smoking (b) alcohol (c) physical activity (d) consumption of fruit and vegetables) (e) body mass

The suggested data sources are the Health Survey for England, Scotland and Wales. The Active People Survey and taking part surveys are included within the discussions in the paper.
• Measure 4.2 (E,W): Percentage who are living in an area with less favourable environmental conditions

The data source for this is the DEFRA Sustainable Development Indicator 60 matched to household survey data, for instance HIS.

The data sources all suggest that while disability can be disaggregated from the data there is no breakdown available regarding whether the disability is physical disability, a learning disability or one related to mental health.

The Health Survey for England/Wales/Scotland data is available at a national and regional level but not at a local/trust level. The DEFRA data appears to be available at a national and regional level.

2.14 Primary Health Care for People with Learning Disabilities: Facilitating Better Health in Coventry Report

This report discusses the development of the Coventry approach to Health Checks for people with Learning Disabilities using a Health Facilitation Team approach and the outcomes of the health checks that were delivered for 1082 people with learning disabilities within primary care settings between July 2005 and October 2008.

A large amount of unmet needs were uncovered through the health checks particularly prevalent conditions were overweight and obesity, impacted ear wax, mental health issues, fungal infections of the skin (particularly the feet), urinary tract infections and issues around epilepsy.

The Method stated in the report is as follows;

“The Health Facilitation Team (of three Registered Learning Disability Nurses) made contact with doctors’ surgeries, typically with the Practice Manager. Working together with the PHCTs and using the existing specialist services’ data on known clients, a list of people thought to have learning disabilities was made up. Letters of invitation were then sent to these people for a full health check, explaining the nature of the HFT and what would happen during the check. The health check took place either at the surgery or at the person’s home. If the person was found not to have a learning disability, a minimum health check was performed. Those people identified with a learning disability were allocated a Read code, ensuring that more accurate health-related statistics could be more easily attained in the future.”
The checks incorporated the following:

- Brief medical history
- Height
- Weight
- Body Mass Index (BMI)
- Blood pressure
- Physical examination (including feet)
- Checking skin
- Urinalysis and discussions around urinary tract health
- Discussion of physical and mental health issues including any psychological issues
- Screen for dysphagia
- Dietary intake
- Ear check (for impacted wax and infection)
- Checks for eyes, teeth
- Highlighting need for regular checks (eyes, teeth, etc)
- Circulation and breathing
- Checking the impact of long term use of medication
- Discussion of sleep quality
- Discussion around testicular examination and prostate
- Breast and cervical screening (check mammography and follow up)
- Smoking cessation advice and health promotion
- Discussion of health issues around genetic make up
- Discussion of health issues around ethnicity.

Between the 23rd April 2004 and 28th September 2009, 1428 health checks were offered, with 1082 health checks completed. 749 had a health check in the first round of checks (T1) (346 females; 403 males) and 333 in the second round of checks (T2) (157 females; 176 males).

**Obesity figures detailed in the report:**

684 health checks generated BMI calculations (310 females; 374 males).

207 (30%) were deemed to be of an ideal BMI,

45 (6.5%) were underweight,

433 (63%) were either overweight or obese (BMI ≤ 25)

24 (6.8% of the total number of BMIs) were morbidly obese (BMI ≤ 40)).

Measurements were unable to be obtained for 87 people mostly because of non-compliance.

**Outcomes**
• 175 referrals to Dietetic services were made

• 99 referrals to Health lifestyle/weight loss groups were made.

The report recommends that;

• The number of referrals to services needs to be monitored closely and capacity should be built in if these services are unable to cope with the increase. This is a serious challenge to the NHS at a time of financial uncertainty.

• Work is required (and initiatives are under way) to raise the awareness of health needs of the client group and particularly for the need for improved nutrition and physical activity.

• Primary and specialist services need to anticipate future increases in overweight and obesity and should act now to encourage a healthier population. Specialist Dietetic services are available locally but tend to have much more demand than can be met. The commencement of a Healthy Lives Group and the local One Body One Life have proved popular with people with learning disabilities, their carers and staff members.

• GPs and members of PHCTs should be supported to ensure that people with learning disabilities identified on their case lists are offered regular (annual) health checks. This process can be made easier through this learning disability nurse-led model which is useful at providing base-line data which can be shared.

2.15 Baseline Metrics Report for Learning Disabilities West Midlands

This report details the metrics available to support the development and improvement of services for people with learning disabilities. It takes into account the paucity of available and reliable data and the lack of a coordinated process for considering and using the data to assess the quality of services and supporting them improve.

The report selects metrics for us that

“Reflect the key priorities facing people with learning disabilities – good health, having a job, a home of your own, and having choice and control over your life”.

The authors intend the report to provide a baseline for metrics and something that can be built upon to ensure the robustness of the data

The indicators detailed in the report are:
**Indicator 1: Quality of Services**

**Numerator:** Observed GP LD List Size. Number of people on LD list size/Total number of people on GP register from QOF.

**Denominator:** Expected GP LD List Size. Based on applying prevalence rates a defined by Emerson and Hatton (2004) to ONS mid-year population estimates.

Source: QOF Data and ONS mid-year population statistics

**Indicator 2: Quality of Life**

Proportion of adults with learning disabilities living in accommodation outside of local area (18-64)

Numerator: Residents with learning disabilities supported outside the CSSR area in registered accommodation (18-64), from Comm Care council returns sheet S10.

Denominator: Council residents supported residents with learning disabilities in CASSR and independent care homes (18-64), from Comm Care council returns sheet S10.

Source: Information Centre - Community Care Statistics

**Indicator 3: Quality of Life**

Adults with learning disabilities helped to live at home (Aged 18-64)

Numerator: Adults with LD helped to live at home, from PAF council returns column AO-C30.1.

Denominator: Estimated population with LD. Based on applying prevalence rates a defined by Emerson and Hatton (2004) to ONS mid-year population estimates.

Source: Information Centre – Community Care Statistics and ONS mid-year statistics.

**Indicator 4: Choice and Control**

Proportion Council Supported Adults with learning disabilities receiving direct payments (aged 18-64)

Numerator: Total number of clients with LD receiving direct payments aged 18-64 from council RAPS returns table P2F1.B.

Denominator: Total number of clients with LD receiving services aged 18-64 from council RAPS returns table P2F1.B.

Source: Information Centre - Community Care Statistics
The report details a number of desirable metrics that are not available at the time that the report was written. The report indicates that further discussions within the clinical pathway group for learning disabilities will take place to establish ways in which these metrics can be measured in future. The desired metrics are:

Metric 5: Proportion of people with a learning disability with a health plan.

Metric 6: Proportion of people with a learning disability invited for a comprehensive health check if they have not visited the GP surgery in the last 3 years

Metric 7: Proportion of acute hospitals that have a system in place to ensure patients with learning disability are identified and appropriate supported provided

Metric 8: Mortality rates of people with a learning disability

Metric 9: Proportion of people with a learning disability in paid full time and part time employment

2.16 Learning Disability Read Codes

Read Codes are a coded thesaurus of clinical terms. Read Codes have two versions:

- Version 2 (v2)
- version 3 (CTV3 or v3)

They enable clinicians to record patient findings and procedures in health and social care IT systems across primary and secondary care settings (e.g. General Practice surgeries and pathology reporting of results).

These codes are used to facilitate efficient modern electronic communication and support patient records, public health and activity reporting, payments, audit, research and the automation of repetitive manual tasks.

The codes used for learning disabilities can be seen in the table below

Source: Clinical Terms Browser; supplied by NHS West Midlands

Version Date: 1/4/2010

Domain: Clinical Findings

Developmental disorders
<table>
<thead>
<tr>
<th>Code</th>
<th>Term Id</th>
<th>Current/option</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>X00TI</td>
<td>Y01LC</td>
<td>C</td>
<td>Developmental disorder</td>
</tr>
<tr>
<td>E3...</td>
<td>Y01Ky</td>
<td>C</td>
<td>Mental retardation</td>
</tr>
<tr>
<td>Xa1aW</td>
<td>Ya3CJ</td>
<td>C</td>
<td>Borderline mental retardation</td>
</tr>
<tr>
<td>XE2a3</td>
<td>Y01L0</td>
<td>C</td>
<td>Mild mental retardation, IQ in range 50-70</td>
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<tr>
<td>Eu700</td>
<td>YMB6i</td>
<td>O</td>
<td>[X]Mild mental retardation with the statement of no, or minimal, impairment of behaviour</td>
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<td>[X]Mild mental retardation, significant impairment of behaviour requiring attention or treatment</td>
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<td>Eu70y</td>
<td>YMB6k</td>
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<td>[X]Mild mental retardation, other impairments of behaviour</td>
</tr>
<tr>
<td>Eu70z</td>
<td>YMB6l</td>
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<td>[X]Mild mental retardation without mention of impairment of behaviour</td>
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<td>Eu71y</td>
<td>YMB6p</td>
<td>O</td>
<td>[X]Mod retard oth behav impair</td>
</tr>
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<td>YMB6q</td>
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<td>[X]Moderate mental retardation without mention of impairment of behaviour</td>
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<td>Current/option</td>
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<td>-------------------------------------------------------------------------------------------------------</td>
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<td>Profound mental retardation with IQ less than 20</td>
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<td>Xa0ER</td>
<td>Y01L3</td>
<td>C</td>
<td>Educationally subnormal</td>
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<td>Xa3HI</td>
<td>Ya5af</td>
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</tr>
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<td>Mental retardation NOS</td>
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<td>YMB71</td>
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<td>YMB7A</td>
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<td>Y01LH</td>
<td>C</td>
<td>Disorder of speech and language development</td>
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<td>YMB7E</td>
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<td>Developmental expressive language disorder</td>
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<td>Developmental aphasia</td>
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<td>Y00P8</td>
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<td>Acquired epileptic aphasia</td>
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<td>[X] Developmental disorder of speech &amp;/or language, unspecified or NOS</td>
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<td>Yao7w</td>
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<td>E</td>
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<td>Term Id</td>
<td>Current/option</td>
<td>Description</td>
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<td>----------------</td>
<td>---------------------------------------------------------------------------------------------</td>
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<tr>
<td>Eu801</td>
<td>YE1CL</td>
<td>E</td>
<td>[X] Expressive language disorder: [developmental dysphasia, expressive type] or [developmental aphasial, expressive type]</td>
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<tr>
<td>Eu80y</td>
<td>YE1CN</td>
<td>E</td>
<td>[X] (Other developmental disorders of speech and language) or lisping</td>
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<tr>
<td>X00TL</td>
<td>Y01LP</td>
<td>C</td>
<td>Developmental disorder of scholastic skill</td>
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<tr>
<td>XaREt</td>
<td>Yatj6</td>
<td>C</td>
<td>Mild learning disability</td>
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<tr>
<td>XaQZ4</td>
<td>Yat7w</td>
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<td>Yatj8</td>
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<td>Specific reading disorder NOS</td>
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<td>Code</td>
<td>Term Id</td>
<td>Current/option</td>
<td>Description</td>
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<td>[X] Overactive disorder associated with mental retardation and stereotyped movements</td>
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<td>YMDrC</td>
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<td>Velar dyspraxia</td>
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<td>YMDrD</td>
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<td>Clumsiness -motor delay</td>
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<td>Other development delays</td>
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<td>YMB7R</td>
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<td>Code</td>
<td>Term Id</td>
<td>Current/option</td>
<td>Description</td>
</tr>
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</tr>
<tr>
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<td>O</td>
<td>[X] Unspecified disorder of psychological development</td>
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<td>X00TQ</td>
<td>Y01M0</td>
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<td>Developmental agnosia</td>
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<td>XE1aB</td>
<td>YMB7b</td>
<td>O</td>
<td>[X] Other disorders of psychological development</td>
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<tr>
<td>Eu8y.</td>
<td>YE1CS</td>
<td>E</td>
<td>[X] Disorders of psychological development: [other] or [developmental agnosia]</td>
</tr>
<tr>
<td>XE1bg</td>
<td>YE1DF</td>
<td>E</td>
<td>Developmental delay (&amp; [learning] or [specific])</td>
</tr>
<tr>
<td>XE1bm</td>
<td>YE1DI</td>
<td>E</td>
<td>(Disturbance in learning) or (development delay - NOS)</td>
</tr>
</tbody>
</table>

### 2.17 Obesity Read Codes

The read codes used by clinicians for obesity can be seen in the boxes below

**Dataset Specification**

1. **Patient selection criteria:**
   a) Registration status

<table>
<thead>
<tr>
<th>Current registration status</th>
<th>Qualifying criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Currently registered for GMS</td>
<td>Most recent registration date &lt; (REF_DAT)</td>
</tr>
<tr>
<td>Previously registered for GMS</td>
<td>Any sequential pairing of registration date and deregistration date where both of the following conditions are met: registration date &lt; (REF_DAT); and deregistration date &gt;= (REF_DAT)</td>
</tr>
</tbody>
</table>
3.0 Recommendations

- Improve national and local data to provide demographic information that includes disability and distinguishes between physical disability, LD and limiting chronic health conditions.

- Nationally investigate the potential for LD read coding to be linked to chronic conditions through QOF so that data extraction queries can include cross referencing of patients with a LD who are overweight/obese at consortia and practice level to aid service planning and development.

- Locally to maximise the opportunities that the LD Health Checks provide for data collection and analysis to aid service planning. It is recommended that the Coventry approach to data collection from LD Health Checks be rolled out across the West Midlands to ensure that effective planning and development of services occurs.

- Locally to identify opportunities to facilitate discussions on data collection with Local LD Partnerships as part of the on-going commitment to the Valuing People Now assessments.

- Locally to adopt data collection as a key strand within the peer review process for Valuing People Now in the West Midlands.

- Locally commissioners should include data collection for LD and Obesity within service specifications and contracting in all commissioning contracts and ensure that this is written into the West Midlands LD and Obesity charter.
• Locally consider rolling out the NHS West Midlands CQIN relating to the coding and flagging of LD within provider trusts to incorporate weight management related data linked to LD status.

• Locally GP practices to implement systems to monitor the number of people with LD who are overweight/obese and those referred/involved in practice and community based weight management/physical activity/healthy eating services.

• Locally develop systems to determine the number and type of organisations providing physical activity, healthy eating and weight management services for people with LD to enable gap analysis to be undertaken.

• Locally support the roll out of the Equality Metrics Framework in the West Midlands localities with physical activity and obesity included within the healthy living indicators.

• Locally to recognise the training and support requirements of staff involved in data collection and ensure that these are met to improve the robustness of data.

• Develop effective links to the Improving Health and Lives Learning Disability Observatory to ensure that effective methods of data collection are shared across the country.

It should be noted that the options and recommendations set out in this report will need to evolve and take note of national level decisions regarding the direction of national outcomes frameworks and the direction of the Public Health Observatories and Special Interest Observatories.

Copies of this document and others relating to the West Midlands Learning Disability and Obesity programme can be downloaded from http://www.obesitywm.org.uk/panlinks.aspx?id=OBESITY_LEARNING_DISABILITIES
REFERENCES


