Improving Health and Lives:
Learning Disabilities Observatory

Health Inequalities and People with Learning Disabilities in the UK: 2011

Implications and actions for commissioners and providers of social care

Evidence into practice report no. 4

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About the author

Sue Turner initially trained as a nurse for people with learning disabilities in Bristol. She has worked within training, as a Nurse Advisor in Gloucestershire, and has managed a variety of services for people with learning disabilities in Gloucestershire and Bristol including community learning disability teams. Sue was the Valuing People Lead for the South West Region for four and a half years, initially job sharing the role with Carol Robinson. During this time, Sue developed the health network in the South West and introduced the health self-assessment to the region. She later worked closely with the Strategic Health Authority on its implementation. Sue is now leading on the Improving Health and Lives project for the National Development Team for Inclusion.

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Introduction

Improving Health and Lives (IHaL) is the Learning Disabilities Public Health Observatory - www.ihal.org.uk – a three year project funded by the Department of Health in response to Sir Jonathan Michael's 2008 inquiry into access to healthcare for people with learning disabilities[1]. The national observatory aims to provide better, easier to understand information on the health and wellbeing of people with learning disabilities and to help commissioners and others make use of existing information whilst working towards improving the quality and relevance of data in the future.

Most IHaL publications are aimed at health commissioners and providers. However, a number of the health inequalities that people with learning disabilities face also have implications for social care commissioners and providers, and social care providers have a responsibility to support people to access health services.

Based on *the Health Inequalities and People with Learning Disabilities in the UK: 2011* report [2] this evidence into practice report sets out the determinants of health inequalities, and asks what they mean for social care including social care commissioners, care managers/social workers, providers and support workers.

Why should social care commissioners and providers bother about health inequalities?

- Some health inequalities are related to wider social care issues like poverty, unemployment and poor housing.
- The impact of health inequalities is serious, affecting both quality of life and life expectancy.
- Social care providers have a legal duty (under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010) to support people to access health care services. An understanding of health inequalities and their determinants can enable support staff to be more effective in this role.
- Poor health can cost money. For example, people with learning disabilities who are in pain associated with untreated medical disorders may develop challenging behaviour. People with poor mobility due to lifestyle issues such as obesity can require costly equipment. Addressing health inequalities can make a significant contribution to the prevention agenda in social care.

Health inequalities

People with learning disabilities have poorer health than their non-disabled peers. These differences are to an extent avoidable, and as such represent health inequalities. The impact of these inequalities is serious. The research indicates that people with moderate to severe learning disabilities are three times as likely to die early than the general population.

There are five key determinants of health inequalities [2]:

1. Greater risk of exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness.
2. Increased risk of health problems associated with specific genetic, biological and environmental causes of learning disabilities.
3. Communication difficulties and reduced health literacy.
4. Personal health risks and behaviours such as poor diet and lack of exercise.
5. Deficiencies relating to access to healthcare provision.

We suggest the actions described below can help social care commissioners and providers, in partnership with health commissioners and community learning disability teams/specialist health staff improve health outcomes for people with learning disabilities.

1. The social determinants of poorer health

The importance of poverty, poor housing, unemployment and social isolation as factors leading to poorer health are well known. People with learning disabilities are more likely to experience some or all of these factors.

Bullying at school and discrimination in adulthood are frequently experienced by people with learning disabilities. They are also related to poorer health. People with learning disabilities from minority ethnic communities may experience poverty and racism, and thus face greater health inequalities than people with learning disabilities from majority ethnic communities.

Suggested actions for social care

- **Social care commissioners** can work with Clinical Commissioning Groups (CCGs) and Public Health to pool knowledge and understanding of the social determinants of health. Information on these issues should be included in the Joint Strategic Needs Assessment (JSNA) to inform Health and Wellbeing Boards. A good example of a JSNA can be found at: www.cambridgeshirejsna.org.uk/

For example: In Devon, care managers who bring support plans to panel are asked if they have considered employment for the individual before funding is agreed. Providers are also asked how many people of working age they support have employment of 16+ hours a week. Asking these questions has helped staff to think about employment as the first option for individuals.

- Plans to increase employment and tenancies/home ownership (settled accommodation) for people with learning disabilities should be part of local strategies. **Social care commissioners and care managers** play a crucial role in changing the culture of local services so that employment and settled accommodation are seen as priorities.

- **Social care commissioners and care managers** can support the creative use of personal budgets to enable access to the community and support people into work. The Jobs First initiative is testing the use of personal budgets, along with other funding streams to fund employment related support. The interim report is available at: www.kcl.ac.uk/sspp/kpi/scwru/res/roles/jobs.aspx

For example: The Inclusive Fitness Initiative (IFI) supports the fitness industry to become more inclusive for all disabled people. It addresses four key areas: accessible facilities, inclusive fitness equipment, staff training and inclusive marketing strategies. South Gloucestershire employed an IFI co-ordinator to encourage the engagement of people with learning disabilities in physical activity, and increase the uptake of the IFI Mark, a quality mark accreditation scheme. Most leisure and fitness facilities in South Gloucestershire are now accredited. For further information on IFI please go to: www.inclusivefitness.org/

- **Social care commissioners** can work with local authorities to enable access to community facilities as this can combat social exclusion and isolation, and result in health benefits. Some local authorities have employed staff to support access to community facilities.

- **Social care commissioners** can work with the police to develop local strategies to address hate crime. Good practice guidance can be accessed at: http://www.inclusionnorth.org/documents/HateCrimeGoodPracticeGuide.pdf

2. Increased risk of health problems associated with specific genetic and biological causes of learning disabilities

There are a number of syndromes associated with learning disabilities which are also associated with specific health risks. For example, people with Down's syndrome are more likely to experience early onset dementia, and people with autistic spectrum disorders are more likely to have mental health problems.

Recent research has highlighted possible interactions between some genetic causes for learning disability and the environment. For example, people with Angelman syndrome may display aggressive or self-injurious behaviour if it is effective in maintaining the attention of carers, as they often find social contact very pleasing.

Suggested actions for social care

- **Social and health care commissioners** need to work with public health and CCGs to understand the local population of people with learning disabilities in terms of age profile, ethnic group and other significant population issues such as number of people with Down's syndrome, so that they can plan strategically to meet future need.
- **Providers and support staff** need to understand the implications of specific syndromes and plan person centred care accordingly. Training should be provided for support staff as appropriate. Community learning disability teams can also provide advice and support.

For example: The Tees integrated commissioning group recognised that they had an ageing learning disability population at risk of dementia. They jointly funded a development post to support the implementation of the National Dementia Strategy[3]. Understanding local demography and providing a population forecast to plan future services was a major part of the project[4]. For further information see: www.phine.org.uk/securefiles/110720_1133//South%20Tees%20LD%20Dementia%20Report%202010.pdf

- **Providers and support staff** should encourage and support people with learning disabilities to have health checks (see next section). There are a number of syndrome specific health checks that can be carried out. For further information see a Step by Step guide to annual health checks for GPs[5]: www.rcgp.org.uk/pdf/CIRC_A%20Step%20by%20Step%20Guide%20for%20Practices%20(October%2010).pdf

3. Communication and understanding of health issues

People with learning disabilities may have poor awareness of their bodies and health issues generally. They may not express pain or discomfort in a way that others recognise. Limited communication skills may reduce their ability to let others know that something is wrong. As a result, those who know the individual well play an important role in the identification of health needs for many people, particularly those with more severe learning disabilities.

Suggested actions for social care

- Support staff are often the first to notice changes which may indicate a health problem if the individual lives in supported living or residential care. However, research indicates that support staff may feel they are lacking in skills, knowledge and training to identify health needs [2]. **Social care providers** need to ensure that support staff receive training so that they can recognise health needs. **Social and health care commissioners** can jointly commission community learning disability teams to support providers, enabling support workers to recognise potential problems, and take action. The way in which individuals express pain or discomfort should be documented, and support staff trained to use this information and react appropriately.

  For example: The Anticipatory Care Calendar (ACC) was developed in 2006 by the Merseyside and Cheshire Cancer Network. It works on a traffic light system and is designed to alert social care staff to health changes and provide clear directions about accessing primary care. For further information please contact Tracie.Keats@mccn.nhs.uk

- **Social care providers** should support people with learning disabilities to understand more about their bodies and general health issues. Community learning disability teams can support providers with these issues. There are also some good accessible resources available at: www.easyhealth.org.uk and www.apictureofhealth.southwest.nhs.uk

- Annual health checks are currently part of a Directed Enhanced Service which requires PCTs to offer GPs the opportunity to carry out health checks on people with learning disabilities known to social care for a fixed payment. There is clear evidence that health checks lead to the detection of unmet health needs, and result in targeted actions to address needs identified [6]. However, although the number of health checks is improving, in 2010/11 just under 50% of those eligible received a health check [7]. GP practices should invite people with learning disabilities who are eligible to attend for a health check appointment. It is good practice to include a pre-health check questionnaire with the invitation [8, 9]. For an example of a questionnaire, please see: www.oxleas.nhs.uk/site-media/cms-downloads/Microsoft_Word_-_Oxleas_HAP_prehealth_check_for_DES.pdf **Providers/support staff** can help the person have a successful health check by:

  - Helping the person with learning disabilities understand the importance of a health check.
  - Supporting them to fill out the pre-health check questionnaire.
  - Arranging for someone who knows the person well to go with them to the health check.
  - Working with community learning disability teams/specialist health staff and the GP practice to put in place any reasonable adjustments necessary (such as longer appointment times) for the person to have a successful health check.

Further information about health checks is available at: www.ihal.org.uk

- Health Action Plans can be a helpful way of supporting the person with learning disabilities to understand about their health. They should be updated after a health check. **Providers/support staff** should ensure that the person knows about and attends any follow-up appointments and referrals. Specialist health staff/community learning disability teams can support providers with the introduction and maintenance of Health Action Plans.

4. Personal health risks and behaviours

People with learning disabilities take less exercise than the general population, and their diet is often unbalanced with an insufficient intake of fruit and vegetables. People with learning disabilities can also find it hard to understand the consequences of lifestyle on their health, and are much more likely to be overweight than the general population.

People with learning disabilities are also much more likely to be underweight than the general population.

Young people with mild learning disabilities have higher rates of smoking than their peers.

People with learning disabilities may not have the same access to information about sex and sexuality as other young people, and may face particular barriers in accessing sexual health services.

Suggested actions for social care

- **Social care providers/support workers** need to understand what constitutes a healthy lifestyle so they can enable people with learning disabilities to make informed choices. **Health and social care commissioners** need to ensure that health promotion and advice is available to social care providers.

- **Providers/support workers** need to ensure that people with learning disabilities have accessible information and support to understand lifestyle choices with regard to diet and exercise. Accessible information is available as referenced above.

- **Providers/support workers** need to be able to recognise if a person with learning disabilities is underweight, and seek medical advice.

- **Providers/support workers** should support people with learning disabilities to access general health promotion initiatives regarding tobacco, alcohol, substance misuse and sexual health in the same way as the general population. **Social care commissioners** should alert health commissioners to any problems with access so that they can be addressed.

For example: Halton has a Community Bridge Building Team which supports people to use community facilities. P was recently referred to the team as on the day he had no activities he was bored and in the past had spent the day drinking. P likes physical activities but had been unable to organise anything for himself. After discussing options with P he decided he would like to use a local leisure centre to get himself fit. P was supported to get a Halton Leisure Card and a bus pass, and began using the leisure centre almost immediately. P now uses the leisure centre independently, and it has been noted how much happier he is. P says he feels fitter, has lost weight and is keen to continue with his new healthier life style. The team keep in touch with P to monitor how things are going but to date P has not needed any extra support and seems to be taking full advantage of his new found independence.

5. Access to and the quality of health care and other services

People with learning disabilities can find it hard to access health services for a number of reasons, including the failure of health services to make reasonable adjustments to enable access, disablist attitudes among health care staff and 'diagnostic overshadowing' (when symptoms of ill health are mistaken for behavioural problems or as being part of the person's learning disability).

People with learning disabilities have a lower uptake of health promotion and screening opportunities than the general population. This means that early stage cancers may not be picked up, and dental, hearing and sight conditions remain untreated. Use of primary care services is also lower than might be expected for people with learning disabilities, who often have chronic health conditions.

People with learning disabilities who have cancer are less likely to be told of their diagnosis or prognosis. They are less likely to be involved in decisions about their care, given pain relief or have access to palliative care.

People with learning disabilities may not get the same access to primary and secondary mental health services as the general population.

A very high proportion of people with learning disabilities are receiving psychotropic medication, most often anti-psychotic drugs, to control challenging behaviour despite lack of evidence for their effectiveness and evidence of considerable harmful side effects.

There is worrying evidence of failure to comply with the Mental Capacity Act including examples of Do Not Resuscitate orders being placed on patients' records without discussion with the individual or family, and family carers being asked to sign consent forms for adults [10]. There is also evidence that social care staff lack understanding of the Mental Capacity Act [2]

Transition between services remains problematic for some people with learning disabilities. This includes transition between children's and adult services, and other transitions such as transition between hospital and home or community.

Suggested actions for social care

Many of these issues are about health services. However it is important that social care providers/support staff understand the difficulties people with learning disabilities face, and their rights to reasonable adjustments, so they can act as advocates where necessary. Providers/support staff also have a role in enabling people with learning disabilities to access health services effectively.

- **Providers/support staff** can make a major contribution to the effectiveness of the care people receive from health services. They can provide important information about the way a person communicates, risk issues and their medical history. If the person needs to be admitted to hospital, there is a helpful guide [11] that sets out what hospitals, family carers and paid support staff can do to help make the person's stay a success. The guide can be downloaded from: www.hft.org.uk/Resources/Home%20Farm%20Trust/Family%20Carer%20Support/Documents/WorkingTogether.pdf

- Patient Passports are a good way of providing vital information about the individual to hospital staff. **Providers** can work with community learning disability teams/specialist health staff to ensure that people with learning disabilities have Patient Passports, and that these are used should the person need to go to hospital. There are numerous examples of Patient Passports. Some are available on the IHaL reasonable adjustments database. See: www.improvinghealthandlives.org.uk/adjustments/

- **Providers** can support people with learning disabilities to understand the importance of health screening and promotion. As referenced above, there is accessible information available to support people through difficult procedures. In addition the Seeability website www.lookupinfo.org/ contains useful information for people who need a sight test and who experience sight problems, and the Hearing and Learning Disabilities website www.hald.org.uk has useful information on audiology and hearing loss.

- **Social and health care commissioners and providers** need to ensure that staff have training and support to understand and comply with the Mental Capacity Act (2005). Helpful guidance on the Mental Capacity Act [12, 13] can be found at: www.hft.org.uk/family_carer_support/MCA_resource_guide and www.rcgp.org.uk/PDF/CIRC_Mental%20Capacity%20Act%20Toolkit.pdf

- Poor transition between services can lead to poor outcomes, as well as causing confusion and anxiety for people with learning disabilities and family carers. **Social and health care commissioners** need to ensure there are robust transition protocols in place. Good practice guidance on transition to adulthood [14] can be downloaded at: www.gettingalife.org.uk/downloads/2011-Pathways-to-getting-a-life.pdf.There is also good practice guidance on young people with complex needs [15] which can be downloaded at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592. With regard to discharge from hospital, **social and health care commissioners** should plan for discharge immediately after admission, or beforehand if the admission is planned. Any discharge planning should be based on the patient's person centred plan and relevant factors in the home environment including any risk factors.

- **Providers** should plan, with the individual if possible, for end of life care. Community learning disability teams can support providers and advanced care planning tools are available [16]. For further information please see: www.endoflifecareforadults.nhs.uk/publications/ppcform

For example: Living Well, 'is a dedicated person focussed service that supports people with a learning disability who have life threatening illness or have a need for terminal health support to have a personalised care package to support their discreet support needs . A support booklet has been developed that captures the 'whole person 'providing information on how to support the individual to continue participating in life to the full. The partnership includes Hull City Council, The Cancer Network, the local hospice, local primary care services including continuing health care and the local CTLD services .The work has reached national recognition through the partnership work undertaken with Helen Sanderson's person centred planning association'. For further information please contact: Tracy.meyerhoff@hullcc.gov.uk

- **Social and health care commissioners** should jointly commission services to work together to address local population need and work towards outcomes.

Summary of suggested key actions

Commissioners

- Develop a joint understanding of the local population, and the health inequalities people with learning disabilities face. Develop joint commissioning plans to reduce and where possible eliminate avoidable health inequalities.

- Ensure that local strategies prioritise employment and settled accommodation, and plan to use personal budgets creatively to support employment and access to the community.

- Work with the police to address hate crime.

- Ensure that providers know how to support people with learning disabilities to understand the importance of health screening and promotion, and work with health commissioners to ensure that people with learning disabilities can access general health promotion initiatives.

- Monitor understanding and compliance with the Mental Capacity Act.

- Ensure good transition protocols are in place.

Providers

- Provide training and advice for support staff so that they can understand the implications of specific syndromes and plan person centred care accordingly.

- Ensure that support staff have the knowledge and skills to recognise changes in an individual's behaviour which may indicate they are in discomfort or unwell, and provide them with information which will enable them to support people with learning disabilities to access health services, including health checks, appropriately.

- Ensure that support staff understand what constitutes a healthy lifestyle, so that they can support people with learning disabilities to make informed choices.

- Work with specialist health staff to ensure that support staff have access to and can use appropriate accessible information to support people with learning disabilities to understand their health issues, including the use of Health Action Plans and Health Passports.

- Ensure that all staff understand and comply with the Mental Capacity Act.

- Plan with individuals for end of life care.

Conclusions

People with learning disabilities experience unacceptable health inequalities that put them at risk of disease and premature death. Many of the determinants of poor health can be mitigated by appropriate preventative measures such as better screening, targeted information, advice and support and reasonable adjustments to ensure people get good quality healthcare. In this document, as well as setting out why health inequalities must be tackled, we have suggested how they can be addressed and have referenced a number of useful commissioning tools and case examples to support better practice in treating people with learning disabilities. Health commissioners have a key role in ensuring progress in this area and in securing a better experience for people with learning disabilities, but social care commissioners and staff also have a role to play.

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