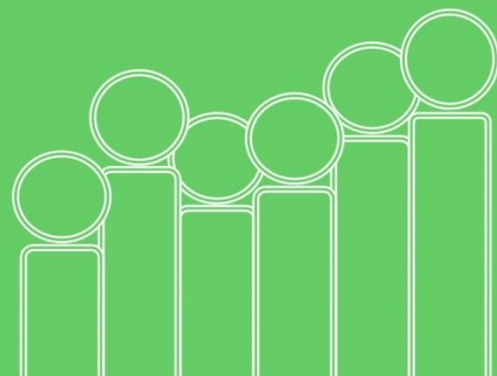




Improving Health and Lives:
Learning Disabilities Observatory

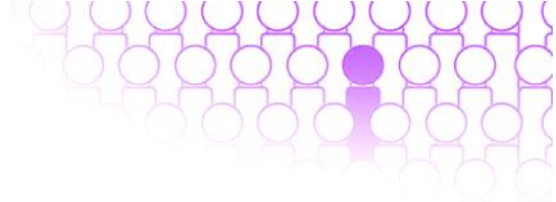
Health Inequalities and People with Learning Disabilities in the UK: 2010 Implications and actions for commissioners Evidence into practice report no.1

Sue Turner and Carol Robinson



Supported by the Department of Health





Health Inequalities and People with Learning Disabilities in the UK: 2010

Sue Turner
Carol Robinson

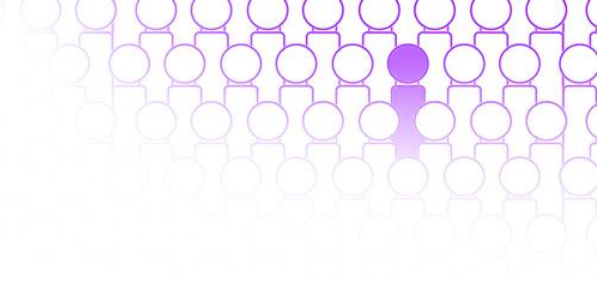
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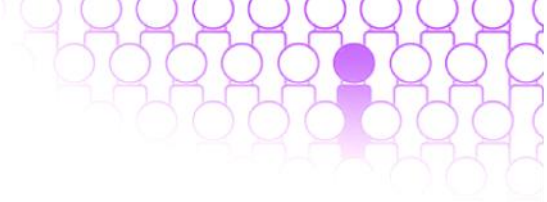
Introduction

Improving health and lives (IHaL) is the Learning Disabilities Public Health Observatory - www.improvinghealthandlives.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 disabilities¹. 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 to make use of existing information whilst working towards improving the quality and relevance of data in the future. This paper is the first in a series written for commissioners. It follows the ‘Health Inequalities and People with Learning Disabilities in the UK report’², written for IHaL by Eric Emerson and Susannah Baines and aims to translate the key messages from that into advice for commissioners (link below).

http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf

People with learning disabilities face serious health inequalities that the health services have a duty to reduce. This document provides guidance for those people with responsibility for commissioning services about ways to increase access to, and improve healthcare. The guidance will also be of interest to family carers and professionals interested in the welfare of people with learning disabilities. Effective commissioning to address these inequalities will involve a number of key actions including:

1. Ensuring that the health inequalities faced by people with learning disabilities are carefully documented in the Joint Strategic Needs Assessment (JSNA).
2. Taking action to commission with all relevant partner agencies, services which address the determinants of health inequalities whether these are linked to:
 - social factors such as poverty and poor housing,
 - specific conditions
 - poor communication and understanding of health issues
 - individual lifestyles
 - the way healthcare is delivered
3. Improving the number and quality of annual health checks.
4. Ensuring that reasonable adjustments are implemented in all health care settings
5. Raising awareness of healthy lifestyles with people who have learning disabilities, their families and paid supporters
6. Measuring progress using tools such as the Performance and Self- Assessment Framework (Department of Health 2009)³.



Background

Emerson and Baines have updated the earlier work conducted by the team at Lancaster University on the health needs of people with learning disabilities⁴. Their recent paper has been published on the Improving Health and Lives (IHAL) web site. In this document, we have translated the findings of their updated work into a set of guidance notes for commissioners. The main aim is to provide clear and concise guidance about appropriate ways to tackle the health inequalities that manifestly exist. In addition, we wish to signpost the reader to some useful tools and case studies that illustrate how some places in England have tried to overcome known inequalities.

The impact of these inequalities on the health of people with learning disabilities is serious. The research indicates that people with moderate to serious learning disabilities are three times as likely to die early than the general population. They are more likely to experience poor general health as reported by their main carer and to have high levels of unmet physical and mental health needs.

It is imperative that such inequalities are taken seriously because failure to address them could place both commissioner and provider NHS Trusts in breach of their statutory responsibilities under the Disability Discrimination Acts of 1995⁵ and 2005⁶ as well as the UN Convention on the Rights of Persons with Disabilities⁷.

The Equality Act 2010⁸ replaced several anti-discriminatory laws with a single act and the current Government is proposing that public bodies should be made more accountable to local people for their performance in implementing their duties under this act.

Emerson and Baines² identified five key determinants of health inequalities:

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 and biological 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.

The actions described below can help commissioners improve health outcomes for people with learning disabilities.

This first policy and practice advice report, as it is concerned with an overview of health inequalities, covers a number of broad strategic issues. Subsequent IHaL policy and practice papers will address a number of the questions raised in this report in more detail.



What can commissioners do to reduce the effects of these determinants?

Joint Strategic Needs Assessment

Issue

Evidence shows that the health needs of people with learning disabilities are often poorly understood, leading to avoidable health inequalities.

Commissioning Action

- In order to make sure that the health inequalities faced by people locally are understood and considered by strategic commissioners, comprehensive and accurate information should be included in the **JSNA**, as JSNAs will inform Health and Wellbeing Boards who will ‘take on the function of joining up the commissioning of local NHS services, social care and health improvement’⁹. A good example of a JSNA that does this can be found at: <http://www.cambridgeshire.gov.uk/business/research/health/default.htm>
- Good quality information is only helpful if it is used to inform service provision. **Health and Wellbeing Boards** should ask for evidence that information in JSNAs has been used to inform strategic commissioning decisions.
- There is still a dearth of good quality information about people with learning disabilities in many local areas. **Health needs assessments** are a good way of gathering information to inform JSNAs, and **health equity audits**¹⁰ enable commissioners to use evidence about health inequalities to inform service planning and delivery. There is a good example of a health equity audit done by Cornwall on the Improving Health and Lives website: <http://www.improvinghealthandlives.org.uk/areas/cornwall/tacklinghealthinequalities>
Improving Health and Lives are doing some work on health equity audits and monitoring. For further information please go to <http://www.improvinghealthandlives.org.uk/talk>
- **Involving people with learning disabilities and family carers** is ‘essential to delivering personalised, effective services and equal outcomes’¹¹. Partnership Boards should be able to advise on the best way of doing this locally.

In summary:

- Include comprehensive and accurate information about the health of people with learning disabilities in the JSNA
- Use this information to inform strategic commissioning
- Complete a health needs assessment and a health equity audit
- Talk to the Partnership Board about involving people with learning disabilities and family carers

Joint Commissioning

Issue

The importance of poverty, poor housing, unemployment, social disconnectedness and overt discrimination as factors leading to poorer health is well documented and are especially important for people with less severe learning disabilities who tend to be in poorer socio economic circumstances. The last Government sought to promote social inclusion generally and introduced Public Sector Agreement (PSA) 16¹², which aims to increase the number of people with learning disabilities (amongst other groups) in both settled accommodation and paid employment. Recent national figures show there are both fewer people in settled accommodation and paid employment in England than last year¹³.

Commissioning Action

- In order to understand **the wider determinants of health**, it is important that information is gathered on these issues and included in the JSNA so that life outcomes can be identified and addressed strategically.
- To improve **life outcomes**, it is important to commission specialist learning disability health services that work in partnership with social work professionals and others who are concerned with wider life outcomes.
- Having **a job and settled accommodation** are important factors in tackling poverty and social exclusion. Plans to increase employment and settled accommodation for people with learning disabilities should be part of local strategies. There are plenty of examples of people

For example

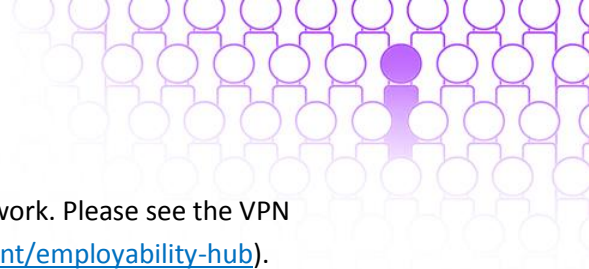
This is a quote from a family carer involved in the sustainable hub of innovative employment for people with complex needs ‘The progress (my brother) has made within the service has been quite remarkable Starting out at a specialist college and moving to Residential Care and now moving into his bungalow has built his self -esteem beyond recognition. Now he has moved into paid employment with support of course from the staff and the team at Shiec. The quality of that support is quite outstanding. You can see how proud he is of this achievement and a spin-off is that his challenging behaviour has reduced. His general state of well- being is also most noticeable and I believe he is much happier and fulfilled”.

For example

Kent County Council Supported Employment Service did a study which considered changes to welfare benefit entitlements, the cost of services received and tax and national insurance payments before and after employment.

The study suggests there are opportunities for achieving greater savings by obtaining more full time jobs for those not in receipt of day services, and/or are unknown to social services, and developing a greater focus on those who are dependent on local day services prior to obtaining a job. Early indications suggest that for every person supported into work there is an average annual saving of £1290 to the council and a saving of over £3,500 to the taxpayer.

¹However, there is considerable concern about the reliability of the baseline dataset from 2008-09 although reliability for the most recent figures appears to have improved.



with learning disabilities who have positive experiences of work. Please see the VPN employabilityhub(www.valuingpeoplenow.dh.gov.uk/content/employability-hub).

- Getting accurate and accessible **benefits advice** is clearly important to people with learning disabilities and their families. Local areas should check that their welfare rights service is easily accessible to people with learning disabilities and that information is provided in easy read formats.

For example

Devon has a Making it Pay project. People with learning disabilities who want work get a 'better off' calculation which looks at all their benefits and makes sure they are getting what they are entitled to. People are then given a breakdown of what they would get if they were in work. The project has yet to find someone who would be financially worse off in work.

- **Good access to community facilities** such as social centres, leisure centres and libraries are important to combat social exclusion and isolation. The Disability Discrimination Act sets out requirements regarding access for public services, but modifications other than to the physical structure of the building are often needed. Steps can be taken to involve disabled people in improving the welcome they receive in such settings.

For example

The Inclusive Fitness Initiative (IFI) supports the fitness industry to become more inclusive for all disabled people. It addresses 4 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 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 <http://www.inclusivefitness.org/>

In summary

- Include information about life outcomes in the JSNA
- Commission services to work in partnership
- Include plans to increase settled accommodation and employment in commissioning strategies.
- Check that benefits advice is accessible
- Ensure good access to community facilities.

Health Checks

Issue

There is considerable variation in the percentage of people reported to have received a health check, both by PCT and SHA^{14 15} and yet it is clear that the introduction of health checks for people with learning disabilities consistently lead to:


- the detection of unmet, unrecognised and potentially treatable health needs (including serious and life threatening conditions such as cancer, heart disease and dementia) and
- targeted actions to address health needs.

Commissioning Action

- Effective commissioning is based on a sound understanding of the health needs of the local population, therefore commissioners should ensure that there is annual updating and validating of **GP registers** (Quality Outcomes Framework (QOF) registers are more comprehensive than the Directed Enhanced Service registers as these only include people known to local authorities). Specialist learning disability services are well placed to support GP practices and some areas have developed primary care liaison posts. Data collection and sharing protocols should be in place locally, however lack of good data remains a barrier to better health care in many areas¹¹.
- The **Directed Enhanced Service**¹⁶ relates to people with learning disabilities known to local authorities, but some areas have offered health checks to all people with learning disabilities with the aim of reducing health inequalities for a wider group of people. Commissioners should prioritise increasing the uptake of health checks for those eligible under the DES as last year's figures indicate that only 41% of people received a check¹¹. Support from community learning disability teams has proved useful in increasing uptake, and some areas have implemented a Local Enhanced Service (LES) with an alternative provider where GPs have been unwilling to sign up to the DES. Commissioners may also wish to consider prioritising health checks for all people with learning disabilities.

For example

Some areas have made additional efforts to ensure health staff have access to accessible information. The South West Strategic Health Authority supported the development of a website and DVD of accessible health information called Picture of Health. The DVD was developed as GPs have found that downloading information from websites can be time consuming. There was a launch of the initiative, to which mainstream health staff were invited, and the website and DVD are being updated for a re-launch during March 2011. For more information go to <http://www.apictureofhealth.southwest.nhs.uk>

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- In order to support people with learning disabilities to understand their health issues, GPs and practice staff doing health checks should have good access to **accessible information** and any relevant research. The Easy Health website is an excellent source of accessible information on health, most of which can be downloaded for free. Go to <http://www.easyhealth.org.uk/>
 - People with learning disabilities are more prone to a number of **health conditions**. Therefore at the annual check up, specific checks should be made relating to any diseases or disorders known to be associated with the underlying condition. . There are some examples of syndrome specific medical health checks in A Step by Step Guide for GP Practices: Annual health checks for people with a learning disability¹⁷

In summary:

- Regularly update and validate GP registers
- Prioritise increasing the uptake of health checks
- Ensure health staff know how to find and use accessible information
- Ensure the health check includes specific investigations for any underlying conditions.

Reasonable Adjustments

Issue:

Evidence shows that one of the barriers to accessing healthcare services is the failure to make reasonable adjustments to enable people with learning disabilities appropriate access to health services. Services often fail to take account of the literacy and communication difficulties experienced by many people with learning disabilities, who may have poor awareness of their bodies and health issues generally. The Six Lives progress report indicates that implementing reasonable adjustments can make a big difference to people's experience of health but lack of progress in this area remains a concern.

Commissioning Action:


- In order **to support people with learning disabilities and their carers to understand health issues**, health professionals need easy access to accessible information. (See above for useful web sites)
- People with learning disabilities may not be able to tell health professionals how they feel, or what they want and need. **Information about how individuals communicate** should be available when people with learning are in hospital and other health settings, so that health professionals can support people appropriately. Progress in this area has also been linked to acute liaison nurse posts¹¹. Commissioners should ensure that processes exist to ensure patient records include this information, and for primary care see A Step by Step Guide for GP practices¹⁷. Commissioners should also consider the appointment of acute liaison nurses where these do not exist.
- People with learning disabilities do not get full benefit from **health promotion and screening opportunities** as there is a low take up by this group. This means that early stage cancers may not be picked up, and hearing and eye conditions remain untreated. Regular health checks are a good way of identifying the need for further screening. As referenced above

For example

Working Together: Easy steps to improving how people with learning disabilities are supported when in hospital is a guide produced by a working group of family carers, hospital staff, learning disability nurses and paid support staff facilitated by HFT. The aim of the guide is to ensure people with learning disabilities get the right support and effective treatment during their stay in hospital. The guide can be downloaded at http://www.hft.org.uk/p/4/121/working_together.htm

For example

For example In North Cumbria, every practice was visited by the Nurse Specialist for cervical screening following an audit showing the low uptake of screening by women with learning disabilities. During this visit, training was provided to health staff about the need to encourage women with learning disabilities to have the test, the importance of keeping women on the screening programme and of not making assumptions about the woman's sexual activity.



there is accessible information available to support people with learning disabilities through difficult procedures. Some areas have also put in extra support to enable people to access screening. The Seeability website <http://www.lookupinfo.org/> contains useful information for people who need a sight test and who experience sight problems. It also contains useful information for professionals. A useful web site on the subject of audiology and hearing loss is Hearing and Learning Disabilities <http://www.hald.org.uk/>. It contains discussion forums for both people with learning disabilities and professionals. Uptake of screening should be monitored to check the situation is improving.

- Some general health care providers may need encouragement to prioritise the health needs of people with learning disabilities. Therefore commissioners can make use of the **'Commissioning for Quality and Innovation'** (CQUIN) mechanism¹⁸. This makes a proportion of providers' income conditional on delivering quality and innovation. The CQUIN payment framework aims to encourage continuous improvement and ensure that improved quality of care, better outcomes and innovation form part of discussions between commissioners and providers.

Further guidance on reasonable adjustments will be published on the Improving Health and Lives website shortly.

In summary

- Ensure patient records include information about how people communicate.
- Commission services with staff who have the skills to communicate with and support people with learning disabilities.
- Ensure screening is accessible and monitor uptake
- Use the CQUIN mechanism to address health inequalities

Raising awareness of healthy lifestyles

Issue

There is evidence that people with learning disabilities take less exercise than the general population and that their diet is often unbalanced with an insufficient intake of fruit and vegetables. In addition, people with learning disabilities often find it hard to understand the consequences of their lifestyle on their health, therefore it is not surprising that many adults with learning disabilities are obese and suffer from conditions that are associated with being overweight.

Commissioning Action

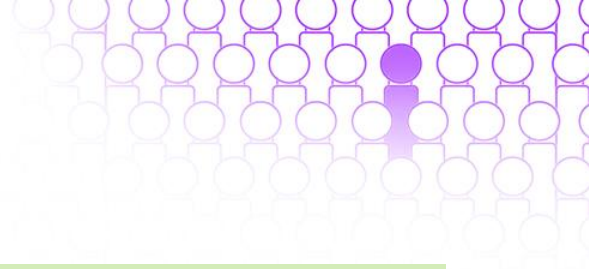
- Support workers and others who support people with learning disabilities need to understand what constitutes a **healthy lifestyle** so they can enable people to make informed choices. There is a need for both health and local authority commissioners to ensure that health promotion and advice is available to social care providers. In addition commissioners can specify staff training regarding diet and exercise in contracts with providers, and for residential services it is possible to specify that the meal plans must include at least five pieces of fruit and vegetables per day. This can be monitored by looking at past meal plans and asking family carers about the diet of their relative.
- Although rates of tobacco smoking and drinking alcohol are lower for adults who use services compared with the rest of the population, rates of smoking among young people with a mild learning disability are higher than among their peers. This group of people are harder to reach as they are not in contact with specialist services. Therefore it is particularly important that commissioning for general health promotion initiatives regarding **tobacco, alcohol, substance misuse and sexual health** takes into account accessibility issues for people with learning disabilities, and includes younger people with learning disabilities in order to prevent health problems in older life.
- In order to make informed choices, people with learning disabilities need accessible information and **support to understand lifestyle choices** with regard to diet and exercise. Accessible information is available as referenced above. In

For example

Westminster has a project called *Choosing the Chance to Change* which includes a detailed action plan with interventions including health promotion, weight management programmes and strategic planning. A DVD (called *Choosing the Chance to Change*) was also developed. The DVD shows different places where you can do physical activities in Westminster and highlights mainstream and specialist services available.

For example

Bristol PCT has employed three Health Trainers with a learning disability and South Gloucestershire PCT has one Health Trainer with a learning disability. The health trainers support people with learning disabilities to understand health issues and increase their uptake of health services. They are all recently trained walk leaders and some have started walking groups.



addition, some areas have put in additional support.

In summary

- Invest in advice and training for support staff
- Commission health promotion initiatives that are accessible for people with learning disabilities including young people.
- Provide additional support to enable people with learning disabilities to make informed choices.

Inequality in service provision and outcomes

Issue

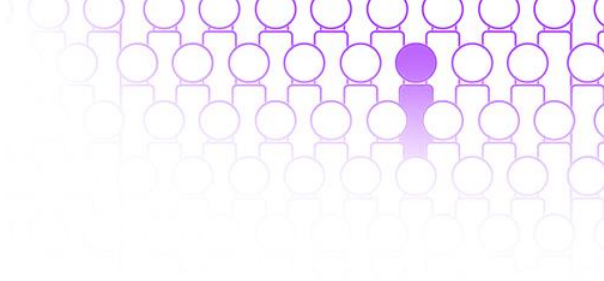
There are significant variations in NHS expenditure on services for people with learning disabilities in England and significant variations in the services provided by specialist NHS Trusts. There is also concern regarding the availability and access of mental health services for people with learning disabilities.

Commissioning Action

- Unless health services have a way in which to measure progress in tackling health inequalities, they will not know how they are doing, and may not understand what they should be aspiring to. **The Performance and Self-Assessment Framework (SAF)** provides a useful tool for highlighting the steps that can be taken towards improving access by people with learning disabilities to, and the quality of, services. For further information on the SAF, please visit the IHAL website www.improvinghealthandlives.org.uk/
- People with learning disabilities are at a higher risk of experiencing **mental health problems**, but despite this, the availability and accessibility of mental health services to many people with learning disabilities remains poor. There is information about mental health services in the SAF. In addition, commissioners can use **the Green Light tool kit**¹⁹ that provides a traffic light system for self-rating on a wide range of measures relating to local psychiatric services by local commissioners and providers.
- A very high proportion of people with learning disabilities are receiving prescribed psychotropic **medication**, most often anti- psychotic drugs, to control for challenging behaviours. This is despite a lack of evidence for their effectiveness in treating challenging behaviours and evidence of considerable harmful side effects. Commissioners should instigate a review of anti-psychotic medication used with people who challenge as well as ensuring that people with learning disabilities, their family and paid carers as well as relevant professionals understand the side effects of different types of medication. Medication reviews can also result in cost savings. There is accessible information about medication on the Easy Health website. A quick reference guide on prescribing such medication is also available²⁰.

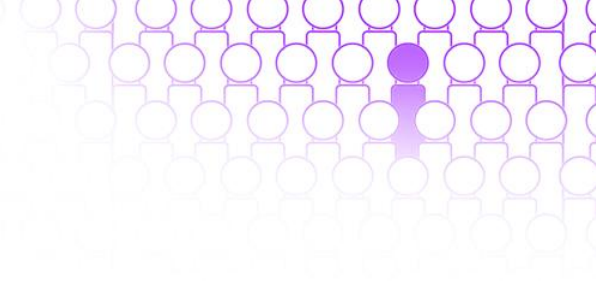
In summary:

- Use the SAF for local self-assessment and regional benchmarking
- Use the Green Light Toolkit to inform the commissioning of mainstream mental health services
- Undertake a review and regularly monitor the use of anti-psychotic medication on people who challenge services.



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. Commissioners have a key role in ensuring progress in this area and in securing a better experience for people with learning disabilities.



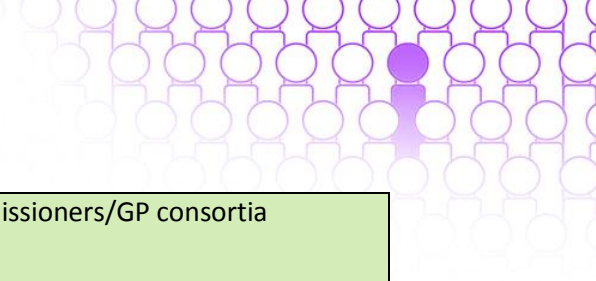
Appendix 1

Table of summary actions

Actions

Who is responsible

<ul style="list-style-type: none"> • Include comprehensive and accurate information about the health of people with learning disabilities in the JSNA • Use this information to inform strategic commissioning • Complete a health needs assessment and a health equity audit • Talk to the Partnership Board about involving people with learning disabilities and family carers • Include information about life outcomes in the JSNA • Commission services to work in partnership • Include plans to increase settled accommodation and employment in commissioning strategies. • Check that benefits advice is accessible • Ensure good access to community facilities. • Regularly update and validate GP registers • Prioritise increasing the uptake of health checks • Ensure health staff know how to find and use accessible information • Ensure the health check includes specific investigations for any underlying conditions. • Ensure patient records include 	<ul style="list-style-type: none"> • PCT community commissioners/GP consortia in partnership with public health and learning disability commissioners • PCT community commissioners/GP consortia. Health and Wellbeing Boards • Public Health departments • PCT community commissioners/GP consortia • PCT community commissioners/GP consortia in partnership with public health and specialist learning disability commissioners • Learning disability commissioners in health and social care • PCT community commissioners/GP consortia • PCT acute and community commissioners/GP consortia • PCT community commissioners/GP consortia • PCT community and acute
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<p>information about how people communicate.</p> <ul style="list-style-type: none">• Commission services which have the skills to support people with learning disabilities.• Ensure screening is accessible and monitor uptake• Use the CQUIN mechanism to address health inequalities• Invest in advice and training for support staff• Commission health promotion initiatives that are accessible for people with learning disabilities including young people.• Provide additional support to enable people with learning disabilities to make informed choices.• Use the SAF for local self-assessment and regional benchmarking• Use the Green Light Toolkit to inform the commissioning of mainstream mental health services• Undertake a review and regularly monitor the use of anti-psychotic medication on people who challenge services.	<p>commissioners/GP consortia</p> <ul style="list-style-type: none">• PCT Acute and community commissioners/GP consortia for general services and PCT mental health and learning disability commissioners for specialist services.• Learning disability commissioners• PCT community commissioners/GP consortia• PCT community commissioners/GP consortia• Mental health commissioners• Community commissioners/GP consortia. Mental health and learning disability commissioners
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Appendix II

About the authors

Sue Turner RNLD, Diploma in Nursing, Cert. Ed (FE), BA (Hons), MSc - Primary Health Care Policy Development and Management.

Sue 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.

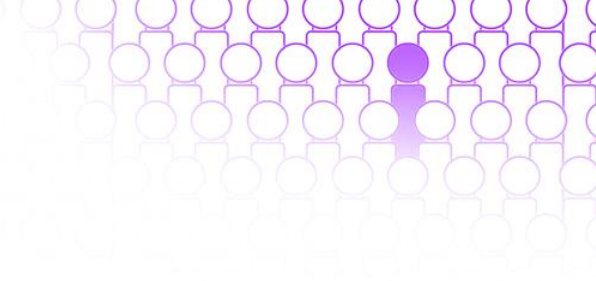
Carol Robinson, BA, CQSW, Dip Applied Social Studies, PhD.

Carol Robinson began her career as a social worker with Essex County Council. She then undertook a PhD in social psychology at the University of Bristol. Afterwards she went into research and became a Reader in the University's Norah Fry Research Centre where she carried out studies relating to support services for families with disabled children. She also had a period of secondment to the Social Services Inspectorate as an analytic inspector (now CQC) before becoming Director of the South West Learning Disability Network known as SWALD. Carol then went onto work half-time for The Care Services Improvement Partnership's Valuing People Support Team and also for the South West Regional Improvement and Efficiency Partnership. Both roles involved working regionally to improve opportunities for young disabled people, adults and their family carers.

In 2008 she decided to undertake consultancy work and now specialises in transition planning and improving employment outcomes for disabled young people. She is currently involved in the cross government programme called 'Getting a Life' which aims to help young people have the life they want including good careers.

She also has a longstanding interest in support for families who have a disabled member and has published a number of articles and books mainly on the subject of short breaks. She has recently become a trustee of the National Family Carer Network.

Carol is an associate consultant with the National Development Team for Inclusion.



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