

10 questions to ask if you're scrutinising ...

...mainstream health services for people
with learning disabilities



The Centre for Public Scrutiny

The Centre for Public Scrutiny promotes the value of scrutiny in modern and effective government, not only to hold executives to account but also to create a constructive dialogue between the public and its elected representatives to improve the quality of public services. The Centre received funding from the Department of Health to run a three-year support programme for health overview and scrutiny committees of social services authorities as they develop their power to promote the well-being of local communities through effective scrutiny of healthcare planning and delivery and wider public health issues.

Acknowledgements

This publication was written in conjunction with the Foundation for People With Learning Disabilities. CfPS is grateful to Richard Poxton at the Foundation and to Rob Mack and colleagues at Haringey Council who helped to develop the guide.

Introduction

This guide is one of a series designed to help health Overview and Scrutiny Committees (OSCs) carry out their scrutiny work around various health, healthcare and social care topics. Other guides in the series include:

- Child and Adolescent Mental Health Services
- Assessing Evidence
- Effectiveness of Your Local Hospital
- NHS Service Redesign and Reconfiguration

Why should Overview and Scrutiny Committees review health services for people with learning disabilities?

People with learning disabilities experience worse health than the general population and poorer access to health services. A Mencap report in 2004 showed that people with learning disabilities faced:

- *Increased risk of early death*
- *Higher prevalence of certain medical conditions*
- *Being part of a disadvantaged group*
- *Having unhealthy lifestyles*

[Treat Me Right! Mencap, 2004]

In 2006 the Disability Rights Commission confirmed these findings:

“...in England and Wales, people with learning disabilities and people with mental health problems are much more likely than other citizens to have significant health risks and major health problems. For people with learning disabilities, these particularly include obesity and respiratory disease...”

The Commission found that the inequalities could not be explained solely by social deprivation:

“In primary care, these high risk groups are actually less likely to receive some of the expected, evidence-based checks and treatments than other patients and efforts to target their needs specifically are ad hoc.”

[Equal Treatment: Closing the Gap, Disability Rights Commission, 2006]

In early 2007 Mencap published a further report following a series of untimely hospital deaths; this pointed to a fundamental lack of understanding and respect towards people with a learning disability and their families and carers. The report alleged that the failure to tackle unequal access for people with a learning disability had resulted in institutional discrimination. It pointed to a number of apparent reasons for this situation:

- Low priority given to people with learning disabilities
- Lack of understanding by many healthcare professionals of learning disability
- Poor consultation and involvement of families and carers of people with a learning disability
- Lack of understanding of the law around capacity and consent to treatment
- Inappropriate estimation of a person's quality of life by healthcare professionals
- NHS complaints system often being ineffectual, time-consuming and inaccessible

[Death by Indifference, Mencap, 2007]

Following this report the Government announced the establishment of an Independent Inquiry into Access to Healthcare for People with Learning Disabilities, to focus on the action needed to ensure people with learning disabilities receive appropriate treatment in general (hospital and primary care) health care in England. [Announcement of independent inquiry into access to healthcare for people with learning disabilities, Department of Health website, August 2007].

The policy framework for addressing this situation now appears to be more encouraging, with an emphasis on addressing health inequalities and on the performance of services. However, too often there are little or no data routinely available to PCTs about the health status of people with learning disabilities or about their uptake and experience of services. [Valuing Health for All, Foundation for People with Learning Disabilities, 2003]

In summary the role of the NHS in relation to people with learning disabilities should be the same as for the rest of the population – promoting good health and well being, treating illnesses etc. as they arise: involving primary, community and acute health services as well as health promotion. Instead people with learning disabilities regularly encounter health inequalities and difficulties accessing services that are often ineffective. Getting it right for people with learning disabilities will undoubtedly help improve access and effectiveness for people generally.

Specialist health services for people with learning disabilities have an important role to play in supporting (and in some cases supplementing) mainstream health services but these services are not the focus of this guide.

10 Questions to Ask:

1. HEALTH NEEDS AND HEALTH INEQUALITIES

What is known locally about the health needs of people with learning disabilities? As a basic, are there data on how many people have learning disabilities, where they live and whether they are supported by a family carer?

To what extent are these needs treated as part of the overall local agenda for addressing health inequalities, e.g. as part of the Local Area Agreement? Is there information on morbidity (illness) and mortality (death) rates?

What is known about the particular health needs of people with learning disabilities from minority ethnic communities?

Is there any system for regularly collecting and monitoring the health needs of people with learning disabilities based upon agreed clinical coding?

As Primary Care tends to be at the 'front line' of healthcare for people with learning disabilities (for every 1000 patients there will be about 4 patients with severe learning disabilities and about 20 with mild to moderate disability), is there a lead local GP, GP with Special Interest or any other local special interest group?

2. CURRENT LOCAL POLICIES AND PRACTICES

Who is doing what and how much is being invested in ensuring that mainstream health services meet the needs of people with learning disabilities?

How are these needs being addressed at policy level: is an overarching Strategy in place that is part of mainstream planning arrangements?

How are the needs and wishes of people with learning disabilities and family carers taken into account at this level?

Is there an agreed commissioning strategy with clear service objectives and intended health outcomes?

Does the PCT's Disability Equality Strategy address the needs of people with learning disabilities?

Does the commissioning strategy take account of people with learning disabilities from minority groups, e.g. black and minority ethnic communities, people in prisons?

Does the commissioning strategy make best use of information to predict changes in need e.g. information about the increasing number of children who are dependent on 'medical technology'?

3. LEADERSHIP AND OWNERSHIP

Is leadership and ownership expressed at a senior level? Does it involve clinicians as well as managers? Has a Strategic Health Facilitator been appointed at a senior clinical level to ensure appropriate expertise and advice? Is there any Executive Councillor involvement?

Are all parts of the health system involved? Is partnership/joint working effective? Are there any criteria in place to judge effectiveness?

Are responsibilities clear, including the role of the Partnership Board?

Is there effective involvement of people with learning disabilities and family carers in developing services? If they were asked, would people say that they felt able to influence change?

4. HEALTH EDUCATION AND PROMOTION

What support is provided to people with learning disabilities and family carers to enable them to take more control over their own health?

Is there access to health promotion and improvement programmes (e.g. weight management, smoking cessation)?

Is health promotion material available in "easy to read" versions?

Are there data on whether women with learning disabilities make equal use of screening for breast and cervical cancer? Have efforts been made to promote these services?

5. FOCUSING ON INDIVIDUAL NEEDS

How adequate are individual patient records and other key data? Do they alert practice staff and clinicians about people with learning disabilities in an effective and proper way (and for onward referrals) so that "reasonable adjustment" might be made to how services are provided?

Are routine, comprehensive and individualised health checks offered and followed up? Have local Community Teams for People with Learning Disabilities been involved in their design?

Are all people with learning disabilities offered a Health Action Plan? Are Health Facilitators offered/appointed where this is necessary?

What support is available to family carers and supporters: for looking after their own health; and for ensuring that they are adequately knowledgeable about the condition and treatment of the person for whom they care? Is there information about the health needs of family carers? Are the training needs of family carers and supporters included in the local workforce strategies?

Are local clinicians familiar with the requirements of the Mental Capacity Act 2005?

Is any particular training offered to health professionals, practice managers and receptionists in order to help them recognize and meet the needs of people with learning disabilities? If training is offered, what is the take-up?

6. CARE PATHWAYS AND ACCESSING SERVICES

How easy is it for people with learning disabilities to get access to GPs' surgeries, what "reasonable adjustments" (e.g. availability of longer appointment times, suitable waiting arrangements in surgeries, accessible information in and from surgeries, support from Community Teams for People with Learning Disabilities) have been made locally? Is any support provided to prepare or reassure people about check-ups as they may become very anxious? Are there any outstanding problems that require addressing?

Dental services, optometry and audiology are particular other areas that are very important for people with learning disabilities – the same issues around access and "reasonable adjustment" apply as for General Medical Services.

Has particular attention been given to access to and effectiveness of pharmacies for people with learning disabilities?

How well do local acute hospitals provide care and support for people with learning disabilities when they attend Accident & Emergency? How well do they support people with learning disabilities when they are admitted for emergency or elective treatment (for medical conditions)? Does the hospital have a learning disability liaison nurse or similar? Is there a protocol between PCT, hospital and Council about who pays for any extra

support needed during admission? Is there any support for family members staying at the hospital bedside of a relative who cannot be easily left alone?

Do local NHS Drop-In Services (e.g. Minor Injuries Units) make adequate provision for people with learning disabilities?

How well do local mental health services meet the needs of people with learning disabilities who have mental health problems? Is the full range of services available to them?

In relation to Specialist Health Services for people with learning disabilities, are respective roles and pathways with mainstream services sufficiently clear?

How effective is joint working between the different parts of the health and social care systems to ensure the good health of people with learning disabilities? Are suitable protocols in place? Is communication effective? Are respective roles and responsibilities clear?

7. TRANSITION FROM CHILDREN AND YOUNG PEOPLE'S TO MAINSTREAM HEALTH SERVICES

What arrangements are in place to ensure that information is gathered on the health of children and young people with learning disabilities to ensure a good transition to adult life?

Are there effective handover arrangements in place between specialist children and young people's services and mainstream health services?

What support is offered to family carers to help with the often significant drop in health support available for adults with learning disabilities?

See also the CfPS '10 question guide to child and adolescent mental health services'

8. ENSURING AND MONITORING THE EFFECTIVENESS OF SERVICES

What steps are being taken to ensure the effectiveness of mainstream health services for people with learning disabilities?

What information is collected regularly and systematically by GPs surgeries on the numbers of people with learning disabilities, healthchecks offered and their health status?

How much use is being made of the “Better Metrics” measures of performance (drawn up by the Healthcare Commission), which has a specific section relating to Learning Disabilities?

What measures are being taken to collect the views of patients and their carers on their experiences of services?

To what extent are Equality Impact Assessments being used to check the effectiveness of services, including for people from black and minority ethnic communities?

9. INVOLVING USERS AND CARERS

Are all local healthcare providers able to demonstrate active engagement with people with learning disabilities and their carers: this should include service development as well as their own care plans?

Are people with learning disabilities and their carers involved in the commissioning of healthcare services?

Are there systematic patient feedback mechanisms in place?

Are complaints procedures effective and accessible?

Are people with learning disabilities involved in the Local Involvement Network?

10. RECOMMENDATIONS

What recommendations can be made in respect of the areas identified above?

FURTHER INFORMATION – KEY REFERENCES

Valuing Health for All, Foundation for People with Learning Disabilities, 2003.
<http://www.fpld.org.uk/publications?EntryId=22388&char=V>

Treat me right! Mencap, 2004.
http://www.mencap.org.uk/html/treat_me_right/report.asp

Equal Treatment: Closing the Gap, Disability Rights Commission, 2006.
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Death by indifference, Mencap, 2007.

<http://www.mencap.org.uk/html/campaigns/deathbyindifference/index.asp>

Primary Care Service Framework, Management of Health for People with Learning Disabilities in Primary Care, NHS, 2007

http://www.primarycarecontracting.nhs.uk/uploads/primary_care_service_frameworks/primary_care_service_framework_Id_v3_final.pdf

There is one scrutiny review in the CfPS review library that looks at the health of people with learning disabilities:

Improving the health of people with profound and multiple learning disabilities, London Borough of Haringey, February 2007

<http://www.cfps.org.uk/reviews/item.php?mainID=7&issue=7®ion=&authority=&year=&type=&keyword=&itemid=2470>

**CfPS/Foundation for People with Learning Disabilities
January 2008**