



My life, My care, My questions

Questions to ask about health and
care services



This guide was written for the Scottish Commission for Learning Disabilities by the Centre for Public Scrutiny (CfPS) as part of a project to support The keys to life, Scotland's strategy for improving the quality of life for people with learning disabilities.

CfPS is the leading national body promoting and supporting excellence in governance and scrutiny. CfPS believes that embedding the principles of transparency, accountability and involvement into an organisation's culture and processes leads to better decisions and improved outcomes. CfPS works throughout the UK, providing specialist training and consultancy to individuals and organisations looking to improve their governance and scrutiny skills, culture systems and processes.

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Who this guide is for

This guide is for people with learning disabilities, but it will also interest people who care for them and organisations that support them. The guide is about ways to check whether health and care services are meeting people's needs and whether services listen to people when decisions are made. Sometimes, checking services are working is called 'scrutiny'.

This guide will help you to understand what 'scrutiny' means and why it is important. The guide will also give you information about questions you can ask and how you can have your say about the way the services are delivered.

Setting the context

People with learning disabilities can have worse health than other people and can find it harder to access care services that meet their needs. They also face other difficulties in their lives, particularly in relation to education, jobs and housing. Everyone should have the right to good health, to choose how they live and to have control over the way they access services. This is called human rights. The Scottish Government said it will carry out what the United Nations says should be done to make sure human rights are protected.

This is about a cultural shift in supporting people to lead healthier and happier lives. The Scottish Government has written a plan called The keys to life that says how services should help people with learning disabilities. Part of the plan is about the way services are checked to see if they meet people's needs – this is called scrutiny.

What is scrutiny?

Scrutiny happens in different ways. Sometimes people carry out scrutiny themselves and sometimes scrutiny is carried out by organisations on behalf of everyone. It is important to check the things that matter to people who use services. The best way to check services is to ask them what they think. Services should do this themselves. People who check services can also go to where services are and talk to people to find out if their needs are being met.

People who plan and deliver care should ask people who use services what they think before they make decisions about which services to spend money on or how services are organised. A name for spending money on services is 'commissioning'. Councils and health boards decide which services to commission. Now they work together to do this through new 'integration partnerships'.

Working together means that health and social care services are working in the same way, and can improve the quality of services as a result.

People who provide services should ask people if their needs are being met, but sometimes people are worried to speak up in case they don't get the right care or treatment in the future. There are also independent organisations to check services on behalf of everyone.

People you can talk to about services

You don't need to wait for people to ask you what you think about the services you receive. You can ask questions about the way services are planned and delivered. You can also ask others to help you do this. Ideas about questions to ask are included at the end of this guide. As well as asking questions yourself, there are other ways you can have your say. Here are some examples of people you can contact:

- **Politicians:**

Local councillors

Councillors can influence decisions about local services and they can use their scrutiny role to ask questions about things that matter to local people, for example residential care, day care, community services, services for carers

There is a list of Scottish councils at this website:

<http://www.gov.scot/About/Government/councils>

Members of the Scottish Parliament (MSPs)

MSP's can influence laws and can hold the Scottish Government to account, often through Parliamentary committees, for example about how hospitals are run, services provided by family doctors, public transport to help you get about

There is a list of MSPs at this website:

<http://www.scottish.parliament.uk/msps/current-msps.aspx>

- **Voluntary sector groups:**

National or local voluntary sector groups

National charities or local voluntary groups can speak up on your behalf and they may have places on groups that make decisions about services.

There is a list of voluntary sector contacts at this website: <http://www.gov.scot/Topics/People/15300/Contacts/Volcontacts>

User-led groups

These are run by people who use services. Members of these groups support each other to get better choice and a stronger voice in the services they use.

There is information for people with learning disabilities at this website: <http://www.sclid.org.uk/who-we-are/>

- **Scrutiny organisations:**

Healthcare Improvement Scotland (HIS)

HIS checks the quality and safety of healthcare provided in NHS hospitals and services, and independent healthcare services

There is information about scrutiny of healthcare at this website: <http://healthcareimprovementscotland.org/scrutiny.aspx>

Scottish Health Council (SHC)

SHC checks that NHS Boards listen and take account of people's views so that the NHS works in partnership with patients, carers and the public.

There is information about involving people in healthcare at this website:

<http://www.scottishhealthcouncil.org/home.aspx>

Care Inspectorate

The Care Inspectorate regulates and inspects care services to make sure that they meet the right standards

There is information about involving people in social care at this website: <http://www.careinspectorate.com/>

Mental Welfare Commission for Scotland

The Mental Welfare Commission protects and promotes the human rights of people with mental health problems, learning disabilities, dementia and related conditions

There is information about human rights for people with learning disabilities at this website:

<http://www.mwcscot.org.uk/>

- **Financial organisations:**

Audit Scotland

Audit Scotland checks that the public money spent by Healthcare Improvement Scotland, Health Boards and the Care Inspectorate is spent properly, efficiently and effectively.

Accounts Commission

The Accounts Commission checks that the public money spent by local authorities is spent properly, efficiently and effectively.

There is information about financial scrutiny at this website:

<http://www.audit-scotland.gov.uk/>

- **Other oversight organisations:**

There are other organisations that help to make sure people get the services they need or that decisions about treatment and care are taken in the right way

Additional Support Needs Tribunals

These Tribunals hear references from parents and young people on specific matters relating to a child's co-ordinated support plan. The Tribunals can deal with disputes about the issue or contents of support plans

There is information about co-ordinated supports plans at this website:

<https://www.asntscotland.gov.uk/content/co-ordinated-support-plans>

Mental Health Tribunal

The Mental Health Tribunal helps make decisions on the compulsory care and treatment of people with mental disorders

There is information about the Tribunal at this website:

http://www.mhtscotland.gov.uk/mhts/Home/Welcome_to_the_Mental_Health_Tribunal

Commissioner for Ethical Standards in Public Life

The Commissioner investigates complaints about Councillors and Members of the Scottish Parliament who are alleged to have contravened their relevant Code of Conduct

There is information about the Commissioner at this website: <http://www.ethicalstandards.org.uk/>

Children and Young People's Commissioner

The Commissioner helps you understand your rights and to make sure those rights are respected so that children and young people in Scotland can be as safe and happy as possible

There is information about how the Commissioner does this at this website: <http://www.cypcs.org.uk/about#main-content>

Scottish Human Rights Commission

The Scottish Human Rights Commission promotes and protects human rights for everyone in Scotland.

There is information about Scotland's national plan for human rights at this website:

<http://scottishhumanrights.com/ourwork>

Scottish Information Commissioner

The Commissioner promotes and enforces the public's right to ask for information held by Scottish public authorities and good practice by authorities, supporting the openness, transparency and accountability of public bodies

There is information about accessing information at this website:

<http://www.itspublicknowledge.info/home/ScottishInformationCommissioner.aspx>

Scottish Public Service Ombudsman

The Ombudsman is a person who deals with complaints about public services if you feel that an organisation provided a poor service, delivered a service badly or failed to provide a service.

There is information about how to make complaints about services at this website: <http://www.spsso.org.uk/fact-sheets>

Standards Commission for Scotland

The Commission encourages high standards of behaviour by councillors and people appointed to other boards. The Commission covers Scottish Local Authorities, National Health Service Boards and Health & Social Care Integration Joint Boards

There is information about standards of behaviour at this website:

<http://www.standardscommissionscotland.org.uk/>

Questions you can ask about services

If you want to ask questions to any of these organisations, you can email them or write to them. You should include your address so they can send a reply to you. There might be groups you can attend where you can talk about services. In this section, we'll give you ideas of questions you could ask when you get in touch.

10 things you can ask about:

1. Health needs and differences in health

- Is there information about how many people have learning disabilities, where they live and whether they are supported by a family carer?
- What is known about the health of people with learning disabilities?
- What is known about the differences in health between people with learning disabilities and other people?
- Is there a way to collect information about whether the health of people with learning disabilities is improving?
- Is there a local GP who takes a lead on support for people with learning disabilities? In hospitals or care homes is there a lead doctor or nurse?

2. Local policies and practices

- Who takes decisions about how much money is spent on services for people with learning disabilities?
- Is there a plan for the local area so that services work together?
- How do the needs and wishes of people with learning disabilities, their families and carers affect local planning?
- Is there an agreed plan that says clearly what services should do and how the health of people with learning disabilities should improve?
- Does the plan make best use of information to predict changes in the health needs of people with learning disabilities?

3. Leadership and ownership

- Is there a senior person (a doctor or a manager) who takes charge of planning services for people with learning disabilities?
- Is there a councillor who has responsibility for people with learning disabilities?
- Are all parts of the health and care system working together? How can people tell if things are working well?

- Is it clear who takes action to improve things for people with learning disabilities, including the role of the integrated joint board?
- If they were asked, would people with learning disabilities say they felt able to influence decisions?

4. Health

- What help is there for people with learning disabilities to take more control over their own health?
- Can people with learning disabilities access health improvement programmes (for example weight management, smoking cessation)?
- Is information about health available in “easy read” versions?
- Is there information about men and women with learning disabilities having health checks or accessing other screening programmes?
- How do services let people with learning disabilities know about important health issues and how to get further help if they want to know more?

5. Meeting individual needs

- Do medical records help staff know a person has learning disabilities in a way that “reasonable adjustments” are made to how services are provided?

- What support is there for families and carers to look after their own health or to help them understand the treatment of the person who they care for?
- Is there information about the health needs of families and carers?
- Are the training needs of families and carers included in plans to train the local workforce?
- Is training offered to health professionals to help them recognise and meet the needs of people with learning disabilities?

6. Care pathways and accessing services

- Is there any help to prepare or reassure people about check-ups as they may be anxious?
- How easy is it for people with learning disabilities to access GP surgeries, dentists and pharmacies?
- How well do hospitals provide care and support for people with learning disabilities when they attend accident and emergency or when they are admitted for treatment and is there any support for family members staying at the hospital bedside of a relative who cannot be easily left alone?
- How well do local mental health services meet the needs of people with learning disabilities?
- 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?

7. Transition from children's services

- What 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 arrangements in place between specialist children and young people's services and health services for adults?
- What support is offered to families and carers to help with the significant drop in health support that is often experienced by adults with learning disabilities?

8. Monitoring and scrutiny of services

- What information is used to check that services work for people with learning disabilities and what happens if things look like they are not working?
- What did the last inspection report say about services and what are services doing to improve if they need to?
- When did a council scrutiny committee last review services for people with learning disabilities?
- What difference do the views of patients and their carers make to way services are run?
- To what extent are health inequalities impact assessments used to check the effectiveness of services for people from different groups?

9. Involving people

- Can all service providers demonstrate active engagement with people with learning disabilities and their carers about service development as well as their own care plans?

- Are people with learning disabilities and their carers involved in decisions about how to spend money on services?
- Are the views of people who use services reported to people who sit on decision-making boards and how do they use it?
- How do services learn from complaints and improve what they do as a result?
- Do services rely on voluntary organisations to tell them what people think or are people directly involved themselves?

10. Making a difference

- What needs to change in the area to make things better for people with learning disabilities?
- If we know what needs to change who needs to take action to make it happen?
- Are there things that need to change at national level to make local actions more effective?

You can find out more about scrutiny by contacting:



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