



Tackling Indifference

Healthcare Services for People with Learning Disabilities

National Overview Report ~ December 2009

NHS Quality Improvement Scotland (NHS QIS) is committed to equality and diversity. We have assessed the performance assessment function for likely impact on the six equality groups defined by age, disability, gender, race, religion/belief and sexual orientation. For this equality and diversity impact assessment, please see our website (www.nhshealthquality.org). The full report in electronic or paper form is available on request from the NHS QIS Equality and Diversity Officer.

In collaboration with:



People First

Cover photograph supplied by PAMIS
Photographs on pages 2,6,10,26 supplied by PAMIS
Images on pages 4,7,12,17,18,21,25,28,29,30,32 from
Photosymbols 3. © Photosymbols Ltd 2009



© NHS Quality Improvement Scotland 2009

ISBN 1-84404-520-X

First published December 2009

You can copy or reproduce the information in this document for use within NHSScotland and partner organisations, and for educational purposes. Information in this report has been supplied by NHS boards and other partner organisations.

www.nhshealthquality.org

Contents

1 About this national overview report	3
2 An introduction from our director	4
3 What we found and what needs to happen	7
4 What are health services for people with learning disabilities like?	11
5 What we learned	27
6 More information	34
a) What is a learning disability?	34
b) What we did on the visits	35
c) How to find out more about this report	36
d) Finding out about health services in your local area	37
e) How to get more general information about learning disabilities	38
f) Word list	40



1 About this national overview report

NHS Quality Improvement Scotland (NHS QIS) wrote quality indicators for services for children and adults with learning disabilities.

The quality indicators are used to check how well health services are meeting people's needs.

During 2008–2009 we looked at services for children and adults with learning disabilities in Scotland to find out what was working well and what could be better.

This national overview report is about what we found.

In this report we sometimes have to use words that need to be explained. These words and what they mean are in a word list at the back of the report.

2 An introduction from our director

There are more than 120,000 people with learning disabilities in Scotland. Many people with learning disabilities have complex needs. Everyone should be able to get the right health and social care services when they need them.

People with learning disabilities often have more health difficulties and can find it hard to get some health services. An example of this is health checks. It can also be difficult for people to get to health centres. This can be because of transport problems, or sometimes a centre is not accessible to everyone.

In 2008 and 2009, NHS QIS reviewed all the NHS boards in Scotland. This was to check how easy it is for people with learning disabilities to get good health services. This review was done with people with learning disabilities and their carers, and with health and social care professionals.

Why did we do this?

Since 2000 there has been lots of work to help make it easier for people with learning disabilities to get health services and to try to stop discrimination. It is important that everyone working in health services understands about people's rights. There have been new laws introduced to help make sure that this happens.

To help health services with this work, NHS QIS wrote two documents:

- 1 a best practice statement called Promoting Access to Healthcare for People with Learning Disabilities – a Guide for Frontline NHS Staff was issued in (2006), and
- 2 Quality Indicators for Learning Disabilities (2004).



What the review teams found and what needs to happen

The review teams found lots of examples of new and helpful projects. They also found that services for people with learning disabilities and their carers are improving. But there are areas that need to be better.

Health staff need to know more about laws that protect people with learning disabilities and how to carry out their work in line with the laws. The Disability Equality Duty and Adults with Incapacity Act are important. The Adults with Incapacity Act allows for ways to help an adult who is not able to make decisions and manage different areas of their life. Now it is possible for another adult to make decisions about medical treatment on behalf of someone who is not able to completely understand the situation.

It needs to be easier for people with learning disabilities to get general health services. This is both for planned visits to hospitals or health centres and also when people need services out-of-hours.

Different services need to work better together. They need to share information and knowledge. All health staff need to understand the needs of people with learning disabilities. This is very important, to make sure that people get the right care and are kept safe.

What we learned

Everyone who has worked on this review has learned a lot about what is happening in Scotland and how we can do even better. People with learning disabilities and their carers and families need access to good health services to make sure they have a good quality of life. People who use health services often are usually known to the NHS. Because of this, it should not be difficult to make sure their needs are understood. We have suggested some simple and useful ways of making sure this happens. Some NHS boards are already doing these things and services are already getting better in these areas.

There is no quick way of making services better. It is a steady process. To make sure that services keep getting better for people with learning disabilities, staff working in health services must make sure that equality is part of everything they do.



3 What we found and what needs to happen

All the information we found across Scotland has been looked at. The following recommendations are ideas for things we would like to happen to make services better for people with learning disabilities in Scotland.

Recommendation 1:

The NHS should make sure Part 5 of the Adults with Incapacity (Scotland) Act 2000 is always used when it should be.

Why we made this recommendation

The Adults with Incapacity (Scotland) Act (2000) protects the welfare of people with learning disabilities who cannot make some or all decisions for themselves. Part 5 of the Act is about how medical and other healthcare staff can legally make decisions about medical treatment on behalf of someone who cannot decide for themselves.

How will this improve healthcare for people with learning disabilities?

This will make sure that each person's ability to give permission for healthcare treatment will be looked at. When people are not able to give permission for a treatment, checks will be made to make sure that the treatment is in the person's best interest. This will help NHS services to give person-centred care to all people with learning disabilities.

What are the risks if this is not done?

People who could be able to give consent might not be given the chance to make decisions about their healthcare. This may happen when information is not given in a way to them that they understand. People who cannot give consent could be given medical treatment without the correct checks being made. People's rights might be violated and healthcare staff might be charged with assault.

Who is responsible for making sure this happens?

- NHS boards - the organisations that provide healthcare
- NHS Education for Scotland
- Scottish Government



Recommendation 2:

Good arrangements should be put in place to make sure that adults and children with learning disabilities can use health services. This is written in the Disability Equality Duty.

Why we made this recommendation

Everyone should be able to use health services. NHS staff need to make sure that people are not discriminated against because they have learning disabilities. NHSScotland must make sure everyone can have the same treatment.

How will this improve healthcare for people with learning disabilities?

There are disability equality rules that make sure that disabled people are treated the same as other people. This may mean that some extra things need to be done to make sure people are treated equally. Extra help is often needed for people with learning disabilities to make sure they can get access to healthcare. Some help is being given to people with learning disabilities but more needs to be done. If more is done this will make sure that people with learning disabilities have the same access to healthcare as other people.

What are the risks if this is not done?

People with learning disabilities who cannot access healthcare will not get the right treatment. This may be bad as was shown in some reports and Fatal Accident Inquiries. If disability equality regulations are not followed this may mean that there could be complaints and the Human Rights Commission may take action against the NHS boards.

Who is responsible for making sure this happens?

- NHS boards - the organisations that provide healthcare
- NHS Education for Scotland
- Scottish Government
- NHS staff - for example doctors, nurses and dentists
- NHS QIS

Recommendation 3:

NHSScotland should make sure that primary care services are able to meet the particular health needs of children and adults with learning disabilities by developing the good things that have happened because of the Scottish Enhanced Services Programme for Primary and Community Care.

Why we made this recommendation

People with learning disabilities have different health needs. Primary care services are a very important part of making sure that people's health needs are being met. Some people with learning disabilities may find it difficult to know if they need help from the NHS. They may also find it difficult to know how to get information.

How will this improve healthcare for people with learning disabilities?

The Scottish Enhanced Services Programme has started to make a list of all adults with learning disabilities that use primary care services. Children with learning disabilities could be added to this programme. The ways that information is collected need to work better. If the lists of people are accurate, then it makes it easier for NHS boards to plan the right services for people with learning disabilities.

What are the risks if this is not done?

If the health needs of people with learning disabilities are not known about, this can mean it is more expensive to give people treatment. Sometimes, hidden health problems can badly affect people's behaviour and mean that they need more support.

Who is responsible for making sure this happens?

- Scottish Government
- GP practices

To find out how we are going to make sure this happens, visit www.nhshealthquality.org/nhsqis/5988.html where you can find out some more information.



4 What are health services for people with learning disabilities like?

These are some of the things that the review teams found were going well and not so well across Scotland.

Quality Indicator 2: Promoting Inclusion and Wellbeing

A.1 Disability Awareness: Staff are familiar with the Disability Discrimination Act (1995) (DDA) guidelines and legislation as it applies to children and adults with learning disabilities.

NHS boards know about the Disability Discrimination Act. Some have a good understanding about the Disability Equality Scheme and include the needs of children and adults with learning disabilities.

Some NHS boards involve people with learning disabilities in writing policies and training staff. However, some do not.

It is good that a lot of NHS boards use the Equality Impact Assessment Tool.

In the NHS boards that were graded not met, there are not many checks to make sure that the Disability Discrimination Act is being used properly. People with learning disabilities should be included in the work.

It is important that healthcare staff are helped to know about the specific needs of people with learning disabilities. NHS boards should check that this is happening.

A.2 Disability Awareness: Children and adults with learning disabilities and their family carers can access health service settings.

When people with learning disabilities use health services, their needs are considered in most NHS board areas, although in some areas the links between primary and secondary care are not very good. This means that it can be hard to arrange someone's healthcare.

It is good when arrangements are in place to help people with learning disabilities when they first contact the out-of-hours service.

Some NHS boards have asked people with learning disabilities and their carers about accessibility. This includes asking about the development of new hospital facilities and joint appointment letters. However, a number of NHS boards were not aware that they needed to get the views of people with learning disabilities about accessibility.

Only a few NHS board areas are good at helping people use direct payments. Some NHS board areas have information in an easy-read format that tells people about direct payments.

It is important that NHS boards keep improving accessibility for people with learning disabilities. This will happen when NHS boards improve the links between primary, secondary and specialist services. There is a Health Inequalities Learning Network, which will help share good ideas and good working.

A.3 Transport: The needs of children and adults with learning disabilities are considered in relation to patient transport and general transport services.

In some NHS board areas there is good patient and public transport because they work well with other agencies. These NHS boards involve people with learning disabilities and carers on planning groups. There is accessible information to help people use transport services.

When transport arrangements are not good, this can mean that people with learning disabilities find it hard to get to the health services they need. This is a problem that has to be solved in a number of NHS board areas.



A.4 Health Promotion and Health Improvement: The NHS board/ community health partnership (CHP) has an agreed policy on health improvement and wellbeing activities, which takes account of the diverse general and complex needs of children and adults with learning disabilities, and addresses health inequalities.

Some NHS boards have a health improvement strategy that includes the needs of children and adults with learning disabilities. These NHS board areas have good health promotion information. Some areas have involved people with learning disabilities in training and also when developing this information. It is important that health promotion ideas and resources are shared across all NHS board areas.

All NHS boards need to have a good health improvement policy that is reviewed often. People with learning disabilities and their carers should be involved with writing the policy from the beginning.

Most NHS boards know about gender issues, sexuality and sexual health. There are some good examples of NHS boards working together with other agencies. However, more work still needs to be done in some NHS boards.

Quality Indicator 3: Meeting General Healthcare Needs

B.1 Assessment and Care Planning: Children and adults with learning disabilities accessing health services have an up-to-date multidisciplinary care plan. Assessment of health and capacity of family carers is considered, and linked to assessment of users' needs. Health services support people with learning disabilities to use direct payments.

People with learning disabilities have up-to-date multidisciplinary care plans in many NHS board areas. This is done by making sure that single shared assessments are used to share information. More work still needs to be done to make sure that everyone gets an assessment who needs one.

Not all NHS boards use electronic systems to record assessments. Not using electronic recording can make it difficult to share information.

Some NHS boards are using the Adults with Incapacity Act properly. However, it is not used well in some NHS boards. In these NHS boards there is not enough training or checks being made.

Across Scotland, people with learning disabilities and carers are usually consulted when planning care. This means that people's communication needs can be agreed and shared. This is to make sure that information is available in the right formats, for example in communication passports. This makes sure that people's care plans are person centred.

The NHS boards that do not meet this quality indicator are putting people with learning disabilities at risk when information is not shared properly. The Adults with Incapacity Act is not being used properly in some NHS board areas. NHS boards need to know about the Donnet Fatal Accident Inquiry so they understand what can go wrong when care is not well planned.

B.2 Educational Needs of Healthcare Staff: There is an up-to-date strategy for disability awareness and disability equality training, which takes into account the needs and rights of children and adults with learning disabilities, including those with associated autistic spectrum disorder (ASD) or mental health problems. This includes a programme of education and training for healthcare professionals in primary, secondary and tertiary settings.

Many NHS board areas have a strategy and training to make sure that staff know about the needs of people with learning disabilities. In these areas, there is a single person who makes sure that this happens. Involving people with learning disabilities and carers means that the training is better. People with learning disabilities are involved with training in some NHS boards.

It is important that there are good courses for new staff in NHS boards and training for NHS staff to make sure they understand the needs and rights of people with learning disabilities. However, some NHS boards do not include information about people with learning disabilities in their introductory programmes. Some NHS boards include information about people with learning disabilities when giving training to staff about disabilities, generally. Other NHS boards have training from learning disability liaison nurses as well as giving all new staff information about learning disabilities.

Some NHS boards have training for new doctors about the Adults with Incapacity Act. However, doctors and NHS staff are often not given refresher training. Not enough training about the Adults with Incapacity Act and the Mental Health Act can put people with learning disabilities at risk. For example, if a person with learning disabilities is not able to make decisions and does not have an Adults with Incapacity Act certificate. This is against the law.

B.3 Primary Care and Community Services: There is a named specialist practitioner known to each primary care team for children and adults.

In most NHS boards, primary care teams have a learning disability nurse that they work with. These nurses always work with adults and sometimes they also work with children. In some places it is hard to make this work well because the nurses have to help primary care services that are a long distance away from each other. Sometimes it is difficult because there is not enough money to pay for this service.

Review teams found that the way the primary care teams worked with these nurses was very different in different NHS board areas of Scotland. In some places they did a lot of work together but in others they only spoke with each other a little. Some NHS boards had information that showed how well they worked together but others could not show that they were checking this.

A problem in some NHS board areas is that primary care services did not know about all the advice they could get about learning disabilities. This means that in some areas people with learning disabilities did not find out about things that could help them. Some NHS boards are teaching primary care staff about what they can do to make things better for people with learning disabilities. They are doing this by teaching people in groups. Some have also given primary care staff special information packs to help them understand what to do.

B.4 Primary Care and Community Services: Primary care services are responsive to the needs of children and adults (including older people) with learning disabilities and their family carers in scheduled care and out-of-hours periods.

Most primary care services are good at helping children and adults with learning disabilities and their family carers. This is for planned and out-of-hours care. There is good communication between primary care and out-of-hours services in some NHS board areas. Some NHS boards use the special notes system. NHS 24 is going to use the special notes system together with emergency care summaries to make sure they know about people's needs.

Primary care services in most NHS boards have a record of adults with learning disabilities. However, this is not happening everywhere. This is part of the Scottish Enhanced Services Programme. Some NHS board areas are keeping these up to date. Some NHS board areas also have a record of children with learning disabilities.



B.5 Primary Care and Community Services: Children, young people, adults and older people with learning disabilities are included and supported to participate in screening programmes.

In quite a few NHS board areas, there is not very much being done for children, adults and older people to make sure they are included and helped to use screening services. Only a small number of NHS boards are checking the numbers of people with learning disabilities who attend screening.

Only a few NHS boards are helping people to use screening services. Often there is not very much information about screening for people with learning disabilities. Some NHS board areas are starting to work on writing leaflets and other information for people with learning disabilities. There are examples of good work, for example breast screening and testicular cancer screening. However, this good work is only happening in some NHS board areas, and it often relies on the support of interested people.



B.6 Primary Care and Community Services: Specific health needs are assessed and monitored, using recommendations from the Scottish Health Needs Assessment for People with Learning Disabilities (2004) and the Scottish Enhanced Services Programme for Learning Disabilities (2007–2008).

In most NHS board areas, people with learning disabilities do not have their particular health needs checked and followed up in a planned way. This is a recommendation that was made in two documents:

- the Scottish Health Needs Assessment for People with Learning Disabilities, and
- the Scottish Enhanced Services Programme for Learning Disabilities (2007–2008).

Only a few NHS boards have an organised plan in place with proper checks, evaluation and follow-up. Some NHS boards are working closely with different organisations. The review teams found some good practice in some areas. These areas included some children moving easily to adult services, services for older people, hearing services, opticians and dentists. However, this good work is not throughout Scotland.

The Scottish Enhanced Services Programme for Learning Disabilities is being used in all NHS board areas except one. Screening tools are not used in all NHS board areas. Where they are used, there is often no checking or follow-up.

B.7 Primary Care and Community Services: There is an agreed approach to joint working with social work and other agencies in line with Joint Future (2000) recommendations.

Most NHS boards have agreed how they will work together with social work and other organisations. This is what was recommended in the Joint Future (2000) report.

Some NHS boards have services that are run by health and social work together. These teams have officially agreed how they will share information. The review teams found that in some NHS boards there was good local area co-ordination and good links with services in the community and partner organisations. However, some NHS boards do not have much involvement in setting up and organising local area co-ordination.

Most NHS boards have formal rules about how to manage risk. These rules have been agreed by health and social work. Most NHS boards have equipment stores that can be used by both health services and social work services. These seem to be working well.

However, the review teams found that this good work is not happening in all NHS board areas.

B.8 Hospital Services: There is a system in place to ensure that paediatric and general hospital services can get advice and support from specialist staff in learning disabilities.

Many NHS boards have been working hard to improve arrangements, to help make it easier for people with learning disabilities to access healthcare. Some NHS boards have good information that is easy for everyone to understand. More work is needed in some NHS boards to make sure that advice and information is always available to all staff. Some NHS boards need more input from learning disability services. Some NHS boards are working on raising awareness about how to get more information about learning disabilities. This is encouraging.



B.9 Hospital Services: General hospital services and services provided by paediatric hospitals/units are aware of the needs of children and adults with learning disabilities, and meet them appropriately.

A number of children's hospitals and general hospitals are making staff aware of the needs of people with learning disabilities. The review teams found some good examples of changes to people's care to make sure they have equal access to services.

In some NHS board areas, good work is being done to look at problems with communication. Plans have been written to help people through their journey of care.

Some NHS boards are making sure that the people with learning disabilities find it as easy as possible to make appointments. However, often this only happens if the hospital knows that the person making the appointment has a learning disability.

All NHS boards have plans for what staff should do when people with learning disabilities come into hospital. It can sometimes be difficult to get advice quickly, especially when people come into hospital unexpectedly or at night.

There are many more learning disability acute liaison nurses now in post. This means there is good support from experienced learning disability nurses to help services meet the needs of people with learning disabilities and their carers.

There are still some NHS boards that need to have better plans in place to make sure that special care is given to people with learning disabilities when they need it.

Only a few NHS boards have been using the NHS QIS best practice statement for learning disabilities.

B.10 Palliative Care: Palliative care services are able to take account of the needs of children and adults with learning disabilities.

Most palliative care services in Scotland can meet the needs of children and adults with learning disabilities. These services are good because they give person-centred support. There is good communication between learning disability services, palliative care services and other organisations. This makes sure that there is good advice and information is available. Local hospices are also important for providing palliative care for people with learning disabilities.

When palliative care services are not available, this has an effect on people with learning disabilities and their carers.

The review teams found lots of examples of good practice. Sometimes there are no official plans and agreements in place.



B.11 Services for Older People with Learning Disabilities: There is appropriate health and social care intervention for older people with a learning disability.

There are lots of well-developed and joint services for older people with learning disabilities. Good working between health and social care services means that the needs of older people with learning disabilities are being met in most NHS board areas.

Many care homes are able to meet to the needs of people with learning disabilities. Many NHS boards have developed good plans to help older people with learning disabilities.

In some NHS board areas, people will start using older people's services as they get older. In these NHS boards, protocols have been developed to ensure the move from adults' services to older people's services goes smoothly.

However, in some NHS boards, services for older people are not well organised. There are often difficulties with planning.

Older people's services will be even more important in the future. This is because people in Scotland are living longer.

B.12 Clinical Guidelines and Governance: Clinical guidelines for specific illnesses are followed and take account of the needs of children and adults with learning disabilities, for example SIGN, NHS QIS.

Some NHS boards make sure that staff understand how to apply official advice about illnesses to the treatment of people with learning disabilities. Clinical governance rules have been put in place to make sure this happens. Information about the advice is sent to staff and checks are made to make sure that the advice is being followed. Staff find it easier to follow this advice when someone from learning disability services has checked to make sure it meets the needs of people with learning disabilities.

However, in half of the NHS boards there are no official arrangements to make sure that when advice and guidelines are given, someone thinks about how this affects people with learning disabilities.

Some NHS board areas were not able to show that they understand how important clinical advice and guidelines are. These NHS boards may not understand how important it is to think about the different needs of people with learning disabilities. It is difficult for these NHS boards to make sure that the best care is given to people with learning disabilities.

B.13 Wheelchair and Seating Services: Wheelchair and seating services are provided which meet the needs of children and adults with learning disabilities.

Most NHS boards understand the needs of people that use wheelchairs. NHS boards are planning to use the Wheelchair and Seating Services document from the Scottish Government to make wheelchair services better.

When NHS boards listen to the views of wheelchair users and carers, it helps them to make sure that the needs of people with learning disabilities get the wheelchairs, information and help that they need. Some NHS boards do not involve wheelchair users and carers enough.

When wheelchair and seating services are not good enough for people with learning disabilities, this has a great effect on their lives. A small number of NHS boards urgently need to improve their wheelchair services, especially the time that people have to wait for some equipment.





5 What we learned

The two quality indicators that we looked at in this review about Promoting Inclusion and Wellbeing and Meeting General Healthcare Needs are vital for people with learning disabilities. The Fatal Accident Inquiries into the deaths of Mr James Mauchland and Mr Roderick Donnett remind us about this.

This review has shown that progress is being made. Many NHS boards and staff are organising things better to try to meet the needs of people with learning disabilities.

However, quite a few of the gradings were not met across Scotland. This shows us that there is still work to be done to make sure services are good enough.

In a number of NHS board areas, people working in learning disability services said that some general health services do not understand the needs of people with learning disabilities. They do not understand that they may need to do things differently to make sure that people with learning disabilities can access health services.

Almost all NHS boards have taken on the Scottish Enhanced Services Programme in primary care for adults with learning disabilities. This has been a good move. However, some NHS boards have made more arrangements for people with learning disabilities than others. The Scottish enhanced services programme is for adults with learning disabilities. Some NHS board areas have also included children with learning disabilities in this.

There has been good work to include people with learning disabilities in national screening programmes. There are some good projects for general health screening for people with learning disabilities. Some of these are linked to the Scottish Enhanced Services Programme.

The review teams found that different screening tools are being used in different NHS board areas. It would be helpful to agree which tools should be used across the whole of Scotland. This would help to check how well the tools are being used, and to help make improvements.

The new learning disability liaison nurses in primary and secondary care have been very good for helping health staff to know why they must understand the needs of people with learning disabilities.

Liaison nurses give good help and support to people with learning disabilities. The nurses also point out where things could be better and help to fix problems. They also teach other staff about learning disabilities.

When new staff start working for NHS boards, they are given training. Some NHS boards ask people with learning disabilities to help with this training. These NHS boards told us that this works really well. However, only a few NHS boards involve people with learning disabilities in training. It would be good if this happened in all areas.

Some NHS board areas do not have much training about learning disabilities for general healthcare staff. However, it was good to see that some NHS board areas have good information packs for general staff about the needs of people with learning disabilities.

A number of NHS board areas have good systems to help them recognise the people with learning disabilities who need support. This can include the use of special cards and alerts on computer systems. Information about health risks are sometimes recorded in patient notes and emergency care summaries and are used well in some NHS board areas.

Some NHS board areas have worked well to help people with learning disabilities to have good access to health services. However, sometimes this good work is only done by one person. If this person moves away the good work may not carry on. This good work should not rely on one person to make sure it happens.



Health improvement is good in some areas but again sometimes this good work is only done by one person. This good work should be part of an official health improvement plan. Only a few NHS boards have clear health improvement plans which look at the needs of people with learning disabilities.

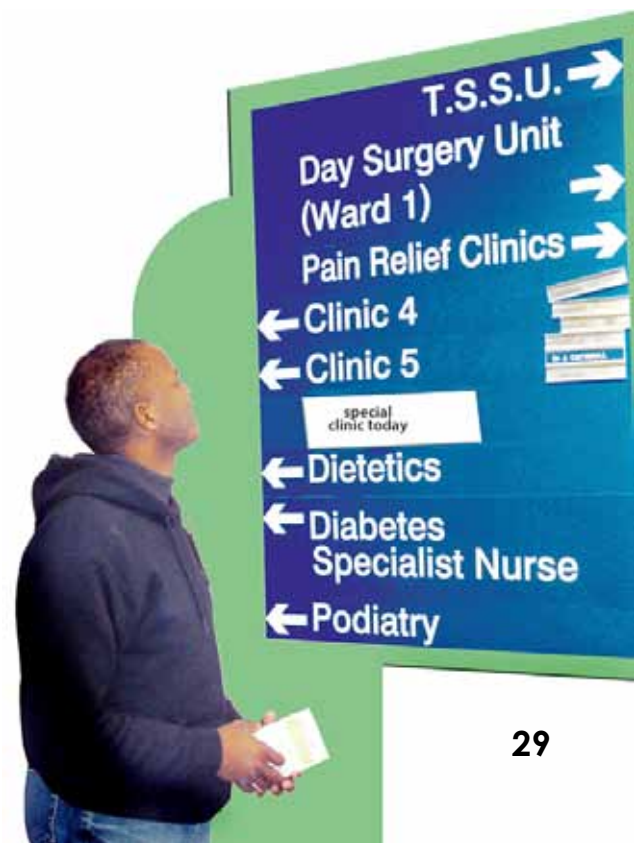
In many NHS boards, there is very good practice in certain services. Sometimes this very good practice is only in a small area of the country. The good practice that is happening in small areas should be happening across the whole of Scotland. NHS boards need to work out the best way to make sure this happens.

Examples of this good practice are in:

- breast screening
- dentistry
- hearing services, and
- vision services.

Palliative care services are good in almost all NHS boards. This is because the services are person centred. Palliative care services also work well with learning disability services.

The NHS QIS best practice statement called Promoting Access to Healthcare for People with Learning Disabilities – a Guide for Frontline NHS Staff was published in 2006. Only some NHS boards are using this to help them support people with learning disabilities.



Staff in most NHS boards know about the Disability Equality Scheme, although when staff are given training, sometimes there is not very much information given about people with learning disabilities. The Disability Discrimination Act is very important to make sure that everyone can get health services. NHS boards need to make sure that they are keeping to the Disability Equality Duty law. Many NHS boards have done a lot of work to make sure that people with physical disabilities can get access to healthcare. However, often the needs of people with learning disabilities can be missed out.

There is some good work to help people with learning disabilities to get health services. For example, making sure it is easy for someone with learning disabilities to get an appointment and that information is easy to understand.



NHS boards do not often check that people are able to get good access to health services. This means they don't know what needs to be improved.

It is important that healthcare staff know about the needs of people with learning disabilities. NHS boards should check that staff understand this. People with learning disabilities and their carers should be involved in training and helping staff understand.

People with learning disabilities who have a plan to go into hospital have a better experience than people who go in as an emergency.

There has been some good work to improve transport arrangements for people with learning disabilities. This work has been helped by involving people with learning disabilities and carers when plans are being made. In some areas, problems with transport can make it hard for some people to get to health services.

Some NHS boards have good clinical governance plans. However, some NHS boards may not understand that they need to pay attention to how the advice and guidelines can help people with learning disabilities.

In 2008, the Scottish Government told all NHS boards that they had to write an action plan about the work they will do after reading the report about the Fatal Accident Inquiry into the death of Mr Roderick Donnett. The plans the NHS boards wrote were mostly about improving primary care and secondary care services for people with learning disabilities. Not many NHS boards chose to talk about these action plans during the NHS QIS reviews.

There has been some training for health staff about the Adults with Incapacity Act. However, it can be hard for staff to get the right training in some NHS board areas.

In some NHS boards, the Adults with Incapacity Act is not being used properly. This is happening in both primary care services and secondary care services.

The review teams found that not many NHS boards are checking how well staff are using the Adults with Incapacity Act. It is difficult to make these checks because the Section 47 form is kept in the patient's notes.

In some NHS boards, it is hard to make sure that all medical staff agree to fill out the forms. Some medical staff do not understand that they must fill out the form and some medical staff do not want to be involved in filling out the form.



In many NHS boards areas, the review teams found good work being done to help people with learning disabilities. Some NHS boards have found it hard to keep this good work going on for a long time. One answer to this problem could be to make sure that the good work happens for all vulnerable people. Helping other groups of people as well as people with learning disabilities means that there might be more support from general health staff. An example of this is that easy-read signs and pictures on menus can also help other patients who find it hard to read or communicate.

Review teams found lots of different ways to make sure that information that is given to people is easy to understand. It is usually learning disability staff that write this information, not general healthcare staff. Not all information that is printed is also available in easy read. It is important that NHS boards understand that they should think about this whenever they give out information.

The review teams found some good examples of changes in general health services. In many NHS boards this work is happening in smaller areas and not across the whole NHS board area. There are also some good projects that have really helped people with learning disabilities and their carers when they are using health services.

During this review we found that a lot of the gradings were not met. There are still a large number of areas in Scotland where people with learning disabilities cannot be sure that they will get a service that is right for their needs. This means that NHS boards might not meet their Disability Equality Duty for people with learning disabilities.

NHSScotland needs to keep up the good work in this report and improve in other areas. This will make sure that people with learning disabilities can get the health service they are entitled to.

6 More information

a) What is a learning disability?

A learning disability is a life-long condition that starts before birth or while a child is growing up.

The term learning disabilities covers lots of different things. People with learning disabilities often find it hard to understand new or complicated information, or learn how to do things. They sometimes find it hard to do day-to-day things without support.

Sometimes people with learning disabilities have physical disabilities too.

About one hundred and twenty thousand (120,000) people in Scotland have a learning disability. Around thirty thousand (30,000) of those people are children and young people under 16 years of age. One person in every four, with a learning disability, has complex needs.

People with learning disabilities need the same healthcare as everyone else and sometimes they also need special care and advice.

b) What we did on the visits

Before the visit:

Teams from NHS QIS visited each NHS board area. The teams included people with learning disabilities, carers, and people who work in health and social work services.

All of the NHS boards filled out a self-assessment which asks questions about how well the health service is working.

The NHS boards also sent in paperwork, called evidence, to help the review teams understand how systems work in each area.

During the visit:

The teams asked questions to check what was written in the self-assessment and find out what was going on in the NHS board area.

The teams gave gradings for each of the quality indicators. They used these descriptions:

Comprehensively developed - whenever it is possible, the needs of people with learning disabilities are fully looked after. There are good plans in place. NHS boards regularly check services to make sure they are as good as they can be. People who use services, and their carers, are asked what they think of the health services. This helps the NHS board improve its services.

Substantially developed - most of the time, the needs of people with learning disabilities are looked after. There are some good plans in place. NHS boards mostly check services to make sure they are as good as they can be. People who use services, and their carers, are asked what they think of the health services.

Partially developed - some of the time, the needs of people with learning disabilities are looked after. There are a few plans in place. NHS boards sometimes check services to make sure they are as good as they can be. People who use services, and their carers, are sometimes asked what they think of the health services.

Scarcely developed - It is not possible to make sure that the needs of people with learning disabilities are looked after. There are not many plans in place. NHS boards do not check services to make sure they are as good as they can be. People who use services, and their carers, are not usually asked what they think of the health services.

The teams agreed that the gradings comprehensively developed and substantially developed mean that an NHS board is good enough to have met the quality indicator. The quality indicator is met.

The partially developed and scarcely developed gradings mean that an NHS board is not good enough to meet the quality indicator. The quality indicator is not met.

After the visit:

NHS QIS uses the information that the teams found to write reports for each NHS board area. The reports talk about the good things and the things that could be better in each NHS board.

All the NHS board reports were used to help write this National Overview report.

NHS QIS is really grateful for the help of all the people who were part of the teams. We could not have done it without them.

NHS QIS would also like to thank the people who helped to organise the visits and those people who came along to talk to the teams and answer their questions.

c) How to find out more about this report

If you want to find out more about the review and our recommendations, you can get some detailed information on our website: www.nhshealthquality.org/nhsqis/5988.html

If you need help with the information on the website, you can ask your carer or support worker. If you would like help from NHS QIS, you can telephone 0131 623 4300 and ask to speak to a member of the learning disability team.

d) Finding out about health services in your local area

You can ask for a copy of the detailed report about services in your local area, or look at it on our website: www.nhshealthquality.org/nhsqis/5988.html

Your local NHS board will have more information on the health services available in your area. The website addresses are below:

NHS Ayrshire & Arran:
www.nhsayrshireandarran.com

NHS Borders:
www.nhsborders.org.uk

NHS Dumfries & Galloway:
www.nhsdg.scot.nhs.uk

NHS Fife:
www.nhsfife.scot.nhs.uk

NHS Forth Valley:
www.nhsforthvalley.com

NHS Grampian:
www.nhsgrampian.org

NHS Greater Glasgow and Clyde:
www.nhsggc.org.uk

NHS Highland:
www.nhshighland.scot.nhs.uk

NHS Lanarkshire:
www.nhslanarkshire.co.uk

NHS Lothian:
www.nhslotthian.scot.nhs.uk

NHS Orkney:
www.ohb.scot.nhs.uk

NHS Shetland:
www.shb.scot.nhs.uk

NHS Tayside:
www.nhstayside.scot.nhs.uk

NHS 24:
www.nhs24.com

NHS Western Isles:
www.wihb.scot.nhs.uk

Scottish Ambulance Service:
www.scottishambulance.com

The State Hospitals Board for Scotland:
www.tsh.scot.nhs.uk

e) How to get more general information about learning disabilities

You can contact these organisations for more information about learning disabilities.

British Institute for Learning Disabilities

Campion House, Green Street, Kidderminster, Worcestershire, DY10 1JL

Telephone: 01562 723010

Fax: 01562 723029

www.bild.org.uk

Enable

2nd Floor, 146 Argyle Street, Glasgow, G2 8BL

Telephone: 0141 226 4541

Fax: 0141 204 4398

www.enable.org.uk

Key Housing

Savoy Tower, 77 Renfrew Street, Glasgow G2 3BZ

Telephone: 0141 332 6672

Fax: 0141 332 7498

www.keyhousing.org

Mencap

123 Golden Lane, London, EC1Y 0RT

Telephone: 0207 454 0454

Fax: 0207 608 3254

www.mencap.org.uk

Mental Welfare Commission

Thistle House, 91 Haymarket Terrace, Edinburgh, EH12 5HE

Telephone: 0131 313 8777

Fax: 0131 313 8778

www.mwcscot.org.uk

PAMIS

Springfield House, 15/16 Springfield, University of Dundee, Dundee, DD1 4JE

Telephone: 01382 385154

Fax: 01382 227464

www.dundee.ac.uk/pamis

People First (Scotland)

77–79 Easter Road, Edinburgh, EH11 1BZ

Telephone: 0131 478 7707

Fax: 0131 478 7404

www.peoplefirstscotland.org

Scottish Government

St Andrew's House, Regent Road, EDINBURGH, EH1 3DG

Telephone: 0131 556 8400

Fax: 0131 244 2162

www.show.scot.nhs.uk/sehd

Social Work Inspection Agency

Ladywell House, Ladywell Road, Edinburgh, EH12 7TB

Telephone: 0131 244 4735

Fax: 0131 244 5496

www.swia.gov.uk

The Care Commission

Compass House, 11 Riverside Drive, Dundee, DD1 4NY

Telephone: 01382 207100

Fax: 01382 207289

www.carecommission.com

The Princess Royal Trust for Carers

Charles Oakley House, 125 West Regent Street, Glasgow, G2 2SD

Telephone: 0141 221 5066

Fax: 0141 221 4623

www.carers.org

The Scottish Consortium for Learning Disability

Adelphi Centre, Room 16, 12 Commercial Road, Glasgow, G5 0PQ

Telephone: 0141 418 5420

Fax: 0141 429 1142

www.sclld.org.uk

f) Word list

Adults with Incapacity Act	Most adults with learning disabilities are able to make choices and decisions about many areas of their life, although they may need help and support in some parts of their daily lives. Other people need a lot of help with skills and decision-making. The Adults with Incapacity Act gives options to help an adult who is not able to make decisions and manage different areas of their life. Now it is possible for another adult to be given the right to make decisions about medical treatment on behalf of someone who cannot act for themselves.
clinical governance	This is the system that NHS organisations use to make sure they are checking and improving the quality of their care and services. The purpose of clinical governance is to make sure that patients receive the best care possible, and that this care is person centred.
complex needs	Someone who has complex needs may have lots of different disabilities and sometimes physical illnesses too. People with complex needs must have lots of support and different services to make sure they stay well.
Disability Discrimination Act (DDA)	This is a law to make sure disabled people are treated fairly.

equality	This means having the same chances in life as everyone else.
general practitioner or GP	This is a local doctor who works at a surgery.
general healthcare services	These are the health services that are there for everyone. This includes health services in the community and hospitals.
health	Good health means you are not ill. It also means you feel well and can lead a full and active life.
local authorities	A group of people who run local services for the Government in a local area.
NHS	National Health Service
NHS boards	These organisations are responsible for running health services in local areas. It is their job to plan for the future and make sure that NHS staff are doing their job properly and that NHS services are safe.
NHS Quality Improvement Scotland (NHS QIS)	It is NHS Quality Improvement Scotland's job to make healthcare in Scotland better for everyone and to make sure that NHS organisations, like hospitals and clinics, are working properly. NHS QIS works with people who use services, carers, members of the public and NHS staff.
public transport	This is buses and trains that everyone can use. It also includes taxis and planes.
quality indicators	A list of items that help check how well a health service is meeting the needs of people.
recommendations	Recommendations are ideas for things we would like to happen to make services better.

review teams	Groups of people from lots of different backgrounds who go out to look at services and ask questions.
reviewers	The people on the review teams.
self-assessment	The document the local health service fills out to tell us how well the service is working.
single shared assessment	This is when a person's needs are talked about and agreed. If the person allows it, this information is shared between local services so they won't be asked the same questions every time they need a new service.
Supporting People	A government programme which helps people to live independently.
palliative care	This is the care that people get when they have a physical illness that cannot be cured.
person centred	This is when health professionals make sure that they make sure the care they give fits in with the needs and wishes of the person.
primary care services	These services are provided by the people you normally see first when you have a health problem. For example GPs, dentists, opticians.
vulnerable adults	Adults who could be easily hurt, influenced or attacked.



You can read and download this document from our website.
We can also provide this information:

- by email
- in large print
- on audio tape or CD
- in Braille, and
- in community languages.

Edinburgh Office
Elliott House
8-10 Hillside Crescent
Edinburgh EH7 5EA

Glasgow Office
Delta House
50 West Nile Street
Glasgow G1 2NP

Phone: 0131 623 4300
Textphone: 0131 623 4383

Phone: 0141 225 6999
Textphone: 0141 241 6316

www.nhshealthquality.org

The Scottish Health Council, the Scottish Intercollegiate Guidelines Network (SIGN) and the Healthcare Environment Inspectorate are also key components of our organisation.

