

NHS Grampian

Local Report ~ *June 2009*

# Healthcare Services for People with Learning Disabilities



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# **Healthcare Services for People with Learning Disabilities**

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](http://www.nhshealthquality.org)). The full report in electronic or paper form is available on request from the NHS QIS Equality and Diversity Officer.

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**[www.nhshealthquality.org](http://www.nhshealthquality.org)**

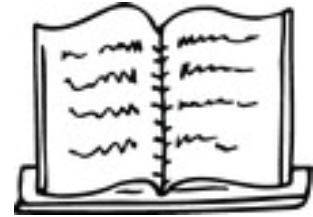
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# 1 Easy read summary of our findings

## About this summary

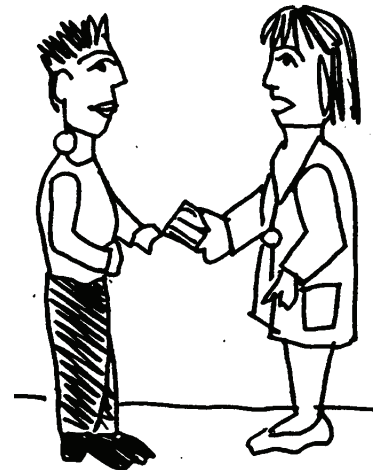
This summary is written for people with learning disabilities, their supporters and family carers.



It tells you how well NHS Grampian is meeting the health needs of children and adults with learning disabilities.

## What is NHS Quality Improvement Scotland?

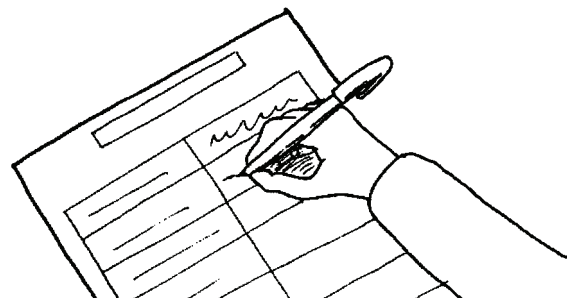
NHS Quality Improvement Scotland (NHS QIS) was set up in January 2003. It is our job to help improve the health services that people in Scotland get.



## How do we find out what the NHS Grampian is doing?

NHS QIS has produced quality checks, which show if a health service is doing its job properly.

The quality checks were used by staff in NHS Grampian to find out how well the service is working. This is called a **self-assessment**.



Then a team from NHS QIS visited NHS Grampian and looked at this self-assessment. The NHS QIS team met with staff to find out more about the service.

This summary was written after the NHS QIS visit. It tells you how well NHS Grampian is doing and what it needs to do to improve.

## **Some information on NHS Grampian**

Grampian is in north-east Scotland and has a population of around 530,000. Nearly half of the people live in Aberdeen. The rest live in smaller towns or in the countryside.

## **How is NHS Grampian doing?**

### **Helping people to be included in their care, and making sure they are healthy**



Good things

NHS Grampian is good at involving people with learning disabilities.

NHS Grampian has an accessible information group that includes people with learning disabilities.

NHS Grampian has information leaflets that are easily available.



Things that need to be improved

There needs to be more involvement from people with learning disabilities in transport groups.

It is important to make sure that the health projects that involve people with learning disabilities take place across Grampian.



## **Making sure people's healthcare needs are met**



Good things

There is a nurse consultant post that helps to improve healthcare for people with learning disabilities.

There are good hearing and optician services for people with learning disabilities.

The Equally Well Project funded by the Scottish Government is helping to improve healthcare for people with learning disabilities.



Things that need to be improved

Staff need to know a bit more about the Adults with Incapacity Act.

All guidelines written for staff need to include information about people with learning disabilities.

Examples of good work happening in NHS Grampian need to take place across the whole area.

## 2 Setting the scene

NHS Quality Improvement Scotland (NHS QIS) was set up by the Scottish Parliament in 2003 to take the lead in improving the quality of care and treatment delivered by NHSScotland. NHS QIS does this by setting standards and monitoring performance, and by providing NHSScotland with advice, guidance and support on effective clinical practice and service improvements.

The revised Quality Indicators for Learning Disabilities were published in February 2004 and have since been used to assess the quality of health services available to children and adults with learning disabilities in Scotland. The learning disability review carried out in 2004–2005 looked at the provision of community-based services for children and adults with complex needs, and progress with learning disability hospital closure.

In response to the findings of the Roddy Donnet Fatal Accident Inquiry, the Scottish Government Health Directorates announced that learning disability services should be reviewed in line with the NHS QIS Learning Disabilities Best Practice Statement and Quality Indicators 2 and 3 from the revised Quality Indicators for Learning Disabilities.

A multidisciplinary and multi-agency project group was appointed in April 2008 to integrate the themes from the two documents and develop a self assessment.

### About this report

This report presents the findings from the peer review of **NHS Grampian's** performance against Quality Indicators 2 and 3.

The review process has three key phases: preparation prior to the visit; the visit; and the report production and publication following the visit. (See flow chart in Appendix 2 for further detail.) During the visit, each multidisciplinary review team assesses performance using the categories as detailed below.

- **'Comprehensively developed'** applies where the evidence demonstrates the systems are in place to ensure that, wherever possible, the needs of the people with learning disabilities are fully satisfied. Procedures and arrangements are based on sound, integrated approaches, deployed in all relevant areas. Robust strategies are in place, together with systems to monitor the impact of these on the quality of services provided. There is an active assessment review, seeking opportunities for further development.
- **'Substantially developed'** applies where the evidence demonstrates the systems in place enable most of the needs of people with learning disabilities to be satisfied. Procedures and arrangements in place are deployed in the majority of areas. Strategies are in place, together with some impact assessment systems. There is some assessment and review activity identifying scope for improvement.

Quality indicator statements graded either comprehensively developed or substantially developed are viewed by the review teams as having **'met'** the standard required.

- **'Partially developed'** applies where the evidence demonstrates the systems in place enable some of the needs of people with learning disabilities to be partially satisfied. Limited procedures and arrangements are deployed in some areas. Fragmented strategies are in place. Little assessment or review activity is being carried out, with a limited agenda for improvement.
- **'Scarcely developed'** applies where the evidence demonstrates the systems in place are insufficient to address the needs of people with learning disabilities. Inadequate procedures and arrangements are scarcely implemented. There is little or no progress in developing relevant strategies. Very little assessment or review is carried out.

Quality indicator statements graded either partially developed or scarcely developed are viewed by the review teams as having **'not met'** the standard required.

A **'no formal grading'** category is used when the nature of the service provided by the NHS board being reviewed makes it inappropriate to formally assess this Quality Indicator statement.

A final category **'not applicable'** is used where a quality indicator and/or criterion does not apply to the NHS board under review.

Each review team is led by an experienced reviewer, who is responsible for guiding the team and ensuring that team members are in agreement about the assessment reached. Membership of the review team visiting **NHS Grampian on 10–11 March 2009** can be found in Appendix 3.

Each NHS board should ensure that the issues highlighted by this report are reported to their clinical governance committee and addressed by their clinical governance and risk management unit.

## 3 Summary of findings

### 3.1 Overview of local service provision

Grampian is situated in north-east Scotland and has a population of around 535,290<sup>1</sup>. About 40% of the local population live in Aberdeen, which is the largest urban area in the region, although a significant proportion live in rural areas.

#### Local NHS system and services

Grampian NHS Board is responsible for improving the health of the local population and for the delivery of the healthcare required. It provides strategic leadership and has responsibility for the efficient, effective and accountable performance of the NHS in Grampian.

Further information about the local NHS system can be accessed via the website of NHS Grampian ([www.nhsgrampian.org](http://www.nhsgrampian.org)).

At the time of the review visit, the total number of people with a learning disability that NHS Grampian served was 3,661. This is made up of 2,569 adults and 1,092 children.

Care is provided for residents within NHS Grampian through 25 hospitals and medical facilities, the largest of which is Aberdeen Royal Infirmary. There is additional service provision for people with learning disabilities within Elmwood learning disabilities unit, Aberdeen, which provides an assessment and treatment unit, close supervision unit, and a day hospital that provides assessment and treatment for both community and hospital clients.

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<sup>1</sup> General Register Office for Scotland. Mid-2007 Population Estimates Scotland. Table 3 - Estimated population by sex, five year age group and administrative area: 30 June 2007. First published on 24 July 2008. Available from: <http://www.gro-scotland.gov.uk/statistics/publications-and-data/population-estimates/mid-2007-population-estimates-scotland/list-of-tables.html>

### 3.2 Summary of findings against the quality indicators

A summary of the findings from the review is illustrated in this section. The most appropriate assessment category is agreed by the review team to describe the NHS board's overall performance against each quality indicator statement – indicated by the shaded areas below. A detailed description of performance against Quality Indicators 2 and 3 is included in Section 4.

<b>Quality Indicator 2 – Promoting Inclusion and Wellbeing</b>					
Assessment category		Comprehensively developed	Substantially developed	Partially developed	Scarcely developed
		Met		Not met	
Quality indicator statement	A.1				
	A.2				
	A.3				
	A.4				

<b>Quality Indicator 3 – Meeting General Healthcare Needs</b>					
Assessment category		Comprehensively developed	Substantially developed	Partially developed	Scarcely developed
		Met		Not met	
Quality indicator statement	B.1				
	B.2				
	B.3				
	B.4				
	B.5				
	B.6				
	B.7				
	B.8				
	B.9				
	B.10				
	B.11				
	B.12				
	B.13				

## 4 Detailed findings against the quality indicators

### Quality Indicator 2: Promoting Inclusion and Wellbeing

#### **A.1 Quality indicator statement**

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.

#### **Grading: Substantially developed – Met**

The NHS Grampian Disability Equality Scheme (DES) 2007–2010 ensures that the rights and needs of people with learning disabilities are taken into consideration. Four involvement seminars took place prior to the DES being written. These included participation from people with learning disabilities, carers and representative organisations. The priorities expressed at the seminars became NHS Grampian priorities in the DES.

The needs of people with learning disabilities are also taken into account within the NHS Grampian action plans.

The review team commended the active involvement of people with learning disabilities, carers and representative organisations (including PAMIS and the Aberdeen Learning Disability Group) in the NHS Grampian disability agenda.

Within NHS Grampian, the needs of people with learning disabilities are mainstreamed within the wider disability agenda. Many issues, such as accessible information and staff training, are common to a wide range of disabilities. However, the specific needs of people with learning disabilities are addressed in the DES and action plans.

The review team noted that NHS Grampian's DES compliance procedures were robust, with active monitoring taking place at both internal and external levels.

## Quality Indicator 2: Promoting Inclusion and Wellbeing

### A.2 Quality indicator statement

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

#### Grading: Substantially developed – Met

NHS Grampian has arrangements to facilitate the appropriate levels of support required for people with learning disabilities as well as carers. Evidence was provided to support this. There is an active service user and carer group in operation with a remit that includes environmental issues, accessible information and how best to improve the level of service provided to people with learning disabilities.

In 2008, a new working group was set up in acute care, supporting people with learning disabilities to access services. The group also identifies existing good practice and areas for development.

A pilot of the NHS QIS best practice statement audit tool was undertaken in 2008 across South Aberdeenshire GP practices with service user involvement. This was supported by a community learning disability nurse and will provide part of the foundation for a GP electronic resource toolkit in the future. Additionally, a questionnaire has been sent out to service users regarding the accessibility of GP practices and the results of this will also aid the development of the GP electronic resource toolkit. It was noted that the consultant nurse in learning disabilities was, at the time of the review visit, in the process of undertaking visits to all GP practices in NHS Grampian and again, this will aid in the development of the toolkit.

Within the acute sector, it is planned that an audit of the NHS QIS best practice statement will take place during 2009 within Aberdeen Royal Infirmary and Dr Gray's Hospital, Elgin, and the results will provide the basis for an action plan.

All NHS Grampian area locations have been adapted to comply with Disability Discrimination Act (DDA) 1995 legislation. It was noted that environmental adaptations have been made where required, in order to facilitate the treatment of people, including those with learning disabilities.

Information about health services within NHS Grampian is available in a variety of formats for people with learning disabilities, including easy read. Going to Hospital leaflets have been developed in Moray and also for the Aberdeen Royal Infirmary. NHS Grampian is in the process of producing accessible generic leaflets commencing with one on taking bloods for people, although, at the time of the review visit, development was at an early stage. Additionally, information is available at various health point locations including supermarkets and pharmacies throughout local and urban Grampian.

A communication toolkit provides acute staff with advice regarding communication with those who have learning disabilities.

There is active dissemination of information leaflets for people with learning disabilities through a variety of channels including the NHS Grampian website and via the corporate communications unit.

The review team was advised that, as part of the single shared assessment (SSA), advice on direct payments is provided to the service user and carer including information leaflets. Direct assistance is also given when required during the completion process.

Out-of-hours services for people with learning disabilities are undertaken via NHS 24 with a special note completed by the GP and forwarded to G-Med, which is then added to the Adastra system and passed to NHS 24 for addition to their system. All information given by the GP is then available electronically to NHS 24.



## Quality Indicator 2: Promoting Inclusion and Wellbeing

### A.3 Quality indicator statement

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

#### Grading: Partially developed – Not met

NHS Grampian has developed some strategies to address the needs of children and adults with learning disabilities in relation to patient transport and general transport services. NHS Grampian operates two patient transport liaison groups. Firstly, general managers meet on a monthly basis and look at delayed discharge and issues relating to service redesign appropriate to transport services. Secondly, there is a newly established service user and ambulance service transport group, and membership includes outpatient departments within Aberdeen Royal Infirmary as well as operational support and representation from Aberdeen City and Aberdeenshire Councils. This group meets every 2 months and includes service users and carers. Both groups are not specific to people with learning disabilities and, as previously indicated, have only recently agreed to involve service users and carers in one of these groups.

NHS Grampian reported that people with learning disabilities are referred to a mode of transport appropriate to their needs eg private hire taxis, in compliance with Scottish Government medical criteria and guidelines. The review team noted that assessment by a GP or consultant is required for service users requiring patient transport. At the time of the visit, the review team was informed that local authorities are responsible for carrying out risk assessments for taxi transport. Trained escorts are also available to accompany people with learning disabilities who have more complex needs. At the time of the review visit, NHS Grampian noted that, because of increasing familiarity and consistency of care, only one taxi firm is used to transport service users and this is an informal arrangement.

NHS Grampian informed the review team that, in partnership with NESTRANS, a health and transport action plan and transport strategy were under development. Consultation on the transport strategy is under way, and the review team noted that the Scottish Ambulance Service (SAS) consulted with service users and carers as part of this process.

A 'First of its Kind' leaflet relating to patient transport services has also been developed in partnership with the SAS. Information regarding access to this leaflet has been circulated service wide via a nursing newsletter.

NHS Grampian has a patient focus and public involvement (PFPI) committee, however, at the time of the visit, links with other appropriate groups were still in the process of being established.

Staff present highlighted the use of community pictorial access cards which are available for people travelling to healthcare services via train or bus.

Within NHS Grampian, SAS has employed the services of an ergonomist who carries out risk assessment on SAS vehicles as well as looking at vehicle and equipment design, although the review team noted that there was no input from service users.

The review team was informed of the transport strategy details, in broad terms, the parking arrangements throughout various healthcare locations, eg major hospital sites. NHS Grampian uses the services of Aberdeen City Disability Access Panel, the Deeside Disability Access Panel and the North Aberdeenshire Disability Access Panel to carry out a wide range of reviews on hospital parking sites. However, at the time of the visit, there was no representation from NHS Grampian to clarify the full extent of the role of these panels.

## Quality Indicator 2: Promoting Inclusion and Wellbeing

### A.4 Quality indicator statement

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.

### Grading: Substantially developed – Met

NHS Grampian has five strategic themes, one of which is improving health and reducing inequalities. This area of work aims to ensure improving health and reducing inequalities in health outcomes, access and use of health services is mainstreamed. In particular, work to improve health and reduce inequalities faced by people with learning disabilities is identified and is being delivered through the Equally Well Project. Each of the three community health partnerships (CHPs) in NHS Grampian have developed health improvement strategies which seek to ensure that the health needs of the most vulnerable are addressed. The funding has allowed for the recruitment of three posts to establish a learning disability health improvement team as well as the development of the GP electronic toolkit, and for health promotion and improvement research to be undertaken.

Joint working is being established between public health and learning disability services in order to ensure continuous improvement.

Health promotion materials are available across NHS Grampian to all professional groups through the NHS Grampian Health Information Resources service. A wide range of dissemination methods are used, including an online (or hard copy) catalogue which provides information leaflets produced both by national organisations as well as NHS Grampian. The materials are subject to annual review and content is quality controlled.

Within learning disabilities services, various topics have been developed into pictorial advice including healthy diet and self-health checks. Self-health check booklets were, at the time of the review visit, due to be trialled by people with learning disabilities to gauge how effective they are in supporting people with learning disabilities in carrying out self examination of breasts and testicles. The review team was advised that the choice of subjects to prioritise came from the health promotion and health improvement group.

All schools are involved with health promotion including senior schools, which allows for children with learning disabilities to be actively involved in the development, implementation and evaluation of health promotion activities.

NHS Grampian was able to demonstrate involvement in health promotion for people with learning disabilities via various local partner organisations including Caledonia Youth, which provides a comprehensive sexual health service for young people, with the focus on vulnerable and priority teenagers. Programmes they have provided are adapted for individuals with learning disabilities.

Another initiative highlighted to the review team was Give Kids a Chance, a multi-agency initiative that provides support with activities. There is an identified referral process which ensures equality of access for children with learning disabilities. However, it was noted that the number of children with learning disabilities accessing the service was quite small.

Following feedback from disabled service users and carers, the Guide to Local Services for People with Disabilities and Their Carers was published in 2007. Feedback has been positive, and over 2,000 hard copies have been printed and distributed via disability organisations. It has also proved popular with hospitals, GP practices, health visitors, district nurses, school nurses, community nurses and community midwives. An updated version was published in February 2009.

The Grampian sexual health strategy details a multi-agency commitment to address sexual health issues and includes hard-to-reach categories including people with learning disabilities.

## Quality Indicator 3: Meeting General Healthcare Needs

### B.1 Quality indicator statement

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' need. Health services support people with learning disabilities to use direct payments.

### Grading: Substantially developed – Met

At the time of the review visit, NHS Grampian had a number of measures in place to ensure that children and adults with learning disabilities have an up-to-date multidisciplinary care plan. The review team was informed that, although no percentage was reported, NHS Grampian confirmed that all children requiring a SSA will receive one. An example of how this is recorded was unavailable at the time of the review visit. Staff confirmed that for adults with learning disabilities, all new referrals are processed using the SSA. For existing service users, the NHS board confirmed that approximately 75% have an up-to-date SSA and are reviewed frequently. Plans by the Grampian integrated partnership group to look at implementing an e-SSA tool were highlighted and piloting of this is scheduled to take place in June–July 2009.

NHS Grampian reported that adults with learning disabilities can access direct payments with help and support from Direct Payments – Caledonia based in Grampian. Within children's services, direct payments can be accessed by families and/or carers at any point in their care management plan. The review team commended NHS Grampian on the promotion and accessibility of direct payments. Information is available via Healthpoint Locations situated in: for example supermarkets and chemists. Leaflets with details of direct payments are also readily available.

Between 2007–2008, NHS Grampian had undertaken a review of record-keeping, monitoring the quality of assessment and ongoing planning for people with learning disabilities. From this, an action plan has been developed, implemented, and a further review of care aims, based on a person-centred approach to individual needs, is being carried out by nursing, clinical psychology and allied health profession staff.

The review team was informed that a satisfaction survey regarding SSA was conducted approximately 2 years ago. The sample group was drawn from care groups across NHS Grampian. Survey questionnaires were available in easy read, pictorial and symbolised formats, as well as individuals being able to feedback by telephone. NHS Grampian provided results of the survey to the review. At the time of the review visit, consideration was being given to a continuation of this survey.

Specific health needs of people with learning disabilities, who are known to healthcare services, are identified via detailed care and/or life plans, and sharing of information is consistent with the NHS Grampian information sharing policy. For people with complex needs, a care programme approach (CPA) is used. Staff noted that to promote access, CPA documentation includes a pictorial reference. People

with dysphagia have joint multidisciplinary guidance which is accessible to staff and regularly reviewed. Staff confirmed that family and paid carers are also informed.

Personal passports are in use, allowing service users to have ownership of their information in an accessible format, as well as allowing staff to access key information.

NHS Grampian ensures that Adults with Incapacity (Scotland) Act (2000) (AWIA) arrangements are in place via the Joint Learning Disability Multi-agency Training Project (Aberdeen and Aberdeenshire), although staff confirmed that the availability of training on AWIA could be improved. The Scottish Government provide an easy read guide, Its Your Decision AWIA, to raise awareness for people with learning disabilities.

NHS Grampian reported that an audit of GP practices was under way. A letter had been sent to all GP practices in Aberdeen and Aberdeenshire in 2008 requesting numbers of people registered within their practice that have a learning disability and also have Incapacity Certificates. The review team noted that, at the time of the visit, only half of GP practices responded.

Communication needs of adults with learning disabilities are met by referral to the speech and language therapists (SLTs). Staff confirmed that there is a waiting list to access the SLT service and referrals need to be prioritised. Within children's services, speech therapy assessments with the use of various communication aids, for example communication passports, are in use.

## Quality Indicator 3: Meeting General Healthcare Needs

### B.2 Quality indicator statement

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.

### Grading: Substantially developed – Met

It was noted that NHS Grampian has strategies and procedures in place for disability awareness. Equality and diversity training takes into account children and adults with learning disabilities. There is a designated equality and diversity practitioner in place.

NHS Grampian's equality and diversity manager has overall responsibility for managing the equality and diversity agenda, including relevant induction and ongoing training around disability (including learning disabilities).

Learning disability DDA training, which is specific to the needs of people with learning disabilities in both children and adult services, is offered through the NHS Grampian training directory. Learning disability DDA training involves both a service user and a carer who speak of their experiences within NHS Grampian. It was noted by the review team that this training is not mandatory, although the nurse consultant in learning disabilities has met with the induction steering group and there had been agreement in making learning disability awareness mandatory in the corporate induction.

The induction training delivered to all new members of staff advises on the legal requirements of the general duty under the DDA and the DES as well as other equality legislations. Information on all equality requirements is available on NHS Grampian's website.

NHS Grampian has a programme of ongoing equality and diversity training for all staff, which was, in part, designed with the involvement of disability engagement groups. The programme aims to ensure that people with learning disabilities are supported and empowered to be part of the decision-making process. Registration of attendance is also recorded for training audit purposes. NHS Grampian has trained level one impact assessors who work with groups developing policies and strategies and inform the equality and diversity process.

At the time of the review visit, a new extended disability awareness training syllabus for NHS Grampian employees was being developed, which will go into greater depth and be co-presented by disabled people. The expected timescale for completion was March 2009.

NHS Grampian advised that AWIA training is carried out through the joint training project, with records of attendance kept. All learning disability staff must attend training.

The review team noted that robust systems and procedures are in place regarding the implementation of the Mental Health (Care and Treatment) (Scotland) Act (2003) which includes all frontline staff accessing training. Training is optionally refreshed on an ongoing basis with all attendance being documented within the training department.

NHS Grampian has involved, where appropriate, service users and carers in training, one example being through the joint training project.



## Quality Indicator 3: Meeting General Healthcare Needs

### **B.3 Quality indicator statement**

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

### **Grading: Substantially developed – Met**

The learning disability nurse from the local community learning disability team is the named specialist practitioner linked to each GP practice team in NHS Grampian for adult services. Learning disability nurses work as part of an NHS/local authority integrated, co-located community learning disability team throughout NHS Grampian. Posters and fliers detail available services as well as how to contact the community learning disability team. Meetings take place at regular intervals between the community learning disability nurses and GP practices to discuss patients on their register that have not been in contact.

At the time of the review visit, the nurse consultant was in the process of undertaking a programme of education and advice meetings with all GP practices within NHS Grampian.

## Quality Indicator 3: Meeting General Healthcare Needs

### B.4 Quality indicator statement

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.

#### Grading: Partially developed – Not met

The review team felt that within NHS Grampian, primary care services that are provided to children and adults with learning disabilities and their carers, both in scheduled care and out-of-hours periods could be improved.

It was noted that at the time of the review visit, all GP practices across the three CHPs had registers in place for adults with learning disabilities as part of the Scottish Enhanced Services Programme (SESP) contract. Reviews of people on these registers are ongoing and take place regularly between GPs or practice nurses and clinicians. Registers identify the cause and severity of learning disabilities, living and support arrangements as well as other medical issues such as epilepsy, challenging behaviour, etc. Some practices within Moray have included children in their registers, however, as this was not a direct requirement of the SESP contract, this is not universal across NHS Grampian. Although four GP practices have opted out of the SESP contract, they still have the support of the community learning disability team and consultant nurse.

NHS 24 does not receive learning disability registers from primary care and, at the time of the review visit, information was being captured by uploading into the NHS 24 system on an ad hoc basis, when a GP provides details within the patient's special notes. Alternatively, information is identified on initial questioning by NHS Grampian staff and recorded thereafter in the patient's clinical summary.

The special notes facility, which allows for additional information regarding a patient's needs to be shared with NHS 24, was identified by NHS Grampian as a work in progress. This was in part due to not being in use across NHS Grampian and there were issues surrounding its use in relation to chronic issues. NHS Grampian acknowledged these limitations and was, at the time of the review visit, working to address these.

## Quality Indicator 3: Meeting General Healthcare Needs

### B.5 Quality indicator statement

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

#### Grading: Substantially developed – Met

Specific information and support for adults with learning disabilities to enable them to participate in screening programmes is available through a range of national screening programmes. People with learning disabilities are supported individually, as required. Boardmaker software is used to customise information. Joint production of self-health checking of breasts and testicles was about to be piloted across Aberdeen city at the time of the review visit, and supported by the city community learning disability team before being rolled out across NHS Grampian.

In relation to screening programmes within children's services, support and information is provided depending on the individual's needs to ensure appropriate participation in child health surveillance programmes. Children are monitored by public health nursing teams as recommended in Health For All Children (2002), with participation by all children being ensured through national child health systems programmes and school systems.

The review team noted that enhanced health surveillance of children with learning disabilities is in place via the use of second tier child development clinics, which are accessed by health visitors on GP referral or by the child development team for tertiary referrals from health visitors, GPs, combined child health, hospital doctors or therapists.

Additionally, support is provided for pre-school assessment through the Raeden Child Development Centre, Aberdeen, which provides multidisciplinary and inter-agency assessment, treatment and education for pre-school children including those with learning disabilities.

## Quality Indicator 3: Meeting General Healthcare Needs

### **B.6 Quality indicator statement**

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 Disability (2007–2008).

### **Grading: Substantially developed – Met**

The review team was advised that care plans are regularly reviewed and updated to ensure that care and support is as appropriate as possible.

NHS Grampian provided examples of how the health needs of people with learning disabilities are monitored and assessed, including specialist audiology and optician clinics for people with learning disabilities.

NHS Grampian is involved in the SESP for learning disabilities which ensures that information is reviewed systematically to optimise care for adults with learning disabilities. This is also ensured clinically, and age appropriate screening and care is delivered to registered people with learning disabilities to the same standards, quality and accessibility as the rest of the population.

In relation to older people, NHS Grampian advised that access to generalist services is on an individual basis with special requirements for older people being tailored to ensure that services are appropriate as people grow older.

NHS Grampian learning disability service has an initial screening tool which is completed by community learning disability nurses for all new referrals. If the client case has been open for over 1 year and there are indications of unmet health needs, a referral is then made to their local GP. It was noted that joint risk assessment tools are completed by health and social work staff as required within all three CHPs.

A health screening pilot questionnaire was undertaken within Moray CHP, to support the identification of gaps in the client's healthcare and to address these where necessary.

## Quality Indicator 3: Meeting General Healthcare Needs

### B.7 Quality indicator statement

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.

#### Grading: Substantially developed – Met

NHS Grampian was able to demonstrate that there is an agreed approach in place to ensure information is shared between appropriate agencies and the three local authorities, through the Grampian integrated partnership group. The group takes forward initiatives around joint assessment, joint care planning and joint reviews, evaluating effectiveness of models as well as service user and carer satisfaction.

Within NHS Grampian, there is a project manager in post to take forward the work of the Data Sharing Partnership as well as the piloting of e-SSA. All joint community learning disability teams across Grampian have regular multidisciplinary team meetings to discuss new referrals. Regular review meetings are held by all key players to ensure a person-centred approach and the smooth transfer of information between partners. All arrangements for information procedures are laid out in practitioner guidance.

Within the three local authority areas, NHS Grampian has been pivotal in the development and implementation of local area co-ordination. Induction of local area co-ordination posts included time spent with the community learning disability teams and learning disability nurses to advise on the role and support that can be accessed via the open referral system. NHS Grampian advised that local area co-ordination will be expanded through the Equally Well Project.

A joint equipment store for children and adults with learning disabilities is in place across health and social work throughout Grampian, which can be accessed by all sites. It was noted, however, that specialist equipment needs to be ordered as required. Additionally, there is a loan bank for communication aids and equipment which is managed using a database.

There are agreed joint protocols in place for risk assessment for adults with learning disabilities, which were under review at the time of the review visit, with the intention of adopting the NHS Patient Safety Root Cause Analysis model. NHS Grampian adopts the NHS critical incident process when required, but adult protection committees were, at the time of the review visit, formalising agreement on the model to be used.

NHS Grampian advised that there had been no joint critical incident reviews carried out for children or adults within the last 2 years.

## Quality Indicator 3: Meeting General Healthcare Needs

### **B.8 Quality indicator statement**

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.

### **Grading: Partially developed – Not met**

Within NHS Grampian, some procedures and systems are in place to ensure that all staff receive appropriate advice and support from specialist staff within learning disability services. An acute setting policy has been in place since 2005 and was updated in 2008 to include the acute learning disability nurse adviser role. The NHS Grampian referral process to the acute learning disability nurse is detailed in a flow chart with contact details, and also a laminated copy is also on display in each clinical area.

A website development group has been set up to share best practice and to ensure information on learning disabilities is easily accessed by all health professionals within NHS Grampian, through new learning disability pages on the NHS Grampian website. No timescales were provided to the review team regarding a completion date.

Although the review team was advised of a number of staff awareness raising sessions that were taking place throughout NHS Grampian, the review team agreed that this was an area where there was an opportunity to improve, thus ensuring equity across the three CHP areas.

## Quality Indicator 3: Meeting General Healthcare Needs

### B.9 Quality indicator statement

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

#### Grading: Partially developed – Not met

Within acute services, protocols and support have been developed in partnership with the learning disability service to support adults with learning disabilities in attending general hospital settings. These include elective and emergency admissions, as well as outpatient departments and going to theatre. It was noted that there are no specific protocols within children's services.

Systems are in place to ensure that appointments take into account the needs of people with learning disabilities and allow for a choice of dates and times of appointments, and to specify any special arrangements required in advance. Referrals can be made directly to the acute learning disability adviser for support from primary care, service users and carers. It was noted that nurse adviser leaflets were at the time of the review visit, being developed in conjunction with the NHS Grampian service user and carer group.

Although not commonplace, consultant home visits at a GP's request can be undertaken by certain specialties, dependant on the requirements of diagnostic intervention. Within children's services, home visits can be undertaken by learning disability child and mental health service nurses, although child development team home visits are not provided.

There are no full-time arrangements to ensure specialist advice is available within 4 normal working hours of a person with a learning disability being admitted to a general hospital. The learning disability liaison team is available during standard office hours, 5 days a week, however, there is no provision made for out-of-hours or weekends.

Adults with learning disabilities are identified at assessment using standard protocols, with appropriate action undertaken. A toolkit is available to support general healthcare staff to communicate effectively. Further guidance is also given in the acute policy and accompanying guidelines.

For children with learning disabilities, carers and parents are recognised as the main source of communication between health staff and the child. Once a child's communication needs are identified at assessment, findings would be discussed between hospital staff and their carer with appropriate communication aids being identified and implemented. NHS Grampian is aware that some of their systems in communication issues are adhoc and, at the time of the review visit, was working to improve them.

NHS Grampian staff are aware of communication passports and patient-held records and would identify their existence as soon as a patient had been admitted to a hospital setting, although, it was noted that they were not in universal use. Communication passports are also mentioned within staff awareness raising sessions.

There are formal systems in place on admission or prior to admission to prepare for communication requirements and to make suitable adjustments, although if a GP highlights that a patient has a learning disability then communication support needs can be prepared in advance. A new acute and community hospital admission document was, at the time of the review visit, being piloted and NHS Grampian aims to roll it out during 2009, once the pilot findings have been evaluated.

At the time of the review visit, NHS Grampian had not implemented the NHS QIS best practice statement directly, although similar guidance to the resources within Appendices 1–4 were being incorporated into guidelines and policy, including the proposed GP electronic toolkit.

Regarding additional needs of children and adults with learning disabilities in terms of general hospital services, it was noted that the needs of children are assessed on an individual basis and care plans reflect this. Within the Royal Aberdeen Children's Hospital, if a child is admitted with a learning disability and extra nursing support is required, the hospital will attempt to provide this, although the pool of bank nurses is not always sufficient to meet this requirement.

For adults, part of NHS Grampian's assessment of people with learning disabilities takes into account specific needs of people through agreed policies and procedures and again, if extra nursing support is required, this would be provided through the pool of bank nurses, if possible.

Discharge arrangements for adults are undertaken by the discharge co-ordinators, and the nurse adviser is involved from pre-admission to discharge, supporting in all stages of the patient journey. For children, discharge planning is done through the care pathway for children with complex needs.



## Quality Indicator 3: Meeting General Healthcare Needs

### **B.10 Quality indicator statement**

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

#### **Grading: Substantially developed – Met**

Palliative care services within NHS Grampian take account of the needs of children and adults with a learning disability based on individual client needs, however, at the time of the review, there were no formal arrangements in place between palliative care and specialist learning disability services. However, work is being undertaken to formalise these arrangements, through a needs assessment, which will include developing training to support implementation.

A nurse consultant in children's and young people's palliative care has been recently appointed, covering NHS Orkney, NHS Shetland, NHS Highland as well as NHS Grampian. Children receive hospice care from Rachel House, Kinross, and Robin House, Balloch.

Hospice care is also available for adults with learning disabilities when required, at Roxburghe House, Aberdeen, a purpose-built specialist palliative care unit as well as within The Oaks, Elgin, a specialist care unit for people with cancer and other terminal illnesses.

Palliative care services are for inpatient and outpatient clinics, domiciliary visits and educational outreach as required, at the request of health and social care professionals looking after adults with and without learning disabilities.

The review team noted that there were close links between the relevant services and support needs could be addressed appropriately by the most suitable professional, as required.

## Quality Indicator 3: Meeting General Healthcare Needs

### **B.11 Quality indicator statement**

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

#### **Grading: Substantially developed – Met**

NHS Grampian reported that it provides appropriate health and social care intervention for older people with learning disabilities. Specialist learning disability services provided by joint integrated community learning disability teams cover adults throughout their life. Staff reported that people with learning disabilities would only transfer to older people services if they did not have specialist needs.

During discussions with staff, the review team was informed that Aberdeen City Council is planning to review current service provision for older people with learning disabilities and may introduce a system whereby re-assessment of the service user is required prior to entry to older people's services. At the time of the visit, no decision had been agreed regarding this review.

NHS Grampian reported that the management of older people with learning disabilities moving between care management teams is supported on an individual basis.

There is a dementia ICP and dementia screening tool for older people with learning disabilities, and joint multi-agency learning disability project training is available specifically around dementia. Staff informed the review team that there are robust links with learning disability services and the dementia integrated care pathway (ICP) group based in Cornhill Hospital, Aberdeen, and both groups meet every 2 months.

NHS Grampian highlighted that provision of age-related care packages are met through the joint future arrangements in place within local authority areas. There is an anticipatory care pathway in place, however, this is not designed primarily to meet the needs of people with learning disabilities, but will effectively provide support if required.

## Quality Indicator 3: Meeting General Healthcare Needs

### **B.12 Quality indicator statement**

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

#### **Grading: Partially developed – Not met**

At the time of the review visit, NHS Grampian was in the process of reviewing the distribution process of all guidelines including SIGN and NHS QIS. NHS Grampian was unable to demonstrate to the review team that there are robust procedures in place for dealing with the dissemination, review and implementation of external guidelines. Although each guideline is considered by a quality improvement group to ensure that they are relevant, considered and appropriately applied, it was noted by the review team that there were not sufficient procedures in place to ensure that guidelines were being suitably adapted to take into account the requirements of people with learning disabilities.

NHS Grampian advised that a pilot audit of the NHS QIS best practice statement on learning disabilities was being piloted in South Aberdeenshire and a report would be provided in due course.

## Quality Indicator 3: Meeting General Healthcare Needs

### **B.13 Quality indicator statement**

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

#### **Grading: Substantially developed – Met**

NHS Grampian reported that it is responsive to the provision of wheelchair and seating services which meet the needs of children and adults with learning disabilities. The review team was informed that the Scottish Government commissioned PAMIS to conduct a review of wheelchair services and, in conjunction with specialist learning disability occupational therapists and physiotherapists, a report and action plan was produced. Staff noted that recommendations from this report will be implemented over the next 2 years, one of which is to involve service users and carers in designing wheelchairs.

Within adult services, the Mobility and Rehabilitation Service (MARS) is responsible for the issue and maintenance of wheelchairs and specialist seating. Staff confirmed that services users are involved in making choices about which devices are available. For children's services, NHS Grampian wheelchair service offers a range of equipment, which is purchased by NHSScotland national contracts, to provide the best match possible to the full range of service user needs within the financial constraints of the service. New wheelchair and seating referrals have the longest waiting times, although current service users are usually screened within 3 days of referral with equipment being dispatched within 10 days, depending on the geographical area the service user lives in.

Guidance on the needs of service users requiring wheelchair services and who also have sensory impairment is provided by the community learning disabilities team.

Funding has been obtained and plans are being developed to operate wheelchair clinics or centres for children's services locally in Moray and Buchan, and for further development of services provided to NHS Orkney and NHS Shetland. These centres will allow for more rapid local delivery of wheelchair and seating equipment, reducing the need to travel to the centre based in Aberdeen.

Staff from NHS Grampian highlighted plans to set up a joint equipment store between Moray and Aberdeenshire which is due to open at the end of 2009. Establishment of a joint store will also help promote joint working around staff training, adaptations and guidance in relation to referral pathways.

Specialist seating for home use is provided by the social work department, although, NHS Grampian liaises with social work occupational therapists around service prescription. Physiotherapists are involved in more complex postural needs and can submit referrals to the social work occupational therapists.

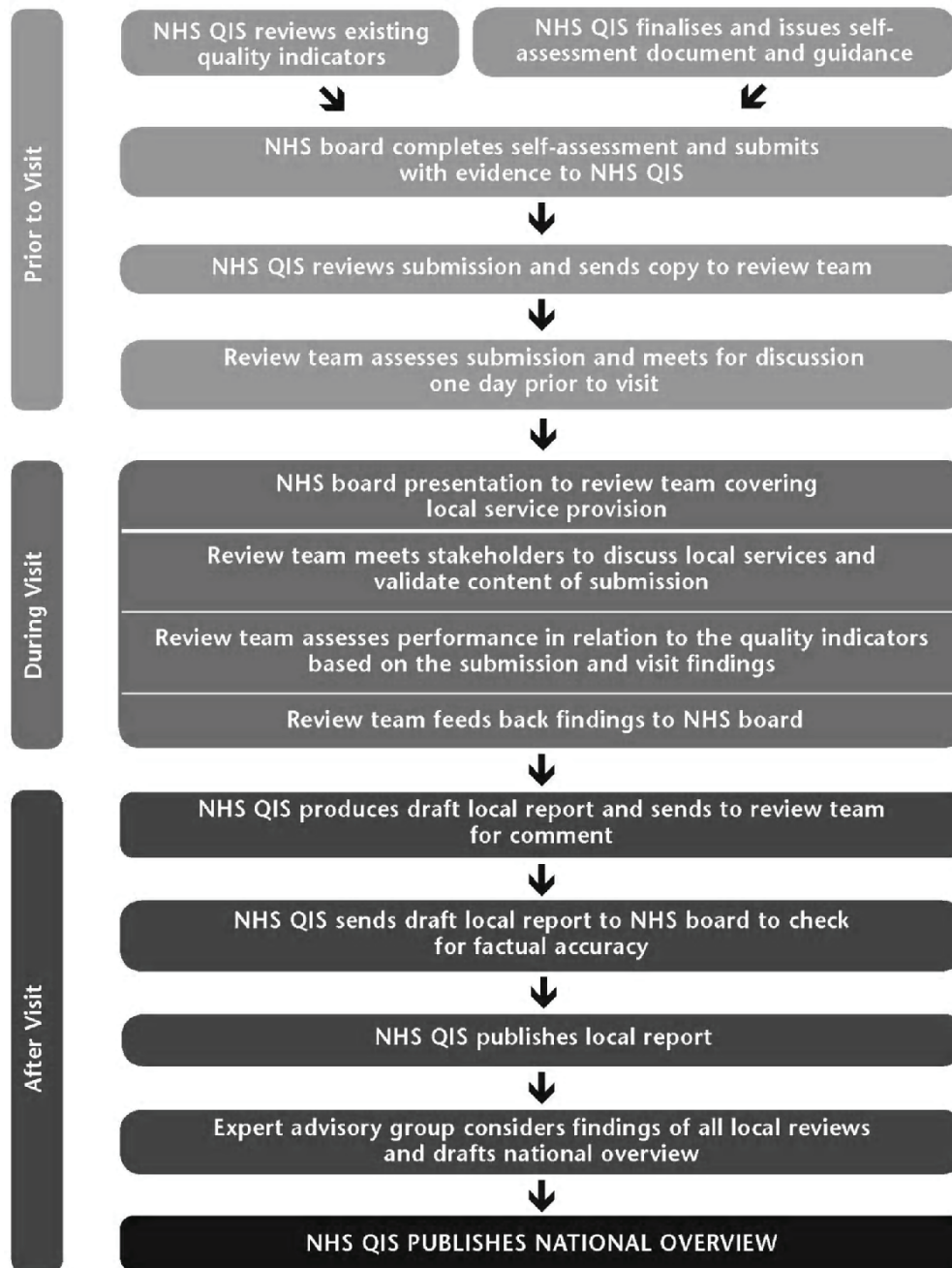
## Appendix 1 – Glossary of abbreviations

### Abbreviation

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<b>AWIA</b>	Adults with Incapacity (Scotland) Act (2000)
<b>CAMHS</b>	child and adolescent mental health service
<b>CHP</b>	community healthcare partnership
<b>CPA</b>	care programme approach
<b>DDA</b>	Disability Discrimination Act (1995)
<b>DES</b>	Disability Equality Scheme
<b>GP</b>	general practitioner
<b>ICP</b>	integrated care pathway
<b>MARS</b>	Mobility and Rehabilitation Service
<b>NHS</b>	National Health Service
<b>NHS QIS</b>	NHS Quality Improvement Scotland
<b>PFPI</b>	patient focus and public involvement
<b>SAS</b>	Scottish Ambulance Service
<b>SESP</b>	Scottish Enhanced Services Programme
<b>SIGN</b>	Scottish Intercollegiate Guidelines Network
<b>SLT</b>	speech and language therapist
<b>SSA</b>	single shared assessment

## Appendix 2 – Review process



## Appendix 3 – Details of review visit

The review visit to NHS Grampian was conducted on 10–11 March 2009.

### Review team members

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Project Officer

During the visit, members of the review team met with NHS staff and local stakeholders from across the NHS board area.

Review teams are multidisciplinary, and include healthcare professionals, staff from social work, representatives of voluntary organisations, people who use services and

carers. The team members have no connection with the NHS board they are reviewing. Both of these factors facilitate the sharing of good practice across NHSScotland, and ensure that each review team assesses performance against the quality indicators rather than make comparisons between one NHS board and another. The team remit does not include reviewing the work of individual healthcare professionals, variations in practice (and potential quality) within a service will be encountered and subsequently reported.





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