

A NATIONAL REVIEW OF HEALTH SERVICES FOR PEOPLE WITH INTELLECTUAL DISABILITIES IN SCOTLAND

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Introduction

People with intellectual disabilities in Scotland, and in rest of the UK, have significantly more health needs than people without disabilities, and they also have more difficulties in accessing health services to have these needs met (NHS Health Scotland 2004; Hatton *et al.*, 2002; Scottish Executive 2002; Scottish Executive 2000a).

The Hospital Advisory Service (HAS) in England and Wales was originally set up in 1969 in response to concerns about abuse of patients and poor health and living conditions. HAS became the Health Advisory Service in 1976. The original purpose of the organization was

protection of vulnerable patients. Only later did the organization evolve a quality monitoring role. The same pattern was seen in Scotland, with the establishment of the Scottish Hospital Advisory Service in 1970, which became the Scottish Health Advisory Service in 1995. This was replaced in 2003 by National Health Service Quality Improvement Scotland (NHSQIS).

There are approximately 120,000 people in Scotland who have intellectual disabilities (the term "learning disabilities" is more commonly used in Scotland). Between October 2004 and August 2005 National Health Service Quality Improvement Scotland (NHSQIS) conducted independent reviews of general and specialist health services provided for

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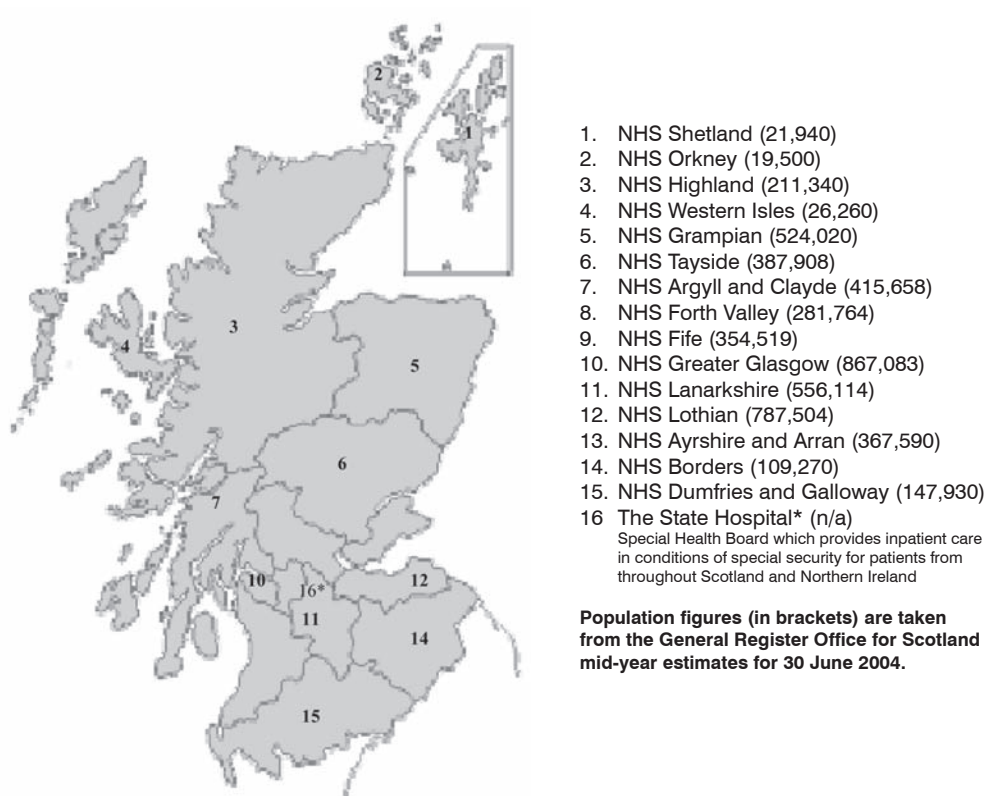
people with learning disabilities in all 15 NHS Boards areas and in the State Hospital in Scotland (see FIGURE 1). Local area reports contain findings of each individual peer review visit and assessment against an agreed set of Quality Indicators.

These Quality Indicators were selected as representative of key elements of hospital closure and community reprovisioning of services: involving people in decisions about their lives; making sure health services are in place to meet their needs; inpatient services for those who need them; and ensuring that the transition into the community is planned in partnership with people with learning disabilities, their carers and local communities, including local authority services. The National

Overview of Services, summarising the 16 local reports, was published in February 2006 (NHS QIS 2006).

Each set of Quality Indicators has an accompanying self-assessment framework. This framework gives guidance to NHS areas about the type of evidence required to demonstrate performance against the Quality Indicators. For example, Quality Indicator Statement 4.3 (Transitions), states, "There is continuity of healthcare in service transitions within, and, to and from health services such as community, hospital, respite care, and locality transitions". The health authority would be asked to supply evidence of suitable written transition protocols and evidence of regular inter-disciplinary discussion on individuals

FIGURE 1
NHS Areas in Scotland



Population figures (in brackets) are taken from the General Register Office for Scotland mid-year estimates for 30 June 2004.

moving between services. Relevant staff would also be interviewed.

In the peer review process, NHS QIS multidisciplinary review teams, including members of the public, carried out site visits to validate the quantitative and qualitative data submitted by each of the NHS Boards. Information was collected during site visits both through interviews and discussions with staff in clinical areas, and observation.

At the time of the last comprehensive review of services for people with learning disabilities in 1998, 19 long stay learning disability hospitals in Scotland were still open (Scottish Executive 2000b, 2003). This paper reports on the main findings of the National Overview in relation to local and national policy and reflects on progress made.

Copies of the full National Overview (2006) and Quality Indicators, with all data can be seen at: <http://www.nhshealthquality.org>.

Method

The methodology used a set of quality indicators which had been developed for clinical services to assess performance by NHS Boards across Scotland.

The review team assessed each of the quality indicator statements, on the basis of the self-assessment and supporting documentary evidence provided by the NHS service being reviewed, and the information gathered by interviews and site visits during the course of the review. In addition, the review team met with local authorities, staff from social work, voluntary organisations, GPs, members of the public and stakeholders from the NHS Board area. The review team then evaluated and agreed how well each

NHS service was performing against each quality indicator and sub-indicator.

The revised quality indicators (NHS QIS 2004) focus on six key elements of the learning disability service that have an impact on the quality of health care experienced by people with learning disabilities. The original *Quality Indicators for Learning Disabilities*, (Scottish Health Advisory Service 2000) were used as a basis to develop the revised indicators. This involved extensive consultation with all major stakeholders.

These six quality indicators are:

1. Involvement of children and adults with learning disabilities and their family carers through self-representation and independent advocacy
2. Promoting inclusion and well-being
3. Meeting general healthcare needs
4. Meeting complex healthcare needs
5. Inpatient services – daily life
6. Planning services and partnership working.

For the review conducted in 2004-5 Quality Indicators 1, 4, 5 and 6 were used to assess performance, in the context of the on-going hospital closure programme in Scotland (Scottish Executive, 2000).

These four quality indicators have a total of 38 sub-indicators which set achievable challenges for services. Each quality indicator is used to review children and adult services separately, where appropriate (TABLE I).

The composition of each review team varied, and members had no connection with the NHS Board they were reviewing. The programme of visits during 2004-2005 included people with learning disabilities and family carers as members of all the review teams, in recognition of the importance of understanding and valuing the perspectives of those who receive

TABLE I
Quality Indicators

Quality Indicator	Sub Indicators
1. Involvement of Children and Adults with Learning Disabilities and their Family Carers through Self-Representation and Independent Advocacy	1.1 Involving People in Planning Services (Planning and delivery of services) 1.2 Involving People in Planning Services (Planning and delivery of people's care) 1.3 Access to Health Records 1.4 Complaints 1.5 Advocacy (Strategy) 1.6 Advocacy (Support of Advocacy)
4. Meeting Complex Healthcare Needs	4.1 Service Integration 4.2 Transitions (Age related) 4.3 Transitions (Between services) 4.4 Access to Specialist Services (Children) 4.5 Access to Specialist Services (Adults) 4.6 Specialist Services (Complex needs) 4.7 Services for Children and Adults with Challenging Behaviour (Community based) 4.8 Services for Children and Adults with Challenging Behaviour (Quality of management and treatment) 4.9 Services for People with Offending Behaviour 4.10 Services for People with Mental Health Problems 4.11 Services for People with Autistic Spectrum Disorder (ASD) 4.12 Services for People with Dementia 4.13 Services for People with Profound and Multiple Impairment 4.14 Services for Children and Adults with Learning Disabilities and Epilepsy
5. Inpatient Services - Daily Life	5.1 Environment (risk management and personal safety) 5.2 Environment (suitability of in-patient accommodation) 5.3 Privacy and Personalisation (privacy and property respected) 5.4 Privacy and Personalisation (privacy and dignity) 5.5 Daily Life (day-to-day choices about activities)
6. Planning Services and Partnership Working	6.1 Strategic Health Improvement and Needs Assessment (Health Improvement) 6.2 Strategic Health Improvement and Needs Assessment (Addressing Health Inequalities) 6.3 Database Developments 6.4 Healthcare Planning (Healthcare provision plans) 6.5 Healthcare Planning (Workforce planning and staff training) 6.6 Healthcare Planning (Community Health Partnerships) 6.7 Healthcare Planning (Children and adults with complex needs) 6.8 Healthcare Planning (Evidence-based outcomes and health gain data used in commissioning health services) 6.9 Hospital Closure and Service Re provision 6.10 Partnership Working (Joint Performance Information and Assessment Framework (JPIAF)) 6.11 Partnership Working (Joint approach to the evaluation of services) 6.12 Partnership Working (Protection of vulnerable adults) 6.13 Partnership Working (Implementation of child protection policies)

health services. The following assessment categories were used to rate each of the 38 sub-indicators (Table II).

Results

Two Scottish Executive reports, *The Same as You?* (2000) and *Home at Last?* (2003) set out the goal for all long-stay learning disability hospitals to close by the end of 2005. Not all of the NHS Boards

met this target, for a variety of strategic and operational reasons, but 11 of the 19 hospitals that were still open in 1998, at the time of the last comprehensive review of services in Scotland, had closed by the end of 2005 (Scottish Executive Health Dept. 2005). There were also still a number of NHS assessment and treatment units, and nursing homes in which long-term residents remained, without commissioning and housing plans.

NHS Boards had adopted a range of

TABLE II
Assessment Categories

Assessment Categories:
<ul style="list-style-type: none"> • <i>Comprehensively Developed</i> Systems are in place to ensure that, wherever possible, the needs of 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 active assessment review, seeking opportunities for further development. • <i>Substantially Developed</i> 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. • <i>Partially Developed</i> 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. • <i>Scarcely Developed</i> 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 activity is carried out. • <i>Not applicable</i> A final category 'not applicable' (0) is used where a quality indicator and/or criterion does not apply to the NHS Board under review, e.g. for Quality Indicator 5 (Inpatient Services) where there were no long-term inpatient services in the NHS Board area.

models to close hospitals and reprovide services in the community. There were particular challenges, especially in agreeing evidence-based models of care within NHS Boards, and in conjunction with partners in social work and voluntary sector services in some areas. Also there were difficulties agreeing financial frameworks with local authorities and other partners, and committing to financial and staff investment in the community infrastructure needed to support people being discharged from hospital, particularly people with complex needs. The high cost of a small number of individual packages of care had especially challenged some NHS Boards and partnerships. In summary, the delays to hospital closure in some areas seriously impacted on the quality of services provided, where re-provisioning of services in the community was delayed (see FIGURES 5, 6 and 7 especially, and comments which follow).

There were a number of concerns about lack of real progress in several key areas, including provision of mental health services for children and adequately meeting complex health needs. Recommendations made consistently in QIS/ Scottish Health Advisory Service reports over the last ten years are made again in the National Overview in 2006. FIGURES 2-8 give a summary of the main findings of the National Overview, measuring quality against the four main Quality Indicators and 38 sub-indicators for the 16 NHS Boards. Relevant comments on strengths and challenges follow.

For children's services the majority of services have made progress in "partially developing" Involving People in Planning Services (Planning and delivery of services and people's care, see Quality Indicators 1.1 and 1.2). Advocacy (Strategy) and Advocacy (Support for advocacy), Quality Indicators 1.5 and 1.6, are scarcely

developed in 9 of the 16 services visited.

For Adult services all six of the sub indicators (1.1-1.6) are at least "partially developed" for more than half of the services.

There are few services for children and young people with learning disabilities and mental illness (see FIGURE 4, Quality Indicator 4.4); 13 out of 16 NHS Boards had only "partially developed" or "scarcely developed" services for children when measured against this Quality Indicator.

Effective joint commissioning and effective joint working between and amongst NHS, Social Work and Education services is still patchy across the country. Providing services for people with more complex needs, including those with challenging behaviour and people with profound and multiple disabilities, posed the greatest challenge to joint funding and joint working. Adequately addressing the complex health needs of people with learning disabilities has proved difficult in many areas (see FIGURE 5, Quality Indicator 4.6). 12 out of 16 NHS Boards had only "partially developed" or "scarcely developed" services when measured against this Quality Indicator.

The ability of inpatient services to provide a reliable and consistent therapeutic service to those inpatients with the greatest needs, and to maintain meaningful inpatient activity levels was also a concern. Opportunities available to residents to participate in activities outside hospital were found to be very limited (see FIGURE 6, Quality Indicators 5.2 and 5.5).

There were also several examples of good practice. Risk management and personal safety in in-patient services was "substantially developed" in 9 services out of 16 (FIGURE 6, Quality Indicator 5.1).

The presence or absence of a fully developed human resource strategy to support, train and redeploy staff has often

been the difference between successful transition from hospital to community, and high levels of sickness and absenteeism, with the knock on effect of additional working hours for remaining staff and a heavy dependence on a nursing bank. The formal training needs of staff were not adequately assessed or met in most NHS Board areas. See FIGURES 7 and 8, Quality Indicator 6.5; in only 1 NHS area was this rated as “significantly developed”; in 5 it was rated as “scarcely developed”.

Nine NHS Boards which did not have a fully operational policy for the protection of vulnerable adults; three of these had policies and procedures which were “scarcely developed” (FIGURE 8, Quality Indicator 6.12).

Joint care planning and joint clinical review activity for both children and adults with a learning disability was seen in several areas. There was also evidence of integration of specialist and general health services, both at operational and strategic levels, including good communication between primary and secondary care services, and the community learning disability teams (FIGURES 7 and 8, Quality Indicators 6.8 and 6.9).

Practical Application

Each of the 16 NHS Boards reviewed now have a local report, with ratings and constructive narrative on the four main Quality Indicators and 38 sub indicators. These reports should provide services with a framework for self-evaluation and a basis for continuing improvement.

NHS QIS has in the past conducted follow up visits to check on the implementation of recommendations made during reviews of NHS services. However it will not be possible to follow up the recommendations in the National

Overview in the same way, as NHS QIS will no longer be doing learning disability reviews. Instead, the monitoring of the quality of services for people with learning disabilities will become the responsibility of a new Scottish Joint Inspection body, involving representatives from all of the major inspectorates including the Social Work Inspectorate Agency, the Care Commission, HMI Education and NHS QIS (Social Work Inspection Agency, 2006). Joint inspections of health and local authority services in each area will use previous inspection data from all agencies as sources of data when planning the focus and extent of the inspection.

The question of whether the recommendations made in past reports have any legislative “teeth” to bring about change has been an issue for NHS QIS and will continue to be so for the Joint Inspection teams. NHS areas that have had a review typically draw up an action plan, with time scales, to address report recommendations. However there has been considerable variation in the extent to which action plans have been implemented. For example the National Overview found that models of care and community services were not always in line with the ‘Same as You?’ recommendations made in 2000 (Scottish Executive, 2000b); in one area, large (40+) care homes for people with learning disabilities had been commissioned, despite recommendations. Other areas of concern, already summarised in this paper, have been consistently identified in previous reports. The question perhaps is no longer, “What have NHS authorities done to improve poor quality of services?”, but rather, “What has consistently prevented them from doing so, and should any inspectorate or regulatory body have a supporting or training role in facilitating necessary changes?”

FIGURE 2
Quality Indicator 1 (Children): Involvement of Children and Adults with Learning Disabilities and their Family through Self-Representation and Independent Advocacy

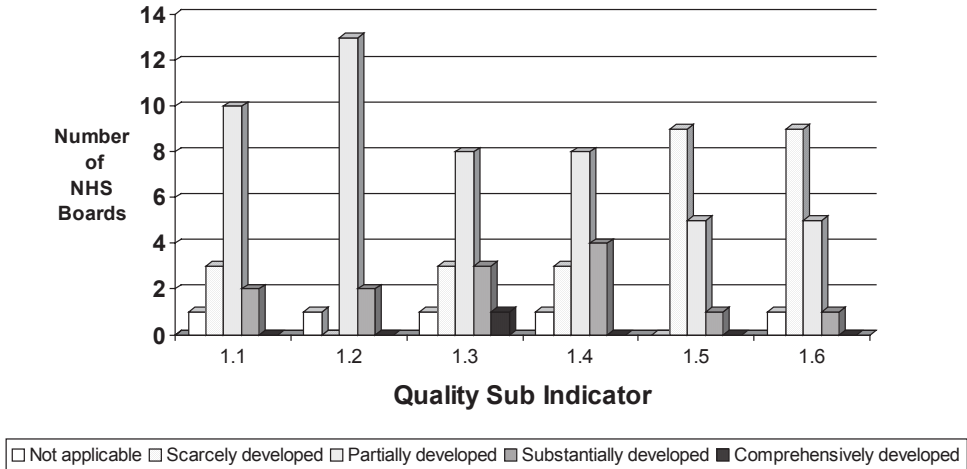


FIGURE 3
Quality Indicator 1 (Adults): Involvement of Children and Adults with Learning Disabilities and their Carers through Self-Representation and Independent Advocacy

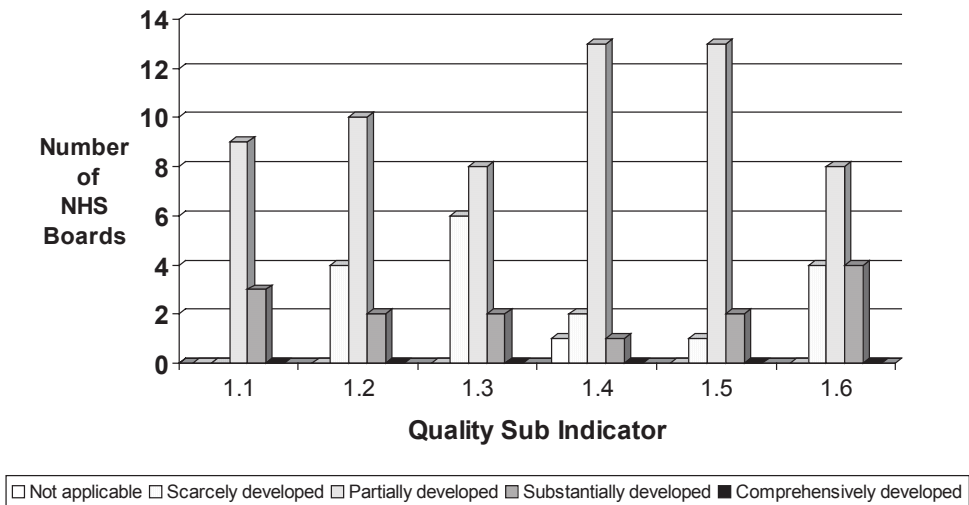


FIGURE 4
Quality Indicator 4 (Children): Meeting Complex Healthcare Needs

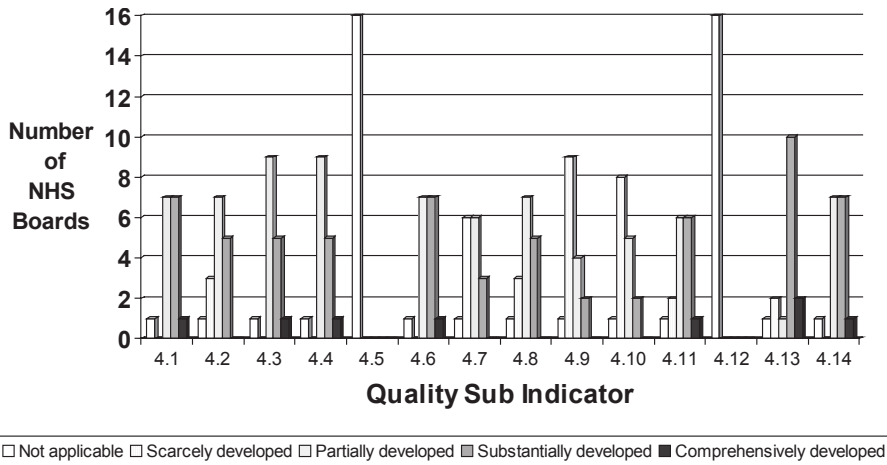


FIGURE 5
Quality Indicator 4 (Adult): Meeting Complex Healthcare Needs

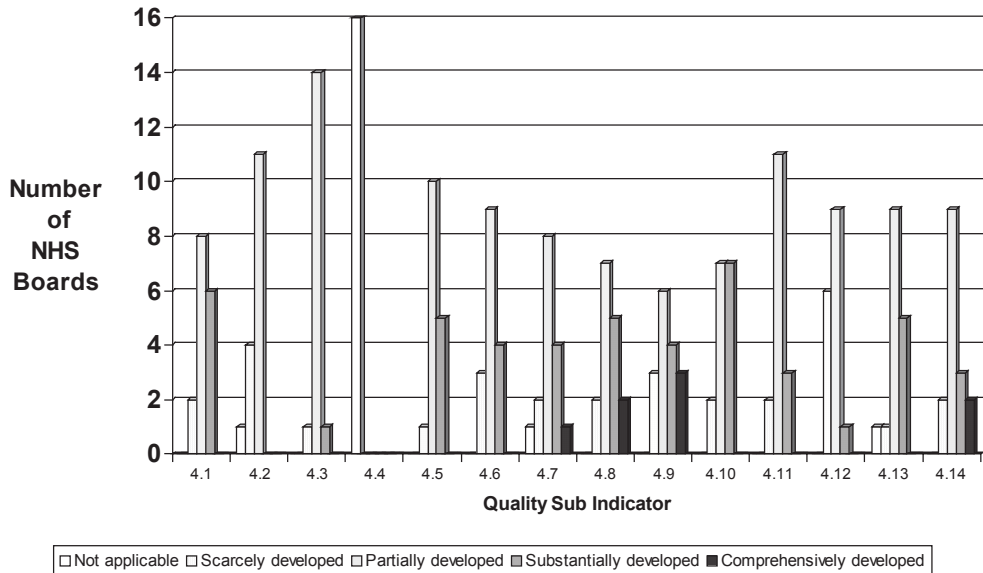
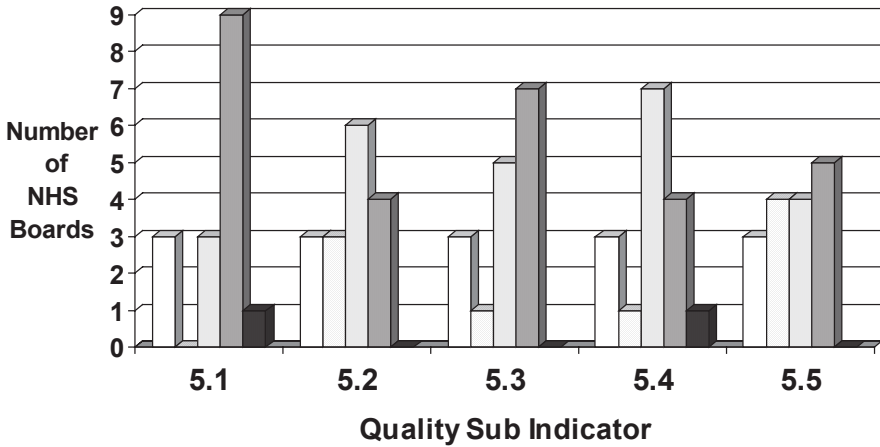
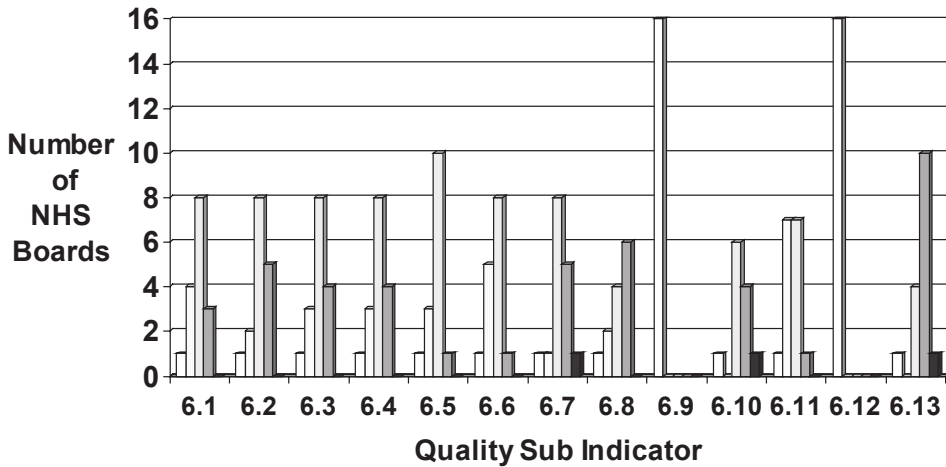


FIGURE 6
Quality Indicator 5 (Adult): Inpatient Services - Daily Life



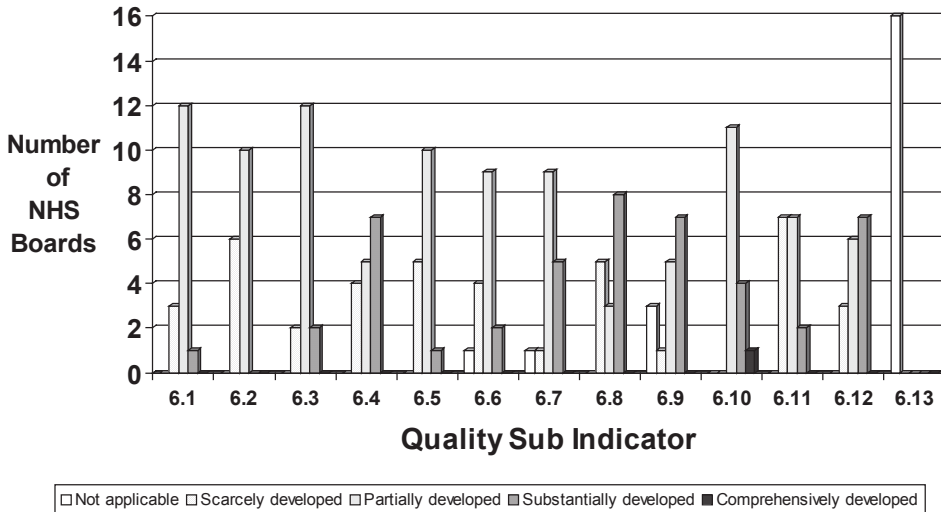
□ Not applicable □ Scarcely developed □ Partially developed ■ Substantially developed ■ Comprehensively developed

FIGURE 7
Quality Indicator 6 (Children): Planning Services and Partnership Working



□ Not applicable □ Scarcely developed □ Partially developed ■ Substantially developed ■ Comprehensively developed

FIGURE 8
Quality Indicator 6 (Adult): Planning Services and Partnership Working



Discussion

The NHS QIS National Overview of services has identified some of the gaps that remain in hospital and community health services for people with learning disabilities in Scotland. It is crucial that the recommendations made in this National Overview, and in each of the 16 local reports are followed up in a systematic way

Most health services, or combined health/social work partnerships in Scotland are challenged by the disproportionately high costs of packages of care for a small number of people with the most complex disabilities, and the knock on effects of funding these packages. The small number of inpatient beds that remain are under considerable pressure for emergency admissions. "Assessment and treatment" services varied in definition and in size across the country, as did definitions of long-term assessment and treatment/continuing care/long stay

beds. The range of services available in some areas of Scotland for people with complex disabilities, including challenging behaviour, is very limited. In England the Commission for Social Care Inspection has recently published some lessons from inspection, calling for a "radical review" of some models of support for this group of people:

"...there are growing concerns as to whether some of the current costs and models of support (in particular single person tenancies with one to one support) are sustainable." Commission for Social Care Inspection (2006)

Delivering for Health (Scottish Executive Health Department, 2005) recommends the way health services in Scotland should be delivered between 2005-2015, including health services for people with learning disabilities. Closer integration of health and social care and the role of Community Health Partnerships are priorities.

However the focus on joint work should not be at the cost of a continuing need to address the significant health needs of people with learning disabilities using the most evidence based approaches.

Summary

This paper reports on some of the key highlights from a National Overview of health services for people with learning disability services in Scotland. The methodology for the review used a set of Quality Indicators, especially developed for the purpose. The main findings suggested a mixed picture nationally, but with a few areas of best practice and some consistent gaps in services. How the quality of clinical services is maintained and improved is a question not just for the services involved in commissioning and delivery, but also for any new joint inspectorate.

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