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The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for regulating and inspecting the quality and availability of health and social care (HSC) services in Northern Ireland. RQIA's reviews aim to identify best practice, to highlight gaps or shortfalls in services requiring improvement and to protect the public interest. Our reviews are carried out by teams of independent assessors, who are either experienced practitioners or experts by experience. Our reports are submitted to the Minister for Health, Social Services and Public Safety, and are available on our website at www.rqia.org.uk.

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Executive Summary

The purpose of this report is to highlight the progress made by the five Health and Social Care (HSC) trusts, in the implementation of 34 standards, relating to Adults with a Learning Disability in the Department of Health (DoH) Service Framework.

This framework was launched by the Department of Health, Social Services and Public Safety (DHSSPS) now Department of Health (DoH) in 2013.

The responsibility for monitoring the implementation of these standards rests with the Health and Social Care Board (HSC Board) in Northern Ireland.

RQIA completed a baseline review of each trusts' initial benchmarking of the standards in 2013.

The review team is satisfied that significant improvements have been made since 2013 in:

- safeguarding of vulnerable adults regionally
- providing access to a much wider range and choice of day activities for adults with a learning disability
- conduct of assessments by General Practitioners (GP) of the health needs of adults with a learning disability, with a much higher uptake of screening noted in four trusts (A lower uptake was noted in the Belfast Health and Social Care Trust (Belfast Trust).)
- establishment of specialist teams, to help carers to manage challenging behaviours improved in every trust
- communication with each trust having developed a range of stakeholder reference groups

More meaningful improvement however is required in the following areas:

- provision of an easy to read page on trusts' websites for adults with a learning disability
- the development of a single unified community based regional information system, as access to clear, reliable information continues to be problematic (This makes it difficult for the commissioner to monitor and measure outcomes across trusts. The review recommends that this matter should be reviewed by the HSC Board as a priority.)
- the use of family support services and in the numbers of direct payments made across the trusts (The uptake of direct payments also continues to lag behind the rest of the United Kingdom. The review team was concerned that the South Eastern Health and Social Care Trust (South Eastern Trust) and the Western Health and Social Care Trust (Western Trust) are only paying the minimum payment rate of £10 per hour, suggested by the HSC Board in November 2015. This matter should be monitored by the commissioner for improvement.)

Progress regarding the implementation of individual Health Action Plans has been slow, despite this being a target for achievement for trusts since March 2015. No regional agreement has been made as to the form these should take. The review recommends that this work is completed by the Public Health Agency (PHA). The trusts should also put in place a plan to measure and report on the health improvements annually to the PHA.

The evidence of admission of people with a mild learning disability to mainstream mental health services remains very low. Given the variation noted in practice regionally, trusts should be held to account by the HSC Board/PHA for the delay in the implementation of this standard.

The composition of learning disability community teams continues to show disparity with a multiplicity of job descriptions for team members evident across the five trusts. There was evidence in four trusts of consultant psychiatrists working in a more integrated way as part of the community teams.

None of the five community teams, however, demonstrated an evidence base for the model of service configuration they have put in place. The community teams have developed more as a result of historic custom and practice in each trust area, with little sharing of practice noted regionally regarding models of care used by each team. It was difficult for the review team, therefore, to effectively compare and contrast the models of service provision across Northern Ireland. The review found that there is no agreed uniform model for behavioural support services across the five trusts.

The Northern Health and Social Care Trust (Northern Trust) was the only trust, able to report having a comprehensive database of outcomes in their positive behaviour psychology support service over the past 11 years.

The review team recommends that the commissioner should consider if the model used by the Northern Trust could be used as a model for other trusts to follow, to determine the effectiveness and outcomes of their challenging behaviour support services.

The review team recommends that a formal evaluation should be undertaken, of the effectiveness of these specialist teams, and this should be commissioned by the HSC Board, involving professional organisations such as the Royal College of Psychiatrists (RCP) and the British Psychological Society (BPS).

The proportion of people with a learning disability in employment continues to be very low. Use of unpaid work experience placements still dominates, which runs the risk of trainee exploitation.

Trusts, as large employers, should consider, as part of their organisational development plans, a model of positive discrimination that seeks to provide employment opportunities for adults with a learning disability.

Young people with a learning disability making the transition to adult services continue to present challenges for carers as arrangements are handled differently across the five trusts.

Earlier planning from the age of 14 years is required in line with best practice guidance. Given the known complex physical and behavioural needs of a growing cohort of young people, clearer financial projections need to be made over the next five years to identify the increased resources required to meet their needs.

The review team found that despite funding being made available by the HSC Board to trusts, it is unlikely that the target of all long stay patients being resettled in the community will be achieved by June 2017. This delay is causing frustration for a number of people in hospital who wish to be resettled to a new home in the community. Sometimes when placements break down, an admission to a learning disability hospital has been used. Trusts should review best practice from other areas in preventing such hospital admissions and involve independent sector colleagues in service developments to help avoid the emerging development of new long stay patients.

A low uptake of carers' assessments was evident across Northern Ireland, but trusts were unclear why this might be the case. The review team recommends that the carers coordinator in each trust should meet with the HSC Board to review this matter and any action required to help avoid crisis intervention planning in the future.

Whilst the review team found staff were mostly familiar with the content of the service framework, the approach used by trusts in applying the standards varied across trusts. Trusts have also not all interpreted key performance indicators consistently. No evidence of comparative benchmarking was evident across trusts regarding the models of delivery of care, or with other models of service provision in the United Kingdom.

The report makes 25 recommendations to support the continual improvement of standards for adults with a learning disability in Northern Ireland.

In view of the closure announcement of the HSC Board, the DoH needs to now agree a future process for monitoring the implementation of the standards contained in the service framework for adults with a learning disability.

1.1 Introduction and Background

Learning disability includes the presence of a significantly reduced ability to understand new or complex information, or to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development. People with a learning disability may also have difficulties with social and/or communication skills and with carrying out activities of daily living independently. They may also have associated physical and sensory disabilities.

It is estimated that there is a population of 26,500 people in Northern Ireland with a learning disability of whom half are aged between zero to 19 years 1. It is projected that the number of people with a learning disability will increase by one percent each year over the next 15 years and that adults with complex needs will be a particularly large growth area.

Societal attitudes to learning disability have changed significantly in recent years. It is now widely recognised that people with a learning disability have the right to live independently within the community and to be provided with the opportunity to make meaningful choices in respect of housing, care and support needs.

In 2007, a United Kingdom Government commissioned inquiry chaired by Sir Jonathan Michael – Healthcare For All² - found that

- People with learning disabilities find it much harder than other people to access assessment and treatment for general health problems that have nothing directly to do with their disability.
- There is insufficient attention given to making reasonable adjustments to support the delivery of equal treatment, as required by the Disability Discrimination Act 1995³.
- Parents and carers of adults and children with a learning disability
 often find their opinions and assessments ignored by healthcare
 professionals, even though they have the best information about and
 understanding of, the people they support.
- The health needs, communication problems and cognitive impairment characteristics of learning disability in particular are poorly understood by healthcare staff.

The Confidential Inquiry into the Premature Deaths of People with Learning Disabilities⁴ (CIPOLD) in 2013 reviewed the death of 247 people with learning disabilities over the period 2010-2012.

¹ Bamford Action Plan, DHSSPS, 2009.

² Healthcare For All, Sir Jonathan Michael, 2007.

³ <u>Disability Discrimination Act 1995</u>.

⁴ Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD) 2013.

The findings demonstrated that people with a learning disability were a very vulnerable group in the context of health needs:

- 17 per cent were underweight compared to two per cent the general population
- 66 per cent lacked independent mobility
- 50 per cent had problems with vision
- 25 per cent had hearing problems
- 97 per cent had one or more long term or treatable health conditions

People with learning disabilities should also be supported to live independently in the community wherever possible. Delivery of the changes necessary to improve services requires effective partnership working with a variety of agencies, to design and provide a range of options to meet assessed needs, such as employment opportunities, day centres, day opportunities and accommodation. People with a learning disability should also be provided with clear information about self-directed support in order to give them control and choice over the type of care and support they receive.

1.2 Context for the Review

A key priority for health and social care services and also for the wider community is to tackle discrimination and inequality and to empower and support people with a learning disability and their families to be actively engaged in their care.

The onus on public authorities to promote equality of opportunity is enshrined in the Northern Ireland Act⁵ which states that "a public authority shall, in carrying out its functions in Northern Ireland, have due regard to promote equality of opportunity between people with a disability and those without."

Other pieces of relevant legislation include:

- the Human Rights Act⁶
- the United Nations(UN) Convention on the Rights of Persons with Disabilities⁷

In October 2002, following similar exercises in Scotland and England, DHSSPS⁸ initiated a major, wide-ranging and independent review of the law, policy and provision affecting people with mental health needs or a learning disability in Northern Ireland. The review was overseen by a steering committee comprising representatives from professional and other interested groups in the mental health and learning disability fields, under the chairmanship of Professor David Bamford of the University of Ulster.

⁶ The Human Rights Act 1998

⁷ Convention on the Rights of Persons with a Disability 2006

⁵ Northern Ireland Act 1998

The Department of Health (DoH) encompasses the functions of the former Department of Health, Social Services and Public Safety (DHSSPS) as of 9th May 2016.

The Equal Lives⁹ report made a number of recommendations, designed to secure improvements in the mental and physical health of people with a learning disability. The aim was to achieve this through developing access to high quality health services that are locally based and responsive to their particular needs.

Broadly the review called for:

- continued emphasis on promotion of positive mental health
- reform of mental health legislation
- a continued shift from hospital to community based services
- development of a number of specialist services, to include children and young people, older people, those with addiction problems and those in the criminal justice system
- an adequately trained workforce to deliver these services

The review also promoted involvement of service users to enable them to access mainstream services and be fully included in the life of the community.

The review envisaged a 10-15 year timescale for full implementation of its recommendations.

The Northern Ireland Executive accepted the broad thrust of the review's recommendations. The Executive's response to the findings of the Bamford Review, Delivering the Bamford Vision, led to the publication, in October 2009 of the Bamford Action Plan 2009-2011. The 2009-2011 plan set out the Executive's commitment across Departments to improving the mental health and wellbeing of the population of Northern Ireland and to improving services for those with a mental health need or a learning disability.

A follow on action plan was developed for 2012-2015 based on the lessons learned from the 2009-2011 evaluation, consultative workshops, new research and evidence based practice and the views of service users and their carers

A further report in December 2011, Transforming Your Care¹⁰ (TYC), set out a review of health and social care in Northern Ireland and provided the blueprint for future health service provision in Northern Ireland. This has many parallels with the Bamford Vision in respect of mental health and learning disability service provision and enhancement including:

- early intervention and health promotion
- a focus shift to community care
- promotion of recovery practices
- personalisation of care
- resettlement
- service user and carer involvement
- advocacy
- provision of clearer information
- access to respite provision

 ⁹ Equal Lives DHSSPS, 2005.
 ¹⁰ <u>Transforming Your Care 2011</u>

In March 2016, the Minister for Health announced his intention to establish a commission¹¹ to reform adult care and support. This new three-person commission will be tasked with assessing the many challenges facing the care and support system and producing a set of recommendations to reform the funding structures, in order to ensure its future sustainability.

Service Frameworks

The DHSSPS Service Framework aims to set out clear standards of health and social care that service users and their carers can expect.

They are evidence based, measurable and are to be used by health and social care organisations to drive performance improvement, through the commissioning process.

The Service Framework for Learning Disability¹² was initially launched in 2013 and revised in January 2015. It sets out 34 standards in relation to the following key thematic areas:

- safeguarding and communication and involvement in the planning and delivery of services
- children and young people
- entering adulthood
- inclusion in community life
- meeting general physical and mental health needs
- meeting complex physical and mental health needs
- at home in the community
- ageing well
- palliative and end of life care

The standards provide guidance to the sector on how to:

- improve the health and wellbeing of people with a learning disability, their carers and families
- promote social inclusion
- reduce inequalities in health and social wellbeing and improve the quality of health and social care services, by supporting those most vulnerable in our society

Baseline Assessment and Review of Community Services for Adults with a Learning Disability 2013

In August 2013, RQIA published a report of a Baseline Assessment and Review of Community Services for Adults with a Learning Disability. This highlighted the role and composition of community learning disability teams and the level of investment in services for adults with a learning disability. The report set out recommendations for trusts and for commissioners in relation to the provision of learning disability services for adults.

Health Minister to Establish Commission to Reform Adult Care and Support, DHSSPS 9 March 2016
 Service Framework for Learning Disability DHSSPS 2015

In November 2015, the Patient and Client Council (PCC) published its report on the findings from their engagement with 11 focus groups across Northern Ireland in relation to learning disability.

The PCC met with 48 service users and 24 carers who highlighted concerns about the following issues:

Service users	Carers
Day opportunities	Respite (short break) services
Supported housing	Transition from child to adult services
Respite (short break) services	HSC staff
Further education	Joined up working
Training and work	Information
HSC staff in learning disability support	
services	

The findings of this report have been considered by RQIA as part of this review.

The review also noted that the Northern Ireland Assembly Committee for Employment and Learning published in 2016 a report on day services that made 44 strategic recommendations.¹³

Focus of this Review

This review assesses the quality of learning disability services against 30 of the adult standards contained in the Learning Disability Service Framework. It also reports on the progress made by the trusts and the HSC Board in the implementation of the recommendations contained in the 2013 RQIA review report.

The report is structured to reflect the four RQIA domains of:

- safe care
- effective care
- · compassionate care
- well led services

1.3 Terms of Reference

The terms of reference for this review are:

1. review the progress made against Phase 1 of RQIA's 2013 report, 'A Baseline Assessment and Review of Community Services for Adults with a Learning Disability'

¹³ Report of the Inquiry into post Special Educational Need (SEN) Provision in education, employment and training for those with Learning Disabilities in Northern Ireland

- review the quality and effectiveness of services for adults with a learning disability against the DHSSPS Service Framework for Learning Disability
- 3. gather the views of service users and carers
- 4. report on findings and make recommendations in a single report for publication

Exclusions

This review excludes services for children, and services provided for adults with learning disabilities that are currently regulated by RQIA, as set out below:

Adult placement	Day care settings	Domiciliary care
agencies		agencies
Independent clinics	Independent hospitals	Nursing agencies
Nursing homes	Residential care homes	Residential family
_		centres

Autism services are not included in this particular review as RQIA is undertaking a specific review of autism in the future. However adults with a learning disability whose service provision is provided by adult community learning disability services were included in this review.

1.4 Outline Methodology

- 1. A review was undertaken of trusts' action plans and progress in relation to Phase 1 of the RQIA review.
- 2. A questionnaire was sent to all trusts asking them to provide information on progress against standards applicable to adults as set out in the service framework for learning disability.
- 3. Validation meetings were held with staff responsible for providing and managing learning disability services
- 4. Stakeholder engagement was held with adults with a learning disability and with carer groups, from all five trusts.
- 5. The review met with a range of voluntary organisations involved in providing adult learning disability services.

Section 2: Findings from the Review

2.1 Introduction to the Findings

In its 2013 report, RQIA made a number of recommendations for improvement. One of these recommendations was that trusts should provide better information regarding the number of people with a learning disability receiving care and their investment in the learning disability programme of care. This includes community service costs, community teams, day services, family support services, day centres and people in receipt of domiciliary care services. This review received updated information from the HSC Board and trusts regarding this area.

Total Number of People with a Learning Disability

The trusts remain unable to provide the HSC Board and the review team with an accurate figure of the total number of people with a learning disability in their area. This information is not collected in a single regional common information system with agreed data sets. All trusts have different systems to record information about people who have been identified with a learning disability. However the population of people with a learning disability is known to be larger than these figures. In addition to those people receiving social care, there are people in hospitals, people receiving only health services, people known to the trust who are no longer receiving any service (so-called dormant cases), and possibly people who would qualify for learning disability services but have never requested them. A figure of 8,326 was provided but it is likely to be much lower than the true prevalence of learning disability in the adult population in Northern Ireland. In the Phase 1 review RQIA reported that in 2010-2011 the number of adults in receipt of services from community learning disability teams was 7965. There has been an increase of 361 since the last RQIA review.

Number of People with Learning Disability in receipt of Health and Social Services in each HSC trust in 2014-2015

The number of people with learning disability in receipt of social care services in each trust in 2014-2015 is shown in Table 1 (note: social care includes social work, nursing homes residential homes, supported and other accommodation, day care facilities, domiciliary care grants, goods and services, meals delivered to clients' homes). In order to facilitate comparisons across trusts, the number of adults with learning disability is expressed as a proportion of the adult population in each trust area. Variation is evident across the trusts with proportionately more people with a learning disability receiving social care in the Southern Health and Social Care Trust (Southern Trust) and fewer in the Western Trust.

Table 1: The number of adults with learning disability receiving social care services 2014-2015

	Belfast	Northern	South Eastern	Southern	Western	Total
Number of adults with a learning disability receiving social care 2014-2015*	1816	1926	1516	1981	1087	8326
Adult population of trust (NISRA mid-year estimates)	265,372	348,254	263,059	265,794	216,431	1,358,910
2014 rate per 1,000 adult population	6.84	5.53	5.76	7.45	5.02	6.13

^{*}Data provided by HSC trusts to HSC Board as of 31 March 2015

HSC Investment in Learning Disability Programme of Care 2015-2016

In 2015-2016, the HSC Board investment in the learning disability programme of care was £265.2 million, which was 7.79 per cent of the total investment in health and social care in that year (£3.406 million). This proportion has remained around this level since 2005-2006 (range 7.21per cent to 7.79 per cent). This investment covers services to children as well as adults. A breakdown of the apportionment is not available.

The amount invested by each Local Commissioning Group (LCG) in the learning disability programme of care is shown in Table 2. This includes specialist hospital costs as well as community service costs. Please note the following cautions regarding the tables.

Cautions

As all trusts do not keep a single common information system of people with learning disabilities, it is difficult to accurately calculate the number of people who receive services in any one year.

Variations in record keeping across trusts may also account for some of the differences noted above, which results from the lack of a common information system for community services.

Some of the information presented to the review was for 2013-2014 and may in some instances not reflect recent changes. However there are unlikely to be substantial variations from the patterns reported here.

Table 2: Investment by the HSC Board in the Learning Disability Programme of Care (PoC) compared to other non-acute programmes of care (based on Strategic Resource Framework Investment 2015-2016)

	Local Commissioning Groups (LCG)					
	Belfast	Northern	South Eastern	Southern	Western	Grand Total
Learning Disability PoC £k	£57,106	£60,708	£53,615	£55,418	£38,357	£265,204
All non-acute programmes of care £k (excluding regional investment)	£415,074	£448,916	£342,503	£358,371	£322,455	£1,887,318
Percentage invested on Learning Disability PoC	13.76%	13.52%	15.65%	15.46%	11.90%	14.05%
Population of Trust - Weighted for Learning Disability need	383,107	430,093	285,799	384,594	345,543	1,829,136
Average cost per capita of LCG	£149	£141	£188	£144	£111	£145

Table 2 shows the 2015-16 SRF investment split by Local Commissioning Group areas (LCGs). The learning disability PoC figures cover all people with a learning disability including children, adolescents and adults. The HSC Board uses a capitation formula to help inform the allocation of new funds across localities. Trusts may provide services to residents across a number of localities and residents from localities may access their local trust or another trust depending on the services used.

It should be noted that caution should be exercised when comparing investments at programmes of care level and between individual LCGs. For example, it is recognised that capitation formulae are less robust at smaller population levels and at individual programme of care levels and therefore variations between individual Programmes of Care at LCG level would not be unexpected. Within programmes of care, services may also be delivered differently across localities. The capitation formula for the learning disability programme of care is being reviewed.

Variation across trusts in the total investment in non-acute programmes of care is evident. The South Eastern LCG has a higher proportion of this investment, 15.65 per cent, allocated to the learning disability programme of care with the Western LCG having the lowest percentage at 11.90 per cent. When the differing size of the population in the trusts is taken into account and weighted for learning disability need, the South Eastern LCG has the highest per capita investment with the Western LCG having the lowest. These figures are however skewed by specialist hospital costs as outlined further in Table 3 which demonstrates that a differential continues to exist across trusts.

Investment in learning disability services is further subdivided into monies invested in specialist hospitals and in extra contractual referrals (generally used for person(s) with complex needs to be treated outside of Northern Ireland) and in community services. In 2015-2016 the planned investment in extra contractual referrals amounted to £1.110 million.

Table 3: The investment (£k) by HSC Board in Learning Disability Programme of Care in community and hospital services (Based on SRF Investment 2015-2016)

	Belfast	Northern	South Eastern	Southern	Western	Grand Total
Community/ Personal Social Services £k	£49,875	£52,665	£46,522	£50,676	£34,441	£234,180
Hospital £k	£7,231	£8,042	£7,093	£4,742	£3,916	£31,024
Total £k	£57,106	£60,708	£53,615	£55,418	£38,357	£265,204

Around 11.7 per cent of the total investment provided by the HSC Board, to trusts, was invested in specialist hospitals, notably Muckamore Abbey Hospital which serves three trusts with total costs of £22.3 million. The HSC Board reported commissioning 147 beds in 2015-2016, across the region which gives a cost per bed of £203,497 for hospital services (excluding ECR investment). However the number of beds should reduce as the resettlement of long stay patients continues, although it is not yet complete.

Community and Personal Social services costs accounted for around 88 per cent of the total investment. It is not possible to calculate an average cost per person in receipt of community services as the numbers of people in receipt of such services is not available.

The trusts in their financial returns provide a further breakdown of the monies spent on community services (i.e. AHPs expenditure, nursing costs, day services, residential accommodation, community medical/dental expenditure, grants, goods and services step up step down facilities, incontinence products) and on personal social services.

Usage of Social Care Services

The number of people availing of various social care services across the trusts is shown in Appendix 1 Table A1. Although information on costs per place was not available to the review, this data could perhaps account for the variation in trust's investment in learning disability social care services.

Supported Accommodation

There is a marked differential in the proportion of people in residential and nursing homes, with the highest in the Western Trust (23 per cent) and lowest in the Southern Trust (12 per cent). The variation was less marked for people in supported housing. However, taken together, these figures would suggest that most adults with a learning disability, using social care services are living with family carers or independently, with the Southern Trust having the highest proportion (76 per cent) and the lowest noted in the Western Trust (65 per cent).

Day Centres and Day Opportunities

Overall, around two-thirds of people with a learning disability, use day services, although the proportion that do so, is markedly higher in the Western Trust compared to the Southern Trust. The provision of day opportunities places compared to day centre places is most equal in Belfast and Southern trusts. Day opportunities in further education courses, horticulture and gardening enterprise schemes, or in catering establishments are procured by the trust to provide experiences leading to upskilling of people with a learning disability, to enable them to apply for work. A greater use of day centre places, solely run by the trusts was evident in the Western and South Eastern trusts as shown in Appendix 1 Table A2.

Family Support Services

Adults with a learning disability who live at home with carers may require additional support to help them live a full life in their community. Trusts provide a range of family support services including short break services, domiciliary care and direct payments.

Appendix 1 Table A3 shows the number and percentage of people in receipt of family support services in 2013-2014. Some disparity was evident in the use of family support services across the trusts. More families availed of short breaks in the Northern Trust with least doing so in the Western Trust. Domiciliary Care was provided to higher percentages of people in the South Eastern and Southern trusts but fewer in the Belfast and Northern trusts. Direct payments provided to either the person or family and carers were noted to be highest in the Belfast Trust, with a lower but similar proportion across the other trusts.

The variation in both the financial investment and services provided across the five trusts suggests that inequities persist across Northern Ireland in provision of these services for people with learning disabilities.

Recommendation 1	Priority 1

The commissioner should ensure effective use of resources through accountability meetings and seek evidence based improvements in learning disability services across trusts. The investment in learning disability hospital provision should also be kept under review given the current resettlement target set for achievement in 2016.

2.2 Standards Reviewed Relating to SAFE Care

The review aligned specific standards for adults contained in the service framework to RQIA's four key stakeholder outcomes selected for use in 2016 – 2017. These are described in Table 4.

Table 4: Four RQIA Stakeholder Outcomes.

Is care safe ?	Avoiding and preventing harm to patients and clients from the care, treatment and support that is intended to help them.
Is care effective?	The right care, at the right time in the right place with the best outcome.
Is care compassionate?	Patients and clients are treated with dignity and respect and should be fully involved in decisions affecting their treatment, care and support.
Is the service well led?	Effective leadership, management and governance which creates a culture focused on the needs and experiences of service users in order to deliver safe, effective and compassionate care.

Questionnaires were sent to the five trusts and the line of questioning during discussions with staff focused on these four areas.

Findings

Safeguarding

All trusts had a safeguarding policy in place with a named safeguarding lead, who oversees the learning disability programme. A designated non-executive director with a particular responsibility for safeguarding was in place, with the exception of the Northern Trust, where the non-executive directors assume responsibility collectively. A new regional policy, Adult Safeguarding: Prevention and Protection in Partnership¹⁴, was published in July 2015. Trusts await further operational guidance from the HSC Board before they can finalise their procedures. Currently all trusts are following the extant HSC policy and procedures.

¹⁴ https://www.dhsspsni.gov.uk/publications/adult-safeguarding-prevention-and-protection-partnership

All trusts had their own whistle blowing policy, the implementation of which is subject to a separate review by RQIA.

Equality of Access to Health Services

The HSC Board provided the following information from their 2015 file audit:

- 100 per cent of GPs have a system for identifying people with a learning disability.
- Over 70 per cent of the files had evidence that people with a learning disability and their family and carers have been involved in making choices or decisions about their individual health and social care needs.

A directed enhanced service (DES) for general practitioners to undertake health checks had a good uptake by GP practices across four trusts, except the Belfast HSC Trust.

A higher uptake of health checks by people with a learning disability was noted in the Northern Trust. The review was informed that some practices were more difficult to engage with. Where there is proactive engagement by a health facilitator, with local GP practices, better outcomes are evident.

A separate review was undertaken by the HSC Board in 2013 of The Enhanced Service Specialising in Health Care for Adults with a Learning Disability Provided by General Medical Services (GMS) Practices and of the effectiveness of Health Facilitators provided by HSC trusts. The report shows there is significant variation across the trusts in relation to the uptake of health checks with the Belfast Trust GPs providing fewer health checks than other trusts.

This may be due to their lower levels of staff in this service. The review noted that the HSC Board has provided the Belfast Trust with temporary additional funding for one year to drive improvement in this area.

Employment of Health Facilitators

Health Facilitators are funded across the five trusts using GMS monies. The trusts were able to produce a wide range of examples ranging from easy read health screening materials to evidence of service users consenting to the health care facilitators undertaking their health checks.

There were examples of all HSC organisations making information accessible to people with a learning disability. Despite this, progress around the implementation of individual Health Action Plans (HAP) has been slow, with no agreement across trusts as to the form these might take. HAPs are an easy read plan for an adult with a learning disability to keep, usually formatted into a table that lists goals for better health and engagement with healthcare staff. In those instances where a plan was in place, there was also no demonstrable evidence of the trust demonstrating improvements in health outcomes arising from the HAPs.

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¹⁵ Professor Roy McConkey. University of Ulster and HSC Board. October, 2013

The Regional Health Facilitators Forum, a sub group of the Regional Learning Disability Health Care Improvement Forum chaired by PHA, has been developing guidance on the regional implementation of health and wellbeing plans (formally known as health action plans). These are currently out with trusts for comment. The guidance will be agreed by the Bamford Monitoring Group and disseminated to trusts.

The development and use of health action plans for adults with a learning disability needs to be reassessed, with agreement as to their final format and a method of recording health outcomes arising from their use.

A process also needs to be agreed regionally by the PHA for implementing the recommendations arising from the health screening as this differs from trust to trust.

Recommendation 2

Priority 1

The Regional Learning Disability Health Care and Improvement Steering Group, set up by the Public Health Agency should ensure each trust has a plan that can demonstrate measureable evidence of health improvements for adults with a learning disability.

The trusts all advised of a range of staff who provide support and advice, including community learning disability nurses, speech and language therapists, epilepsy nurses, district nurses and a wide range of AHPs. A number of examples or specific initiatives undertaken with small groups or on specific topics were provided.

The review was advised of a number of regional screening programmes that trusts promote and utilise for adults with a learning disability.

In meetings with service users across all five trusts, adults with learning disabilities advised the review that they had received information on smoking cessation, healthy eating, levels of physical activity and alcohol consumption from health facilitators and general practitioners. The review was given limited examples of improvements in fitness of adults with a learning disability across the region, or in e.g. reduction of obesity to promote better health.

Health Related Outcome Measures

In 2014, a Regional Learning Disability Health Care and Improvement Steering Group was established by the PHA, to agree a regional approach to health screening and improving health and social care outcomes.

Trust databases in relation to adults with a learning disability, involved in regional screening programmes, do not contain health related outcome measures. There is no plan to collate the health outcome measurement information gathered about individuals, or to record details of action required in the future, to ensure improved health outcomes, although the Belfast Trust indicated their intention to review this in the future.

Development of a Clinical Quality Dashboard

A clinical quality dashboard is a tool, developed to provide clinicians, with relevant and timely information to inform daily decisions that improve quality of patient care.

Although the trusts provided examples of their dashboards, these were used to demonstrate e.g. figures for delayed discharges, admissions to specialist hospitals and staff absences. There was an absence of data which demonstrated for example a reduction in smoking, obesity, diabetes or a reduction in challenging behaviours. Dashboards had not been designed to capture information on health outcomes or service users' health improvements. This makes it difficult to gauge the effectiveness of clinical interventions, for adults with a learning disability.

Trusts reported using other reporting tools such as a RAG (red, amber, green) rating to report on their general activity in learning disability services, to senior management and to the HSC Board.

Other reports included local facility plans, statutory function reports, risk registers, incident databases and monitoring reports to ensure their managers have access to quality checks in a timely manner.

Recommendation 3

Priority 1

The PHA in conjunction with trusts should develop a regional dataset of information in relation to outcome measurement in 2016-2017 across two key areas to drive improvement in the health status of people with a learning disability. Targets should be considered in relation to the reporting of a reduction in smoking and obesity in the 2017-2018 year.

Development of Interfaces between Services

All trusts described progress in improving their interfaces with mental health and older peoples' services; this work, however, remains at an early stage. The Northern Trust Rapid Assessment Intervention and Discharge (RAID) Team indicated they had developed a learning disability pathway and coworking arrangements with learning disability teams. Individuals with a learning disability within an acute hospital or presenting at an emergency department are assessed and supported by the RAID Team who help provide them with direct support at times of crisis. Some examples were provided by the Northern Trust of access to mental health services for people with mild learning disability. The other trusts described difficulties in getting an adult with a mild learning disability into mental health services. The pathway used by the Northern Trust should be reviewed by other trusts to see if it can be applied elsewhere.

There is also little interface with older peoples' services except in respect of people with dementia.

Some progress however appears to have been made with forensic and palliative care teams – possibly because of the small number of people involved in these more specialised areas.

The Belfast Trust stated that service users have access to psychological and psychiatric services provided by both specialist learning disability and primary mental health teams. The Northern Trust confirmed its PROMOTE team provides specialist learning disability interventions for people with complex mental health needs. PROMOTE is a treatment service for adults with a learning disability with additional forensic and or mental health needs.

The RQIA review found that there had been slow progress in relation to adults with a mild learning disability accessing mainstream mental health services. Further collaboration across teams is required to ensure appropriate access to mainstream mental healthcare services for patients with a mild learning disability.

Recommendation 4

Priority 2

The HSC Board should set an access target for inclusion of people with a mild learning in mental health services in order to achieve the standard set up in the service framework.

2.3 Standards Reviewed Relating to EFFECTIVE Care

Findings

Provision of a Community Service

The review team looked at the composition of learning disability teams and models of service provision, developed since the last review.

Learning disability services continue to sit within different directorates across the five trusts. Broadly, teams include the same range of professionals identified in the initial RQIA review e.g. social work, learning disability nurses, specialist occupational therapists and speech and language therapists. The multidisciplinary team composition was being reviewed by each trust and deemed by trusts to be appropriate to the discharge of their functions.

A continued disparity exists since the last RQIA review, in the composition and in the description of roles across community teams that make comparisons of effectiveness difficult. A positive development since the last review is that the psychiatrists are now working directly in learning disability teams.

The Belfast Trust informed the review team that it had fully reviewed its community treatment and support services, agreed a new model of service provision and is in the final stages of implementing their new structures and processes. The trust visited services in Scotland in 2013 and out of hours

behaviour support services in England. The new model of service provision is based on prevention and early intervention. It was described as being multi-disciplinary with co-ordinated working, with the aim of creating a person centred, flexible and responsive service.

The Northern Trust has moved from a locality management model to a multidisciplinary model of management that delivers services according to their functions. A service improvement project commenced in September 2015, to build on progress already made, with a focus now on consolidating their new team structures for service delivery across all their learning disability services.

In the action plan provided to the review the South Eastern Trust did not clearly provide information on the overall outline of their adult community learning disability team, but rather described how services are delivered through a tiered process and the types of professionals involved in the adult learning disability teams.

The Southern Trust reported that a review of their team structures has been recently completed. A new model of service delivery has been agreed that includes clearer multi-disciplinary roles and responsibilities for staff.

The Western Trust has restructured its teams and now operates a social worker led service, supported by a multi-disciplinary team model as required. At the time of the review, recruitment for social workers, occupational therapists, family support workers and team leaders was nearly complete. The trust acknowledges that further work is required to secure the investment needed to enhance its new model in working with adults with a learning disability.

The review team notes that the leadership of the teams in each of the trusts and their lines of accountability varies as do referral procedures and the criteria for access to learning disability services.

Despite the changes made by the trusts in the delivery of learning disability services, the review found limited evidence of trusts actively seeking information about new service models beyond Northern Ireland.

There was very little evidence of trusts learning from other trusts' experiences or of those of the voluntary sector in the revision of their structures.

Recommendation 5

Priority 2

The HSC Board should review the current models of service provision in place in the five trusts in terms of evidence of best practice and ensure that this is disseminated regionally.

Delivery of an Extended Hours Service by Community Learning Disability Teams

The review found little evidence of Community Learning Disability Teams (CLDT) operating outside of 09.00 to 17.00. Four trusts had plans to extend their intensive support services, particularly for people who are at risk of breakdown in the community from 17.00 to 20.00 or 22.00 on weekday evenings. While a welcome development, this leaves weekends uncovered except by out of hours social services.

At the time of the review, the Western Trust had no plans to extend the CLDT hours of service.

The South Eastern Trust has recently commenced a pilot of an out of hours intensive support service which will operate Monday to Friday 17:00 to 21:00.

This service was set up to support service providers outside of normal working hours and to help manage individuals with challenging behaviours, to prevent hospital admission and placement breakdown. On call practitioners advise and support service providers and if appropriate will refer patients to the trust community team for follow up the next working day.

Establishment of Challenging Behaviours/Specialist Teams

Positive changes were noted in the development of challenging behaviour teams in each trust since the review in 2013. However, the five trusts are developing their own unique teams and models to deal with challenging behaviours. The trusts have been provided with financial resources by the HSC Board, to enable challenging behaviour teams to be strengthened.

All trusts had increased the support services that staff in the community teams can offer. There was evidence in four trusts of consultant psychiatrists working in a more integrated way as part of the community teams. The review lacked clarity in terms of their role in community teams which should be reviewed by each trust. It was unclear to the review how they were involved in leading service changes to become more effective, especially for clients with challenging behaviours and or mental health problems who are on psychotropic medications.

Recommendation 6

Priority 2

Each trust should review the specific role of the consultant psychiatrist in their community team in terms of how best they can assist in the delivery of improvements in clinical outcomes for people with a learning disability.

The Belfast Trust is providing positive behaviour interventions support to address challenging behaviours using a stepped model of intervention. Part of the trust's community infrastructure development plan has resulted in an increased capacity in services for prevention and earlier intervention. The introduction of behaviour practitioners to community teams and the integration

and enhancement of psychology services within their community teams is designed to support this approach.

The trust advised that when recruitment is complete, all the trust's day and residential/supported living services will have a behaviour support link person who will work with them to develop effective positive behaviour support models. Individual behaviour support for service users can be provided by a range of and combination of practitioners in the community teams, depending on the nature of the presenting problem. An intensive support service is also available.

The Northern Trust's clinical psychology learning disability services are available to adults with a learning disability, offering interventions for a range of psychological difficulties. These include offering assessment, support and advice in relation to behaviours that challenge.

If service users have behaviours that severely challenge, more intensive support is provided by the Positive Behaviour Support Service (PBSS), which operates at Tier 3 of the stepped care model. This service consists of a consultant clinical psychologist, supported by behavioural specialists, behavioural associates and a speech and language therapist. All those referred to the PBSS have been identified as either displaying high risk behaviour or having their community placement deemed at risk. The PBSS completes comprehensive assessments, develops, implements and supports behaviour support plans. They may offer training to staff teams, carers and families in order to increase their understanding and skills and how to follow specific behaviour support plans.

The South Eastern Trust has developed a behaviour support service (BSS) to assess those with challenging behaviour, to identify their needs and determine how they can be supported by the service.

The service consists of a skill mix of behaviour nurse therapists, psychology assistants and clinical psychologists. A number of band 6 behaviour practitioner posts, and band 3 behaviour assistant posts, were being recruited at the time of the review.

Referrals can be made to this team by any professional working with an individual with challenging behaviours.

The BSS works in partnership with families, community learning disability teams, statutory, voluntary and private service providers, schools and others to provide advice, support and behaviour support plans to meet the needs of the individual. Service users are reviewed at least annually, but more frequently as necessary.

The trust expects that this team will provide a more intense and flexible service to individuals with challenging behaviours, their families and service providers as required. The service is led by a senior manager and a consultant clinical psychologist. A speech and language therapist is also employed to provide advice and support, in relation to communication and swallowing assessments.

The Southern Trust community learning disability BSS comprises a team with a wide range of professional backgrounds including clinical psychology, nursing and social work. This team works collaboratively with a range of community learning disability staff, including AHPs, clinical psychologists, psychiatrists, day care, supported living and respite staff, as well as parents or carers and independent sector providers.

Comprehensive behavioural assessments are carried out, depending on the needs of service users, from which appropriate interventions are developed. To enhance the service, new protocols and proformas were developed to ensure collection of relevant information. The BSS team has developed a number of visual strategies and evidence based resources for use in direct work with service users and their families, in order to enhance the effectiveness and the likelihood of positive behavioural outcomes.

The Southern Trust advised that to manage increasing referral rates, it is developing a Tier 2 and Tier 3 level of intervention as required and provides a variety of training programmes for staff. The aim of this approach is to build capacity both in the BSS team and within community teams and the wider multidisciplinary service including service users, parents and carers. To further build capacity within the team, a number of BSS staff are currently pursuing further training in Positive Behaviour Management Support.

The Western Trust reported that service users with challenging behaviours are supported by both staff and carers to ensure that they are managed safely and that agreed strategies are in place to provide support. Intensive support workers have recently been appointed in the Western Trust. Their role is to provide rapid and intensive support in cases where there are significant challenges in managing behaviour, with a risk of breakdown of the family or placement.

They also have a behavioural support service which plays a key role, ensuring that people are properly assessed and that behaviour plans are in place. This service provides direct support and advice to staff on these issues. Advice and support is also provided through the sensory occupational therapy (OT) service on a case by case basis.

The Northern Trust is the only trust which has a comprehensive database of outcomes in the positive behaviour support service for over 11 years and their psychology services have outcome data on all their service users. The review team considers that this model should be reviewed by other trusts for effectiveness.

The review found that there is no agreed uniform model for behavioural support services across the five trusts. Some of the teams established with new funding are more expensive than others. An evaluation of the effectiveness of these teams would be valuable. The review was not told of any plans to do this by the five trusts. The Belfast Trust is collecting a range of data in preparation for a review of their Intensive Support Services, including outcome measurements for individual service users.

Given the extra financial investment provided to the trusts, it would be prudent for the commissioner to commission research on the outcomes and effectiveness of these teams, as well as review the costs of each of these teams. The commissioner should also gain insurance that policies are aligned with the principles of positive behaviour management.

Recommendation 7

Priority 2

An assessment of the activity and effectiveness of challenging behaviour teams should be undertaken by the commissioner. The outcome model used by the Northern Trust should also be reviewed to see if it could be applied regionally.

Carers and Public Actively Involved in the Planning and Delivery

The five trusts described in their written submission to the review, how they involve service users and carers in meetings, forums, public consultations and also in some reviews of services, for example day opportunities or short breaks.

Meetings called 'Carers Voice' occur two to three times a year in the Western Trust. These meetings have included presentations on self-directed support, reporting on outcomes of the day care review or short breaks services.

Every trust had various parents and carers groups some of whom met with the review team. The review did not routinely find robust evidence that parent and carer groups were actively involved in the planning, delivery and monitoring of health and social care at all levels. Rather, meetings seemed to focus more on informing carers about trust plans to modify service provision. This does not meet the Service Framework for Learning Disability, Standard 3 (all patients, clients, carers and the public should have opportunities to be actively involved in the planning, delivery and monitoring of health and social care at all levels). This has resulted in some carers groups stating to the review that they considered their views are not valued.

Developing a Personalised Pathway of Care for Learning Disability Services

All five trusts advised that they completed service users' assessments and reviews in an individualised and person centred way.

Recommendation 8

Priority 1

Each trust, as part of their Personal and Public Involvement (PPI) Strategy, should proactively involve people with a learning disability and their carers in the planning of change to service delivery or in creating new service developments.

Each trust described to the review individual pathways of care for assessments, care planning, monitoring and reviews of the needs of an adult with a learning disability.

However, these care pathways were not necessarily inclusive of all services provided to the person, such as residential care, day services and short breaks, even when provided by the trusts and also do not include non-statutory provision.

Direct Payments

All trusts reported that they were progressing the implementation of self-directed support and had updated their information for carers and service users in relation to accessing direct payments. It was reported to the review that this information is now in an easy read or an accessible format. The trusts provided training for their staff in arranging self-directed support.

The Belfast, Northern and Southern trusts are not paying the HSC Board recommended minimum rate of £10.00 per hour for self-directed support as suggested in November 2014 by the HSC Board senior management team. This was communicated to the HSC trusts in a letter to the chief executives in January 2015.

The uptake of direct payments and self-directed support in Northern Ireland lags behind the rest of the United Kingdom¹⁶. The trusts claim they are unable to fund direct payments from existing budgets and further monies cannot be extracted from ongoing service provision. The current limitations on the amount paid through direct payments and what it can be used to buy requires to be urgently reviewed. The existing disparities across trusts also need to be addressed. Consistency of provision of direct payments between child and adult services is also variable.

A number of carers stated to the review that the services they were provided with, in terms of meeting the needs of young people under 18 years cannot be replicated by adult learning disability services. This makes the transition difficult for many families who stated that on reassessment of their young person's needs by adult services, they were not provided with services at a similar level.

Recommendation 9 Priority 2

The commissioner should review the regional disparity in the uptake of direct payments and continue to monitor the consequences of trusts paying below the directed standard rate.

Assessment of Clinical and Social Care Needs

All trusts advised the review of the information they gather from a wide range of areas including day opportunities, outcomes from service user

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¹⁶ Community Care Statistics, Social Services Activity, England 2013-14

assessments, directed enhanced services (DES) and engagement with carers. The Belfast Trust reported they were carrying out a needs assessment in the areas of accommodation needs, transitioning from children's to adult services and short breaks usage.

The Northern Trust reported on completing audits of their screening process and care management. The Western Trust has completed a review of day care and short breaks and is currently working on the first draft of a day care review report. They have also completed a five year projected accommodation needs analysis.

Trusts advised that they are using other forms of assessment tools and not the Northern Ireland Single Assessment Tool (NISAT) to assess the need of adults with a learning disability, over 65 years of age. The DoH has not introduced the NISAT tool for adult learning disability services as a requirement.

However, the Southern Trust reported using the NISAT after making some modifications to it, but not an electronic version. The Belfast Trust uses its own easy read assessment tool About You, which it developed in line with the content of NISAT.

The appropriateness of the use of NISAT within learning disability services needs to be addressed urgently at a regional level and revised regional guidance issued by DoH to HSC trusts concerning their expectation about the use of this tool in the future.

Recommendation 10

Priority 1

The Department of Health should review the appropriateness of NISAT for use within adult learning disability services and issue guidance to trusts in respect of the trusts' use of this tool to assess needs regionally.

Information Systems

Many trusts described the manual collection of information, which is time consuming, can create errors in reporting of information and does not make bench-marking easy for the commissioner. No trusts were using an identical system. Trusts reported there are many limitations to existing systems, resulting in a lack of robust information to inform trusts and commissioners about clinical and social care needs of adults with a learning disability.

There is no agreed single regional information database system to record activity, performance or outcomes in community learning disability services. There was some evidence of collaboration commencing across trusts, to seek a single unified community information system that would capture information about adults with a learning disability in the community, whether attending hospital or general practice. A community informatics group had been recently formed to review information requirements and current databases used by trusts.

Patient Record Information System (PARIS) is a community information system used in adult learning disability services in the Belfast Trust. The Western and Southern trusts will change to PARIS in the future. The South Eastern Trust prefers to retain its own community information systems. The Northern Trust would prefer one regionally agreed information system.

The review team considers this is an area that must be addressed at a regional level in order that accurate and up to date information is available for meaningful planning of service delivery, investment and monitoring of outcomes.

Recommendation 11

Priority 3

The regional informatics group should consider and agree how best to capture information in a single unified regional IT solution, to ensure meaningful planning and consistency of reporting on learning disability services and outcomes across the five trusts.

Day Services and Day Opportunities

Current thinking in relation to most school leavers with severe learning difficulties is to move away from traditional day centres towards other options such as college, vocational training, work experience and supported employment. Service users availing of directly provided day services require an annual review by the trust. This provides an opportunity to discuss their ongoing needs and aspirations.

Each trust had different schemes and a range of different opportunities for the provision of day services and day opportunities.

The Belfast Trust described to the review a range of day opportunities and appropriate employment opportunities provided through direct payments or contractual arrangements with the independent sector. These included buildings based day opportunities, community day services and a number of activity clubs. The trust contracts with Mencap, NOW¹⁷ and Orchardville to provide work and training opportunities and works closely with the Belfast Metropolitan College in relation to further education. The trust also purchases individual day-care and day opportunity packages from the independent sector. Adults with a learning disability are referred for trust day support services using the About You tool, which outlines the specific needs and aspirations of the individual in relation to their day opportunities requirements.

The Northern Trust reported that it has invested in its day opportunities programme to develop a range of community-based day opportunities in four service areas, leisure; vocational; volunteering and further education. These opportunities are processed using a 'Railtrack' Model ensuring individual need

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¹⁷ NOW – a training and employment social enterprise group in Belfast

is met in line with assessed need, using local provision. A range of opportunities are in place, which are monitored and reviewed.

The trust advised that it has developed social enterprise vocational training provision across its 12 sites, involving four voluntary sector partners and also a trust-wide supported employment scheme, in partnership with the Department for Employment and Learning (DEL) and two voluntary sector providers. Individual employment progression is tracked, from training to paid employment, through monthly provider meetings.

As part of its Widening Choice and Opportunities Strategy, the Northern Trust has developed a number of satellite facilities, staffed by trust employees, which provide adults with a learning disability with a structured day service, in a smaller setting, in their local community away from larger adult centres. A satellite can also provide an assessment centre in order to prepare individuals, where appropriate, for community based day services such as employment and further education. The Northern Trust had positively evaluated the outcome of provision of care in one of their satellite units. The South Eastern Trust's adult learning disability services had a range of contracts with providers of day care and day opportunities, to provide support in order to access volunteering and employment based opportunities. Ongoing contract monitoring by staff ensures service delivery is provided against agreed targets and activity levels.

The South Eastern Trust advised that it has reviewed all current day care and day opportunities provision and is working actively with key stakeholders, including service users, carers, provider organisations and community groups to develop a range of options to increase choice for individuals. Adult services are also offering self-directed support as a means of delivering person centred day opportunities. Sector based day opportunity panels provide a local approach, which links service users with their local community. At the time of the review, a number of people with a learning disability and their carers had raised concerns with the trust about the trust's plans for the future development of their day care services.

The Southern Trust described to the review how community key workers seek to access appropriate day opportunities, to meet individual service users needs within their local community. These opportunities may be leisure based, volunteering, training, educational, full and part time or supported employment. The trust has directly employed two support workers and is in the process of recruiting a third, to ensure that every service user assessed as needing support to avail of day opportunities, is provided with appropriate support.

The Southern Trust is also in the process of procuring an independent brokerage system, which will be responsible for creating and expanding the range of day opportunities available to service users in each locality and for maintaining an online resource listing these opportunities. The trust already holds a number of contractual agreements with voluntary organisations including Clanrye Developments, Mencap and Appleby Print It Employment Services to promote supported employment opportunities for service users

with a learning disability. A number of patients spoke to the review team and expressed concern about the trust's management of the change process.

A draft directory of partners was supplied by the Southern Trust to some parents and carers which in terms of supplying information was expected to be a positive development. However, it caused some anxiety for carers, as prospective providers when telephoned by carers, were not aware of the inclusion of their respective services in the directory. This emphasises the need for information to be reviewed and updated as required, given the service availability in the community by a range of providers.

The Western Trust reported that it is continuing to develop its approach and a review of care and day opportunities is yielding useful information which they are using to make service improvements. Community teams and day care managers continue to work proactively with service users and their carers, to assess need and source appropriate opportunities for day services for each individual. This is undertaken as a normal part of care and support planning and results in access to a range of trust, voluntary, independent and other statutory provision. The Western Trust also stated that it is participating in a review of day care and day opportunities, which will assess the projected needs for the next five to 10 year period.

The trust also has a new dedicated community access worker whose role through the New Directions Service is specifically to source bespoke packages, where requested, including day care, supportive employment opportunities or college placements. This is working effectively for 27 service users on a trust-wide basis and is continuing to develop.

There was no evidence of the trusts having evaluated the effectiveness of their different schemes in relation to provision of day services and day opportunities.

Recommendation 12

Priority 2

Each trust should annually update their directories of services for people with a learning disability to ensure they provide information about current services.

Recommendation 13

Priority 3

Each trust should evaluate the benefits and effectiveness of outcomes for adults with a learning disability of the various models of day care and day support. This should be reviewed by the HSC Board regionally in terms of their future commissioning plan for day care and day support services.

Development of Partnership Arrangements

The trusts advised the review of close working partnerships with a range of providers of day care and day opportunities. These were in the areas of education, leisure, employment and vocational training for adults with a learning disability.

In addition, there is ongoing work involving supported employment and social enterprises with the Department for Education and Learning and volunteering with the Department of Social Development and the voluntary sector.

Although all trusts outlined their involvement with the non-statutory sector, the review team considered that there was no real sense of sustained partnership around broader service development plans but rather engagement takes place on a specific project basis as required.

All five trusts advised the review of close working relationships with a range of partners, in particular Northern Ireland Housing Executive (NIHE), but also the Department of Social Development (DSD) and a range of housing associations. A move towards tendering of services runs the risk of setting up competition among non-statutory providers with the lowest price becoming the most significant factor, which should be monitored by the HSC Board.

Supported Employment Opportunities

There are some very good examples of innovative and possibly very costeffective schemes taking place in individual trusts, such as the Rail Track model in Northern Trust. This model illustrates a clear process from referral through to allocation of services.

It illustrates a person centred approach commensurate with the HSC Board's regional day opportunities model and Equal Lives report for vocational opportunities and educational opportunities. The review notes this good practice was not replicated by other trusts and types of service models were not routinely shared across trusts.

The proportion of people with learning disability even in part-time employment remains very low. Unpaid work experience placements still dominate, which run the risk of trainee exploitation.

Protection of their social security benefits may be a contributory factor in the low percentage in full time employment, but the review team saw evidence of a number of people who could graduate to paid employment. Some people subsequently reported that they had not been provided with an opportunity to do so. The review noted that trusts had employed very few people with a learning disability. The trusts as large employers should consider providing paid employment opportunities for people with a learning disability, as this would serve as an example to other statutory agencies and private businesses.

Recommendation 14

Priority 3

The trusts, as large employers should, as part of their organisational development strategies, seek to provide a model of positive discrimination by promoting more employment opportunities for people with a learning disability.

Managing Transitions from Children's to Adult Services

None of the five trusts were approaching transition planning in the same way. All trusts reported that a regional protocol or pathway for children transitioning to adult services is in place. In some trusts the protocol is still in draft.

A number of families reported experiencing difficulties, when transitioning to adult services, particularly with continuing provision of short break services, therapeutic input and alternative options to school.

Many families indicated that they face a significant reduction in services yet with no change in the person's needs. It was reported to the review team by carers that they understand that this is solely driven by capacity of trusts to provide services.

Carers are finding it difficult to manage the interfaces between services in the absence of a lead medical consultant, especially where a young adult has a number of complex needs which cover more than one medical speciality. Up until a young person was 14 years old their needs were coordinated under paediatric services.

In the Belfast Trust, the learning disability service has engaged the Orchardville Society and NOW¹⁸ to provide two transition officers to support young people, from the age of 14, to plan their transition from children's to adult services. The transition officers work routinely with education, children's and adult services.

The Belfast Trust has updated its policy on transition pathways; relevant managers from children's and adults services meet bi-monthly to share information, plan and track progress on plans made by the trust.

The Northern Trust has recently completed a baseline report, detailing potential known transitions for the next five years. Using a Transition Coordinator and working in partnership with children's services and education transition services, the trust now has incorporated transition work as part of the community learning disability team rather than as a separate transition team.

The South Eastern Trust reports that they hold a monthly community integration meeting. One aspect of this is to specifically consider children with

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¹⁸ NOW - a training and employment social enterprise group in Belfast

complex needs or who have been looked after by the trust, who will require placements within adult services.

The Southern Trust reported to the review team that a scoping exercise is underway to identify all young people from age 14 years so that a transition database may be collated. The trust is prioritising young people who turn 18 in 2016 and young people on an extra contractual referral who will return to the trust.

The Western Trust is currently managing transition from children's to adult services on a case by case basis. There is joint working by children's and adult services, in most cases, in advance of a young person's 18th birthday.

Arrangements are in place with local schools, to co-ordinate efforts to manage effective transitions for children from school to day care and day opportunities placements.

In the Western Trust, transition from children's to adult services has seen some improvement since the last review, due to the appointment of two people within adult teams.

They have a remit to work with children's services, to develop a transition plan for school leavers and to help adults make a transition to other services in the trust e.g. older peoples services. However, resources do not normally follow young people in transition and are often not available to adult services to maintain the levels of support provided in children's services.

Transition planning needs to be consistent with legislative requirements, guidance and best practice standards.

An options appraisal needs to be undertaken of how resources could follow the person across service boundaries in order to maintain services following their transition to adult services. It was unclear to some trust staff, if the transition funding for Looked After Children could be made available to cover services from 14 to 25 years and if funding is drawn from both children's and adult services.

Recommendation 15

Priority 1

Each trust involved in making transition arrangements should ensure that they follow legislative requirements and best practice standards and that the criteria for the continuity of service provision are made clear to people with a learning disability and their carers.

The review team noted that the proportion of school leavers with more complex physical and behavioural needs continues to rise. This will create further pressure in adult services in the future.

Recommendation 16

Priority 3

All trusts should carry out an assessment of the needs of school leavers over the next five-year period to enable financial projections to be made for the increased resources required to maintain adults with a learning disability in the community adequately.

Managing Transitions from Hospital to Community

All trusts were asked to provide information regarding their arrangements for adults transitioning from specialist hospitals. Resettlement of patients from Muckamore Abbey Hospital remains incomplete. The Belfast Trust has a dedicated care manager attached to Muckamore Abbey Hospital who works closely with the hospital and community teams in relation to all resettlement and delayed discharge patients.

The Northern Trust has developed effective alert and discharge planning arrangements with their hospital social workers, to ensure suitable planning for adults transferring from general hospital to the community. The Northern Trust's senior staff responsible for learning disability services meets quarterly to review all admissions to and discharges from Muckamore Abbey Hospital to assist in identifying any patterns and gaps in services.

The South Eastern Trust reports it has two dedicated transition workers who provide in reach services for patients in Muckamore Abbey Hospital, to help facilitate person centred discharge planning arrangements. The Southern Trust follows the pathway agreed with Belfast Trust for patients from Muckamore Abbey Hospital who are transitioning from hospital into the community. Trusts are continuing to work with patients who refuse to leave hospital despite a number of placements being identified. One trust is awaiting advice from the HSC Board and DoH in this matter. The Western Trust has completed its original resettlement strategy. At the time of the review they had only two patients on the delayed discharge list to relocate. This was expected to be completed by July 2016.

The review team looked at the number of beds in Muckamore Abbey Hospital in 2013-2014 and the number of people continuing to require resettlement in the community, as shown in Appendix 3 Table A7. Twenty beds are available for treatment, ten beds each in the Southern and Western Trusts. The trusts have been unable to fully meet the expectation of the DoH in terms of all long stay hospital patients being discharged to the community by March 2016, due to some of the above factors. It is anticipated that the patients referred to in Appendix 3 awaiting resettlement, will leave in November 2016, January 2017 and June 2017. Placements are provided mostly in nursing homes or other group living arrangements, when indicated by the person's assessment of need.

Number of Patients in Active Treatment and Delayed Discharge

There is a concerning trend of new patients experiencing delays in their discharge to the community. A snapshot of the position at the end of January 2016 is set out in Table 5.

Table 5: Numbers of Patients by Trust in Active Treatment and Delayed Discharge at the 31 January 2016.

	Inpatient Treatment	Delayed Discharge
Belfast Trust	15	18
Northern Trust	10	16
South Eastern Trust	9	14
Total in Muckamore	34	48
Southern Trust	5	3
Western Trust	2	7

Figures in Table 5 are based on end of month positions as reported in the returns for Muckamore Abbey Hospital to the HSC Board.

By 16 May 2016 the position was 68 patients were delayed in their discharge, 29 from Belfast Trust and 39 from the other trust areas in Muckamore Abbey Hospital.

Supported Accommodation and Support Services

The South Eastern Trust has worked with the NIHE, Supporting People and Housing Associations to create new and extended supported living schemes.

The HSC Board expressed concern about continued availability of funding from the DSD to support adults with a learning disability in supported living accommodation, if, in the future, they do not strictly meet their criteria, in the future. Discussions are being held with NIHE and trusts about the future of commissioning of these services and the intentions of NIHE.

Accommodation Needs of Adults with a Learning Disability

The Belfast Trust has reviewed the likely accommodation needs for people with a learning disability for the next four years. This information is used for financial and accommodation planning purposes. Individual accommodation plans are progressed through their care management processes which assess need, source accommodation and commission and review the service.

The Northern Trust has undertaken a similar exercise to examine the current and future accommodation needs of young adults in residential care, including individuals living with their parents long term and adults awaiting resettlement or involved in a delayed hospital discharge.

The Western Trust has carried out a five year needs analysis of accommodation and is anticipating accommodation needs of various types for 222 people between 2015 and 2019. This is more likely to increase than decrease based on changing needs within families. Most service users are

living in residential, nursing care, and supported living with day care support or 24 hours seven days a week support needs as required.

The availability of emergency accommodation in the community, for a short period, to support the work of behaviour support teams was commonly noted as a means of avoiding unnecessary hospital admissions. Sometimes patients whose placements break down in a crisis have returned to Muckamore Abbey Hospital. They risk becoming a new category of delayed discharges. However no trust to date has been able to provide such a crisis facility. The Northern Trust provides two stepdown beds in two separate facilities at Hollybank and Woodford Park to assess patients at risk of their placements breaking down and work with them intensively in the community.

Recommendation 17

Priority 2

The HSC Board, supported by the five trusts, should review the models of best practice in preventing hospital admissions and consider the feasibility of developing a pilot of a regional crisis admission house.

Placements Out of Own Trust Area

The review was aware of a number of people who are placed out of their own area due to the lack of suitable care options in their home trust.

This creates funding implications for host trusts as new community services are needed to support the person in the new trust area. In the Northern Trust, in one new facility, 19 out of 20 beds were being purchased by other trusts.

Recommendation 18

Priority 3

Each trust should review the impact of the transfer of people to other trust areas in relation to the consequences for their learning disability team's infrastructure, the cost to the receiving trust and the possible disruption to family relationships and share their findings with the HSC Board.

Review of Needs of Older Parents

All trusts informed the review of identifying, profiling, recording or reviewing older carers and their needs. This was frequently undertaken as part of other work, such as Transforming Your Care respite projects, review of short breaks or an exercise in scoping future accommodation needs. In addition to annual reviews and direct payments, all trusts advised that, based on the assessment of need and eligibility criteria, adults with a learning disability parents, carers and families are supported with short breaks. These take many different forms, such as day sitting, night sitting, flexible respite or direct payments.

The uptake of assessments by carers remains low across all trusts. Trusts advised that some carers have declined the recording of their needs. The

trusts all reported that they continue to offer carers assessments; in 2015, one trust wrote to all carers offering an assessment.

The HSC trusts advised that some families had declined to discuss future planning and reported that it is a subject that some families find difficult to talk about.

A number of families involved in the focus groups, stated they were unaware that support was available from the trust, to assist with future planning and would welcome this input. Set rules about when future planning should commence will not suit every family, although trusts should try to encourage this discussion during the review of the care plans for adults with a learning disability. This may help in reducing crisis intervention planning in the future.

Recommendation 19

Priority 1

The carer coordinator in every trust should report to the HSC Board about the reasons given by carers specifically not wishing to progress with a carer's assessment. The HSC Board should consider if any further action should be taken by trusts to increase the uptake of assessment.

Recommendation 20

Priority 2

Each trust should monitor and ensure that effective future planning is taking place and monitor crisis admissions to care annually and disseminate any lessons for learning.

Developing Capacity to Give or Refuse Consent

The trusts advised the review that staff have undertaken capacity and consent training. Where the service user has been assessed and does not have capacity, advocates can be used by the trust to ensure the best interests of the service user are considered. The majority of trusts also advised that leaflets explaining consent are made available for service users. Trusts currently await the implementation of the new Mental Capacity Act (Northern Ireland) 2016 and further guidance in relation to assessing capacity.

Advocacy

All trusts made advocacy services, funded regionally by the HSCB, available during the resettlement process. Four trusts advised of a contracted arrangement with an independent advocacy service, provided by ARC, Bryson House, Disability Action or VOCAL. The Northern Trust is undertaking a review of their current advocacy arrangements and developing a paper to confirm their future model. The Western Trust had just ended a contract with VOCAL and will now negotiate a new contract, although their funding to do so is very limited. TILII is used by the Belfast and South Eastern trusts to provide peer and self-advocacy.

The Belfast Trust is also supported by MENCAP to assist in the development of advocacy skills, which has led to significant improvements in the services provided by the transport department.

The Belfast Trust commissions separate advocacy services for the hospital and community.

The contract for community advocacy services prioritises cases where the trust is seeking some form of legal authority in relation to the service user and cases where there is some form of conflict between the trust and the service user.

The Southern Trust has used independent advocacy services for adults involved in the resettlement process and for adults living in trust supported living schemes. Speech and language therapy input was dedicated to this to ensure as many views as possible were captured, by assisting with service user communication. A number of service users and carers said they did not like group sessions, so the trust changed its plans. People are met in their own homes on an individual basis. The Western Trust has invested £20,000 in the provision of advocacy services.

Commissioned advocacy schemes seem to be more focussed on resettlement in other trusts.

The review team did not detect any initiatives to promote advocacy for persons with learning disability more widely; rather they are available on demand, although the Southern Trust stated that self-referral and referral from other agencies can be made to this service. The trust has doubled its investment in this service in the past two years. Advocacy may be especially crucial for the successful uptake of direct payments and other new service options. All trusts indicated that they promote people's human rights, although few specific instances were provided to the review as to how this occurred.

Recommendation 21

Priority 3

Each trust should review their investment in advocacy services and ensure it is available to a wider group of people, other than just those involved predominately in resettlement from hospital.

Appropriate Support for Service Users in Contact with the Criminal Justice System

All trusts referred to advocacy services as part of the support available to adults within the learning disability service that come into contact with the criminal justice system. The Belfast and South Eastern trusts advised that they provide both peer and self-advocacy using the TILII group. The Southern Trust is using Disability Action to provide an independent advocacy service. The Northern, Southern and Western trusts have social work support available in their forensic teams to support people in contact with the criminal justice system.

Increased Staff Training and Awareness

Generally, trusts responded to this question by describing training for learning disability staff that includes the previous RQIA recommended areas of human rights and good communication. The Belfast and Western trusts reported that, where possible, service users had input into staff training.

The review notes that the Belfast Trust's two day induction programme for learning disability staff was shortlisted for a social work award in the learning and development category in 2013.

2.4 Standards Reviewed Relating to COMPASSIONATE Care

Findings

All trusts described to the review that they have established a carers' forum and carers' groups in their respite units to allow carers to freely express their views. Others ways in which the carer's voice was heard were described: during carers' assessments, annual satisfaction questionnaires, surveys, reviews of services users and during the care and support planning processes.

In addition, the Belfast Trust contacts two carers per day centre every month to seek feedback on their level of satisfaction with services.

Engaged through Effective Communications

In addition to the groups and structures that the trusts had previously described, they all made reference to the provision of some easy read material and accessible formats.

The Belfast Trust informed the review of service user committees in each of its day services. Each committee sends a representative to the trust wide service user forum.

The Northern Trust has provided information in accessible formats, and described the speech and language therapists training provided to other trust staff to promote better communication with service users. A pilot has been established using social media to share information with a wider group of service users and carers. The trust has also produced a DVD of the last 10 years provision of day opportunity services, to help promote uptake of this service.

The South Eastern Trust uses trust wide speech and language therapy services and has devised a person centred template titled How Best to Support my Communication. The trust provides accessible information about Promoting Quality Care assessments, videofluroscopy, numerous health appointments and the use of a hospital passport.

The Western Trust reported using communication plans, has developed easy read material and has some accessible information on the trust's website.

While supporting all initiatives described above, the review found that the trust websites are not very user friendly and have limited information available instead of specific easy to read information.

Recommendation 22

Priority 1

Each trust should have an identified area on their website for people with a learning disability which has more easily accessible information in terms of easy to read material with more use of signs / symbols for ease of access to information.

End of Life Care Needs

All service users in nursing and residential homes should have end of life or dignity plans in place. The review found that community staff engage with families to produce end of life plans when requested.

Many positive examples were provided to the review from across Northern Ireland, which provided evidence of trusts supporting service users requiring palliative care with person centred care, in their home at the end of their life. All trusts described working with GPs, hospital staff, community nursing, rapid response teams, psychology, hospices and Macmillian nursing care to provide appropriate end of life care.

In the Northern Trust, learning disability services are represented on the trust's Palliative Care, End of Life Programme and the Bereavement Forum. The Belfast and Northern trusts described palliative care training opportunities available to their staff.

Care plans are agreed with service users, carers and families and updated following service user reviews. The Western Trust advised that its staff identify people with learning disabilities with no relatives, to ensure dignified end of life plans and arrangements are in place.

2.5 Services are Well Led

Findings

This review assessed the effectiveness of the leadership, management and governance of services while focusing on the needs and experiences of service users. Levels of leadership were assessed at both team and senior management levels in focus groups and from written responses to self-assessment questionnaires which were analysed by the review team. In addition, a meeting was held with the HSC Board as commissioner, to validate some of the information provided about actions taken by trusts.

Use of Service Framework by Trusts as a Tool for Improvement

Following the 2013 Phase I, Review of Community Services for Adults with a Learning Disability, all trusts reported in their action plans that they were progressing the service framework and contributing through regular reports, to monitoring by the HSC Board.

All trusts described their structures, confirmed the governance arrangements in place for learning disability and demonstrated linkages across their own trust with other directorates. Professional leads have responsibility to ensure that staff remained up to date with contemporary theories, interventions and best practice guidelines. Trusts advised the review of the types of processes in place, to gain assurance as to performance against the Service Framework for Learning Disability, including contributing to the HSC Board's monitoring of key performance indicators (KPIs) and participation in the HSC Board's file audit. The trusts provided a list of their internal audits of practice; for example audits of safeguarding, staff supervision, direct payments and carers assessments.

Proposals for gathering evidence to demonstrate improved outcomes for service users were reported to the review by three trusts, Belfast, Northern and Western. The Belfast Trust is introducing a Health Equality Framework as an outcome measurement tool.

This will be piloted across part of adult learning disability services later in 2016. The Northern Trust has an outcome evaluation framework for people in receipt of psychological services.

The Northern Trust reported increased numbers of direct payments, increased opportunities in supported living and day services and described their bespoke packages for resettlement.

The Western Trust similarly demonstrated an increase in supported living placements for resettlement of patients out of hospital, increased numbers of direct payments and developments in self-directed support.

The review team noted that most staff they met were familiar with the content of the service framework, although the review team received assurances that the Service Framework for Learning Disability has been rolled out across trust staff

The Service Framework for Learning Disability should guide service developments, monitor outcomes and underpin the formulation of annual disability service development plans. The approach used by trusts in applying the standards varied across trusts.

Recommendation 23

Priority 2

The formulation of annual learning disability service development plans in trusts should be consistently underpinned by the standards set out by DoH in the Service Framework for Learning Disability.

Use of Best Practice Evidence and Guidelines

All trusts advised that they use best practice evidence and that appropriate guidelines were available. Sources listed by the trusts included National Institute for Health and Care Excellence (NICE), Royal Colleges, external reviews and RQIA Quality Improvement Plans. The Belfast Trust is currently exploring membership of the National Health Service Bench Marking Network of Learning Disability Services.

Transferability of Skills between Mental Health and Learning Disability Teams

The Belfast Trust reported that their teams are working closely together in a number of ways such as audit forums and in monthly monitoring meetings with independent providers. The Northern Trust is developing opportunities for co-working with their RAID and Promote teams. The South Eastern Trust described the link between the CLDT's approved social worker, who engages directly with mental health services through a forum. The Western Trust advised that learning disability staff share knowledge and expertise on a case by case basis.

The Department of Health advised that students on the Approved Social Work Course (who are already experienced social workers) have to undertake a placement in mental health and or learning disability depending on their specific learning needs. Mental health social workers will undergo a Learning Disability placement in order to widen their experience and vice versa. However the review was not advised of any placements of learning disability staff in mental health services and vice versa to encourage experiential learning, or consideration of secondments of staff to learn more about mental health or learning disability services.

The trusts did not provide any data to quantify any skills exchange between mental health and learning disability teams. Limited improvement has been noted in this area.

There continues to be reluctance for mental health services to take people with a mild learning disability into their services, despite the standard set out in the Service Framework for Learning Disability.

Leadership of Services, Governance and Service Improvements

All trusts advised the review of a wide range of ways in which their staff are supported. Staff have regular supervision, attend team and MDT meetings, professional forums, knowledge and skills framework (KSF) appraisals, participate in staff surveys, complete induction training and specialised training for existing staff is available.

The trusts described regular learning disability team meetings, MDT meetings, supervision and visits by senior managers and directors. This demonstrates that staff are supported, able to make suggestions, have a team approach to addressing key concerns and is included in decision making.

Additionally, the review was advised that workshops are held in the Northern and Southern trusts to enable staff to offer suggestions for improving the service.

Trusts had service plans, directorate plans and corporate plans in place for adult learning disability services. Managers are described as having an open door policy when listening to their staff; staff were encouraged in many ways to be involved in decision making, for example the Southern Trust Assistant Director wrote to all learning disability staff asking them to identify any ineffective or inefficient practices.

Learning from incidents is disseminated across the teams during de-briefings by managers, in MDT meetings and regular incident review meetings. The trusts have incident review forms, Datix processes and risk registers, to ensure that learning is captured and shared. All trusts provided evidence of numerous audits carried out within learning disability services; files and care plans are regularly audited to ensure services users' notes are current and that relevant information is recorded. The Northern Trust continues to have leadership walk arounds involving both the Assistant Director and the Director and promotes staff engagement across all services.

All trusts have complaint, compliment and feedback systems and indicated that they reviewed the outcomes.

The chairman, non-executive directors, directors or heads of service conduct walk around visits to services. In the Southern Trust, this was developed further into a patient and staff safety leadership walk around programme. All trusts reported having person centred planning processes with Promoting Quality Care (PQC) risk assessments being completed with service users.

Difficulty in Implementation of the Service Framework for Learning Disability

Trusts stated that there is still a need to update the service framework, and amend the language in some parts to ensure trusts are meeting the KPIs consistently. The review noted that trusts have not all interpreted the KPIs in exactly the same way. Further work is required by the commissioner to agree definitions to ensure accuracy of reporting and comparability of outcomes.

Trusts described their difficulty in obtaining data, as it was not readily available or accessible. This has resulted in some cases in estimates being submitted. This can lead to inaccuracies if comparisons are made about performances of trusts. There are concerns therefore that this potentially inaccurate information is being used to measure performance by the HSC Board.

All trusts expressed concerns about the lack of specificity in some of the standards set out in the service framework and consider that the information provided to date, is unlikely to have enough reliability or validity to make accurate comparisons between trusts. However the HSC Board advised the review team that they consider the comparative data to be sufficiently robust.

The following benchmarking information of the KPIs to date, has been provided by the HSC Board to the RQIA review.

Table 6: Status of key performance indicators (KPIs) from Service Framework for Learning Disability

The Service Framework for Learning Disability contains 34 standards, 4 are specific to children and there is a set of 10 that are identified as generic. These essentially are intended to apply to all the population, or all HSC professionals or all service users, regardless of their health condition or social grouping.

The HSC Board is monitoring performance against the 20 standards that specifically relate to adults with a learning disability. The HSC Board reports separately on the generic and children's standards to the Department of Health.

Within the 34 standards there are 85 KPIs, however within the 20 standards relating to the adults with a learning disability there are only 56 KPIs.

Status of KPIs	Green	Amber	Red	Total number
Number of KPIs	27	25	4	56

This indicates that at the time of the review 27 KPIs were achieved, 25 KPIs were with an acceptable tolerance and four KPIs were not met.

Given that the Service Framework for Learning Disability is now in its third year, the review concluded that a higher level of achievement should have been evident. Closer partnership working by trusts would have been helpful to achieve a more consistent approach across Northern Ireland.

Recommendation 24	Priority 3
The DoH should assess the progress and the implementa standards contained in the Service Framework for Learning	

Recommendation 25	Priority 1
Each trust should produce action plans to demonstrate ho KPIs in the Service Framework for Learning Disability and their Trust Board for monitoring and to evidence their demimprovement.	present this to

Section 3: Stakeholder Consultations

The review team met with over 200 adults with a learning disability, from all of the HSC trusts across Northern Ireland, in 17 separate groups and in a range of one to one meetings with service users. The composition of the groups included adults with learning disabilities, adults with a learning disability who advocate for others, parents, carers and advocates. The review team met adults in settings ranging from their own homes, to day centres and trust facilities. Some groups were organised by the trusts, others by the voluntary sector, such as ARC, Destined, Positive Futures, TILII and VOCAL.

Generally, information obtained from this consultation process agreed with findings from interviews with trust staff. Annual health reviews were experienced by everyone with a learning disability, in general practice settings involving both nurses and GPs. However, parents wanted to receive a copy of appointment letters as the adult with a learning disability easily forgot the appointment and the family might not be aware of the date and time. GP practices also provided most of the health promotion advice regarding smoking cessation, healthy eating and exercise to service users who were also able to describe the process of consent and knew they could say no. The general consensus across the groups was that GPs were flexible and understanding of the needs of adults with a learning disability.

There were several examples of available work opportunities all unique to the services user's particular circumstances. Some people with a learning disability said they would like to be paid for work undertaken but as they relied on their social security benefits, they could not risk losing these as they were vital to them managing in the community. The cost of transport to attend day opportunities was raised by service users and parents as an issue.

Future planning was an area that was difficult to approach for people with a learning disability and their carers. There was a low level of acknowledgment of any plans in place. Parents and carers were quite concerned that plans have not been developed and that emergency planning would be the only fall-back position when carers were ill or no longer able to manage. Other parents whose current situation was more stable reflected that they would like to commence planning for the future, although no discussions had taken place with trust staff.

Transitioning to adult services was not a recent experience for most people we interviewed, but for the few adults who had experienced this, they described being offered one choice of accommodation at resettlement. No service user interviewed described being offered two or more alternatives for either a day activity or accommodation. When children with a mild learning disability are in mainstream education, they were not identified as needing to make the transition into adult learning disability services until they finished their education. Consequently no planning and preparation was in place for these young people. A lack of structure and drift in the engagement by trusts was experienced by some carers.

Whilst the South Eastern Trust had examples of effective engagement with parents and carers, a number of parents and carers in the South Eastern Trust and Southern Trust also expressed their frustration to the review at the lack of engagement in ongoing development of learning disability services. Lack of contact and lack of support were both expressed by parents who felt that they were not being heard. Parents explained that they know their own son or daughter's needs best and found it difficult when trust staff did not take their views into consideration. Parents described being offered services that were very different and in their opinion, irrelevant to what their young person needed.

A group of parents and carers in the Southern Trust expressed dissatisfaction with communication from the trust in respect of day opportunities and respite. In Londonderry, parents and service users commented on the lack of contact with social workers. Most service users who met the review team did not have a social worker. A number were living fairly independent social lives and may not necessarily have required a social worker but stated they would value a telephone number to ring for advice if required. They believed the trust had difficulties in recruiting social workers who did not stay in employment very long.

Day centres and their satellite units were praised by service users and the parents. The staff were highly thought of and local community involvement was recognised as providing a significant contribution towards their success.

GPs highlighted that referrals made to learning disability services were managed well, however a referral to other secondary care services often required a second referral. Some adults with a learning disability did not understand the trusts' letters from partial booking systems. When no action is taken by an adult with a learning disability, because they do not know to phone the hospital to make an appointment or share the letter with someone who would understand the appointment process, they are discharged without having attended an appointment. Some concern was expressed by voluntary organisations, around the small but growing numbers of adults with a learning disability whose first language was not English, and the requirement for translators.

In Londonderry a group called Destined was very proactive in providing classes and services for a wide range of adults with learning disabilities. Activities and sports were developed for different age groups. Young adults were provided with classes and opportunities more appropriate to their age, while more mature adults had their preferred activities at alternative times of the day. Adults with a learning disability were supported to become involved in a wide range of activities across the city.

This scheme demonstrated an excellent model of community integration and also provides placements for young people who are considering a career in social work or social care services. Grant aid had been obtained from the European Union which has enabled a multiplicity of day options and services for young people with a learning disability to be developed.

Section 4: Conclusion

It is estimated that there is approximately 26,500 people with a learning disability in Northern Ireland, of whom; half are aged between zero to 19 years ¹⁹.

The Service Framework for Learning Disability was disseminated to all HSC trusts in September 2013. It contains 34 standards to provide guidance to trusts on how to improve the health and wellbeing of people with a learning disability.

This review assessed the quality of services delivered to adults with a learning disability against 30 standards. The standards relating to children will be reviewed at a later stage by RQIA. The processes established by the HSC Board to monitor and seek assurances regarding the delivery of safe, effective, compassionate and well led services were also reviewed. The review found evidence of improvements in a number of standards. In particular, the regionalisation of adult safeguarding practices, the enhancement of health promotion and screening undertaken by GPs, and the establishment of specialist teams to manage behaviours that challenge staff and carers.

In addition, a large array of creative day opportunities have been offered in place of the previous more limited choice of attendance at a day centre in each trust.

An evaluation of the effectiveness of different models of day opportunities in terms of improved outcomes for service users would be helpful regionally. Whilst there have been very welcome developments, trusts are still on an improvement journey and gaps remain in the full implementation of the standards in many areas.

Multiple information systems exist in very trust, to record activity, with a heavy reliance on paper based files. A more collaborative approach is required by trusts to develop and agree one single unified community based information system that will enable the commissioner to compare and contrast the effectiveness of outcomes in relation to the funding invested in learning disability services.

Guidance was delivered by the HSC Board in November 2014 regarding the introduction of a minimum payment rate of £10 per hour for direct payments as Northern Ireland considerably lags behind the rest of the United Kingdom. To date, only the Western Trust and the South Eastern Trust are paying this amount per hour. The review recommends this should be reviewed by the commissioner.

The uptake of carers' assessments continues to be low in Northern Ireland, as does the number of people with a learning disability in paid employment.

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¹⁹ Bamford Action Plan, Dhssps (2009-2011)

However, a number of people we spoke to expressed fear about losing their entitlement to their social security benefits.

This factor needs to be reviewed further by trusts, to ensure that people who can work daily can progress without fear into more meaningful employment opportunities.

There were examples of more consultations being held by each trust, with service users and carers, but less evidence of trusts actually developing services jointly or in direct partnership with service users, in keeping with the standard.

Transition planning between children and adult services continues to be problematic. Clearer projections of numbers and costs are required across all five trusts to identify the financial resources required to meet the known physical and behavioural needs of young people who have now entered adolescent services.

A low number of people with a mild learning disability are able to access mental health services which is not in keeping with the expectations set out in the standard.

Community learning disability teams continue to have a similar composition of professionals, as in 2013. Due to the varied range of roles, tasks, job descriptions, size and types of teams, it was difficult to compare and contrast teams for effectiveness. It is surprising given the small size of Northern Ireland, that such a variance is required to deliver essentially the same type of service provision.

Despite numerous targets being set by the HSC Board, the resettlement target of all long stay patients leaving learning disability hospitals by June 2017 may not be achieved.

The review noted a limited access to advocacy apart from those living in supported living schemes or transitioning from long stay hospitals. This inequality should be reviewed to ensure that all people who require this service can access this in the future more equitably.

In relation to the achievement of the key performance indicators contained in the service framework, the HSC Board demonstrated to RQIA that 27 of these have been fully achieved, 25 are in progress and 4 have not been achieved. The review concluded that a higher level of achievement should have been evident. Closer partnership working across trusts would have been helpful to achieve a more consistent approach to delivery of the standards across Northern Ireland.

Section 5: Recommendations

Recommendation 1

Priority 1

The commissioner should ensure effective use of resources through accountability meetings and seek evidence based improvements in learning disability services across trusts. The investment in learning disability hospital provision should also be kept under review given the current resettlement target set for achievement in 2016.

Recommendation 2

Priority 1

The Regional Learning Disability Health Care and Improvement Steering Group, set up by the Public Health Agency should ensure each trust has a plan that can demonstrate measureable evidence of health improvements for adults with a learning disability.

Recommendation 3

Priority 1

The PHA in conjunction with trusts should develop a regional dataset of information in relation to outcome measurement in 2016-2017 across two key areas to drive improvement in the health status of people with a learning disability. Targets should be considered in relation to the reporting of a reduction in smoking and obesity in the 2017-2018 year.

Recommendation 4

Priority 2

The HSC Board should set an access target for inclusion of people with a mild learning in mental health services in order to achieve the standard set up in the service framework.

Recommendation 5

Priority 2

The HSC Board should review the current models of service provision in place in the five trusts in terms of evidence of best practice and ensure that this is disseminated regionally.

Recommendation 6

Priority 2

Each trust should review the specific role of the consultant psychiatrist in their community team in terms of how best they can assist in the delivery of improvements in clinical outcomes for people with a learning disability.

Recommendation 7

Priority 2

An assessment of the activity and effectiveness of challenging behaviour teams should be undertaken by the commissioner. The outcome model used by the Northern Trust should also be reviewed to see if it could be applied regionally.

Recommendation 8

Priority 1

Each trust, as part of their Personal and Public Involvement (PPI) Strategy, should proactively involve people with a learning disability and their carers in the planning of change to service delivery or in creating new service developments.

Recommendation 9

Priority 2

The commissioner should review the regional disparity in the uptake of direct payments and continue to monitor the consequences of trusts paying below the directed standard rate.

Recommendation 10

Priority 1

The Department of Health should review the appropriateness of NISAT for use within adult learning disability services and issue guidance to trusts in respect of the trusts' use of this tool to assess needs regionally.

Recommendation 11

Priority 3

The regional informatics group should consider and agree how best to capture information in a single unified regional IT solution, to ensure meaningful planning and consistency of reporting on learning disability services and outcomes across the five trusts.

Recommendation 12

Priority 2

Each trust should annually update their directories of services for people with a learning disability to ensure they provide information about current services.

Recommendation 13

Priority 3

Each trust should evaluate the benefits and effectiveness of outcomes for adults with a learning disability of the various models of day care and day support. This should be reviewed by the HSC Board regionally in terms of their future commissioning plan for day care and day support services.

Recommendation 14

Priority 3

Each trust, as large employers should, as part of their organisational development strategies, seek to provide a model of positive discrimination by promoting more employment opportunities for people with a learning disability.

Recommendation 15

Priority 1

Each trust involved in making transition arrangements should ensure that they follow legislative requirements and best practice standards and that the criteria for the continuity of service provision are made clear to people with a learning disability and their carers.

Recommendation 16

Priority 3

Each trust should carry out an assessment of the needs of school leavers over the next five-year period to enable financial projections to be made for the increased resources required to maintain adults with a learning disability in the community adequately.

Recommendation 17

Priority 2

The HSC Board, supported by the five trusts, should review the models of best practice in preventing hospital admissions and consider the feasibility of developing a pilot of a regional crisis admission house.

Recommendation 18

Priority 3

Each trust should review the impact of the transfer of people to other trust areas in relation to the consequences for their learning disability team's infrastructure, the cost to the receiving trust and the possible disruption to family relationships and share their findings with the HSC Board.

Recommendation 19

Priority 1

The carer coordinator in every trust should report to the HSC Board about the reasons given by carers specifically not wishing to progress with a carer's assessment. The HSC Board should consider if any further action should be taken by trusts to increase the uptake of assessment.

Recommendation 20

Priority 2

Each trust should monitor and ensure that effective future planning is taking place and monitor crisis admissions to care annually and disseminate any lessons for learning.

Recommendation 21

Priority 3

Each trust should review their investment in advocacy services and ensure it is available to a wider group of people, other than just those involved predominately in resettlement from hospital.

Recommendation 22

Priority 1

Each trust should have an identified area on their website for people with a learning disability which has more easily accessible information in terms of easy to read material with more use of signs / symbols for ease of access to information.

Recommendation 23

Priority 2

The formulation of annual learning disability service development plans in trusts should be consistently underpinned by the standards set out by DoH in the Service Framework for Learning Disability.

Recommendation 24

Priority 3

The DoH should assess the progress and the implementation of the standards contained in the Service Framework for Learning Disability.

Recommendation 25

Priority 1

Each trust should produce action plans to demonstrate how they meet the KPIs in the Service Framework for Learning Disability and present this to their Trust Board for monitoring and to evidence their demonstration of improvement.

Glossary

BPS - British Psychological Society

BSS - Behaviour Support Service

CLDT - Community Learning Disability Teams

DEL - Department for Employment and Learning

DES - Directed Enhanced Services

DHSSPS - Department of Health Social Services and Public Safety

DoH – Department of Health

DSD - Department for Social Development

EPEX – Electronic Information database

GMS - General Medical Services

GP - General Practitioner

HSCB - Health and Social Care

KPIs - Key Performance Indicators

LCID – Local Community Information Database

NIHE - Northern Ireland Housing Executive

NISAT - Northern Ireland Single Assessment Tool

OT – Occupational Therapist

PARIS - Patient Record Information System

PBSS - Positive Behaviour Support Services

PHA – Public Health Agency

RAID - Rapid Assessment Intervention and Discharge

RCP - Royal College of Psychiatrists

SLT – Speech and Language Therapist

TILII - Tell It like It Is (An ARC advocacy group)

TYC - Transforming Your Care

References

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McGill, P., Cooper, V. & Honeyman, G. (2010) Developing better commissioning for individuals with behaviour that challenges services - a scoping exercise Canterbury/Chatham: Tizard Centre/Challenging Behaviour Foundation.

DHSSPS (2015) Service Framework for Learning Disability. Belfast: DHSSPS.

United Nations. Convention on the Rights of Persons with Disabilities. Ratified by UK 2009.

Table A1: The number and percentage of people in receipt of various social care services in 2013-2014

Supported accommodation	Belfast	Northern	South Eastern	Southern	Western	Total
Residential /	313	282	281	234	253	1363
Nursing Home						
% in Residential /	17	15	19	12	23	16
Nursing Homes						
Supported Housing	238	265	234	243	129	1109
% Supported Housing	13	14	15	12	12	13

Note percentages are calculated as a proportion of the total number people in receipt of social care service.

Table A2: The number and percentage of people using day services 2013-2014

Day Services	Belfast	Northern	South Eastern	Southern	Western	Total
Day Centres	673	823	696	509	680	3381
% use day centres	37	43	46	26	63	41
Day Opportunities	604	542	402	402	295	2245
% day opportunities	33	28	27	20	27	27
Total Day Services	1277	1365	1098	911	975	5626
% day service	70	71	72	46	90	68

Table A3: The number and percentage of people in receipt of family support services in 2013-2014

Family Support Services	Belfast	Northern	South Eastern	Southern	Western	Total
Short breaks	470	563	406	515	177	2131
% short breaks	26	29	27	26	16	26
Domiciliary Care	167	179	459	530	162	1497
% domiciliary care	9	9	30	27	15	18
Direct Payments	201	148	101	132	91	673
% Direct Payments	11	8	7	7	8	8

Standards from the Service Framework for Learning Disability grouped by RQIA's four key stakeholder outcomes.

Table A4: Standards reviewed relating to SAFE care

Standard	
1	All HSC staff should ensure that people of all ages are safeguarded from harm through abuse, exploitation or neglect.
19	All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.
20	All HSC staff, as appropriate, should advise people who smoke of the risks associated with smoking and signpost them to well- developed specialist smoking cessation services.
21	All people with a learning disability should be supported to achieve optimum physical and mental health.
22	All people with a learning disability who experience mental ill health should be able to access appropriate support.
23	All HSC staff, as appropriate, should provide people with healthy eating support and guidance according to their needs.
24	All HSC staff, as appropriate, should provide support and advice on recommended levels of physical activity.
25	All HSC staff, as appropriate, should provide support and advice on recommended levels of alcohol consumption.

Table A5: Standards reviewed relating to EFFECTIVE care

Standard	
2	People with a learning disability should as a matter of course make choices or decisions about their individual health and social care needs. These needs to be balanced with the individual's ability to make such decisions and then the views of their family, carers and advocates should be taken into account in the planning and delivery of services, unless there are explicit and valid reasons to the contrary agreed with the person.
3	All patients, clients, carers and the public should have opportunities to be actively involved in the planning, delivery and monitoring of health and social care at all levels.
14	Young people with a learning disability should have a transition plan in place before their 15th birthday and arrangements made for their transition to adulthood by their 18 th birthday.
16	Adults with a learning disability should be able to access support in order that they can achieve and maintain employment opportunities in productive work.
17	All adults with a severe or profound learning disability should be able to access a range of meaningful day opportunities appropriate to their needs.
26	All people with a learning disability whose behaviour challenges should be able to get support locally from specialist learning disability services and other mainstream services, as appropriate, based on assessed need.
28	HSC professionals should work in partnership with a variety of agencies in order to ensure that the accommodation needs of people with a learning disability are addressed.
31	All people with a learning disability should have the impact of ageing taken into account in having their future needs assessed and proactively managed.
32	All people with a learning disability should have access to dementia services at whatever age it becomes appropriate for the individual.

Table A6: Standards reviewed relating to COMPASSIONATE Care

Standard	
4	Adults with a learning disability should be helped by HSC professionals to develop their capacity to give or refuse informed consent.
5	All patients, clients, carers and the public should be engaged through effective communications by all organisations delivering health and social care.
6	People with a learning disability should expect effective communication with them by HSC organisations as an essential and universal component of the planning and delivery of health and social care.
7	People with a learning disability should receive information about services and issues that affect their health and social wellbeing in a way that is meaningful to them and their family.
8	People with a learning disability, or their carer, should be able to access self-directed support in order to give them more control and choice over the type of care and support they receive.
9	Service users and their carers should have access to independent advocacy as required.
15	People with a learning disability should be supported to have meaningful relationships, which may include marriage and individual, unique, sexual expression within the law, balancing their rights with responsibilities.
18	All parents with a learning disability should be supported to carry out their parenting role effectively.
27	All people with a learning disability who come into contact with the Criminal Justice System should be able to access appropriate support.
29	All HSC staff should identify carers (whether they are parents, family members, siblings or friends) at the earliest opportunity to work in partnership with them and to ensure that they have effective support as needed.
30	All family carers should be offered the opportunity to have their needs assessed and reviewed annually.
33	All people with advanced progressive incurable conditions, in conjunction with their carers, should be supported to have their end of life care needs expressed and to die in their preferred place of care.
34	All people with a learning disability being assessed for supportive and palliative care should have their learning disability taken into account in consultation with them, their carers and learning disability services when appropriate.

Table A7: Muckamore Abbey Hospital Indicative Beds and the number of patients still awaiting resettlement into the community

Indicative position	Wards -	Total - Inpatient Beds			
		2013 -	1 April	31 March	
		2014	2015	2016	
Core Treatment	CP Cranfield (PICU)	6	6	6	
Phase 1	CM Cranfield (Men)	14	14	14	
	CM Cranfield (Women)	15	15	15	
	Sixmile (Assessment)	3	3	3	
	Sixmile (Treatment)	16	16	16	
	Donegore	9	9	9	
	Killead	24	24	24	
Total Muckamore As	87	87	87		
Children's Services, under 18	Iveagh Centre	8	8	8	
TOTAL Assessment & Treatment Beds		95	95	95	
MAH -Resettlement	Erne	10	17	21	
	Greenan	15	0	0	
	Moylena	19	16	7	
	Ennis	15	0	0	
	Rathmullan	12	0	0	
	Oldstone	23	3	0	
Total Muckamore Re	esettlement Beds	94	36	28	

Table A8: Southern Trust Learning Disability Hospital Beds

Assessment &	Dorsey	10	10	10
treatment				

Table A9: Western Trust Learning Disability Hospital Beds

Assessment & treatment & PICU	10	12	8

RQIA Published Reviews

Review	Published
Review of the Lessons Arising from the Death of Mrs Janine Murtagh	October 2005
RQIA Governance Review of the Northern Ireland Breast Screening	March 2006
Programme	
Cherry Lodge Children's Home: Independent Review into Safe and	September 2007
Effective Respite Care for Children and Young People with Disabilities	
Review of Clinical and Social Care Governance Arrangements in	February 2008
Health and Personal Social Services Organisations in Northern Ireland	,
Review of Assessment and Management of Risk in Adult Mental	March 2008
Health Services in Health and Social Care Trusts in Northern Ireland	
Reducing the Risk of Hyponatraemia When Administering Intravenous	April 2008
Infusions to Children	
Clostridium Difficile – RQIA Independent Review, Protecting Patients –	June 2008
Reducing Risks	
Review of The "Safeguards in Place for Children And Vulnerable	June 2008
Adults in Mental Health and Learning Disability Hospitals" in HSC Trust	
Review of the Outbreak of Clostridium Difficile in the Northern Health	August 2008
and Social Care Trust	_
Review of General Practitioner Appraisal Arrangements in Northern	September 2008
Ireland	
Review of Consultant Medical Appraisal Across Health and Social Care	September 2008
Trusts	
Review of Actions Taken on Recommendations From a Critical Incident	October 2008
Review within Maternity Services, Altnagelvin Hospital, Western Health	
and Social Care Trust	
Review of Intravenous Sedation in General Dental Practice	May 2009
Blood Safety Review	February 2010
Review of Intrapartum Care	May 2010
Follow-Up Review: Reducing the Risk of Hyponatraemia When	July 2010
Administering Intravenous Infusions to Children	
Review of General Practitioner Out-of-Hours Services	September 2010
RQIA Independent Review of the McDermott Brothers' Case	November 2010
Review of Health and Social Care Trust Readiness for Medical	December 2010
Revalidation	
Follow-Up Review of Intravenous Sedation in General Dental Practice	December 2010
Clinical and Social Care Governance Review of the Northern Ireland	February 2011
Ambulance Service Trust	
RQIA Independent Review of Child and Adolescent Mental Health	February 2011
Services (CAMHS) in Northern Ireland	
A Report on the Inspection of the Care Pathways of a Select Group of	March 2011
Young People who Met the Criteria for Secure Accommodation in	
Northern Ireland	
An Independent Review of Reporting Arrangements for Radiological	March 2011
Investigations – Phase One	

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Review	Published
Review of Actions Taken in Response to the Health and Social Care	August 2014
Board Report Respite Support (December 2010) and of the	
Development of Future Respite Care/Short Break Provision in Northern	
Ireland	
Child Sexual Exploitation in Northern Ireland - Report of the	November 2014
Independent Inquiry	
Discharge Arrangements from Acute Hospital	November 2014
Review of the Implementation of the Dental Hospital Inquiry Action Plan 2011	December 2014
Review of Stroke Services in Northern Ireland	December 2014
Review of the Implementation of GAIN Guidelines on Caring for People with a Learning Disability in General Hospital Settings	December 2014
Baseline Assessment of Access to Services by Disadvantaged Groups in Northern Ireland (Scoping Paper)	December 2014
RQIA Quality Assurance of the Review of Handling of all Serious	December 2014
Adverse Incidents Reported between January 2009 and December	
2013	
Review of the Care of Older People in Acute Hospitals	March 2015
Review of the Diabetic Retinopathy Screening Programme	May 2015
Review of Risk Assessment and Management in Addiction Services	June 2015
Review of Medicines Optimisation in Primary Care	July 2015
Review of Brain Injury Services in Northern Ireland	September 2015
Review of the HSC Trusts' Arrangements for the Registration and Inspection of Early Years Services	December 2015
Review of Eating Disorder Services in Northern Ireland	December 2015
Review of Advocacy Services for Children and Adults in Northern Ireland	January 2016
RQIA Review of the Implementation of the Palliative and End of Life Care Strategy (March 2010)	January 2016
Review of Community Respiratory in Northern Ireland	February 2016
An Independent Review of the Northern Ireland Ambulance Service	March 2016
RQIA Review of HSC Trusts' Readiness to comply with an Allied	June 2016
Health Professions Professional Assurance Framework	
Review of Quality Improvement Systems and Processes	June 2016
RQIA Review of Governance Arrangements Relating to General	July 2016
Practitioner (GP) Services in Northern Ireland	
RQIA Review of the Operation of Health and Social Care	September 2016
Whistleblowing Arrangements	



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