The **Regulation** and
Quality Improvement
Authority

A Baseline Assessment and Review of Community Services for

Adults with a Learning Disability

August 2013

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 are designed to identify best practice, to highlight gaps or shortfalls in services requiring improvement and to protect the public interest. Our reports are submitted to the Minister for Health, Social Services and Public Safety and are available on the RQIA website at www.rqia.org.uk.

RQIA would sincerely thank everyone for their openness, honesty and their willingness to engage with us. We will continue our engagement during the second phase of this review, which is scheduled to commence in 2014/15.

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Executive Summary

RQIA, as part of the three year review programme, planned an initial baseline review of the composition and function of community learning disability teams. The review looked at the services provided across the five health and social care (HSC) trusts in Northern Ireland, both for adults with a learning disability and children with a disability.

This report sets out the position in relation to community services for adults with a learning disability. A separate report is available in relation to children with a disability.

In Northern Ireland there are approximately 26,500[1] people with a learning disability of whom about half are aged between 0-19 years[2]. People with a learning disability should be able to access a person centred, seamless community service, in the right place, at the right time and informed by the views of service users and carers.

The review team met with trust staff from community based teams, the Health and Social Care Board (HSC Board), the Department of Health, Social Services and Public Safety (DHSSPS), other voluntary and charitable bodies involved in providing services, and with a number of service users and their families.

The review team noted that trusts have reduced the need for hospital based care by progressing the resettlement of patients into more personalised services in the community. The slow rate of progress with resettlement into the community has been influenced by inadequate funding and competition with other programmes for access to additional investment in community care.

It was difficult to obtain clear and accurate financial data from trusts, in relation to expenditure on adult services, as staff often work across community teams working with both adults with a learning disability and children's disability services. In 2010-11 the five HSC trusts spent over £30million on the provision of both these services.

The review team commented on the variation in team structures across each trust and how individual professionals are deployed within teams. Several professionals continue to provide lifespan cradle to grave services to this specific client group, contrary to the national driver for a more integrated pattern of service delivery across primary care especially. The overall model of community services for adults was delivered mostly by teams of social workers and specialist community learning disability nurses, assisted by allied health professionals and clinical psychology staff.

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[1] NB: Equal lives applied an incident rate of 1.5% to the overall population which includes a substantial number of children who may not seek HSC services, although they may seek services from education.
[2] Delivering the Bamford Vision, June 2009. DHSSPS. Actual figure, not published figure, from 2009, confirmed by DHSSPS on 29-07-2013

Four trusts had developed specialised services for managing challenging behaviour, and three had developed specialist teams to work with offenders, referred by the courts. There was limited evidence of a tiered model of intervention being delivered due, in large measure, to the blurring and duplication of roles and responsibilities of those employed in community services. The review team found that all of the trusts had relied on informal networking rather than using clear clinical pathways and well developed interfaces between services. There was evidence of the development and use of key performance indicators and outcome measures. These were developed mostly by smaller specialist teams, led either by clinical psychologists or speech and language therapists, to help assess the clinical effectiveness of their services.

Psychiatrists worked mostly in the learning disability hospitals. The review team found little evidence of psychiatrists working as full members of community based teams in any of the five trusts. The role of the consultant psychiatrist is largely restricted to a clinical role, rather than providing clinical leadership in developing or influencing assessment and treatment strategies in the community.

The review team found there was widespread exclusion of people with a learning disability from mental health services and services for older people. An almost total exclusion of people with a learning disability from newly established autism services within trusts was noted.

The review team found evidence of good practice in relation to the development of information packs by speech and language therapy staff, referred to as communication passports in the Belfast and South Eastern trusts. These contain important information about the person, such as their health and social care difficulties, likes and dislikes, and any medication they may be taking. They also assist hospital staff to provide better care for the person. Health facilitators were also appointed to organise health promotion screenings by GP practices.

There was evidence of some sharing of good practice between trusts in relation to supported housing options for people with a learning disability. The review team considered that it would be helpful if trusts could share learning from evaluations of new models of service provision in the community, of which there are a growing number of examples in Northern Ireland, as well as nationally.

The review team believes that the HSC Board should use this report to facilitate a better understanding of the needs of adults with learning disabilities and their families. They should ensure that the most suitable and equitable range of service provision is in place to meet current and future needs. There was limited evidence of the use of caseload weighting or benchmarking across the community teams. However, the Southern Trust has a new initiative in the early stages of development. All of the teams visited reported high levels of bureaucracy and crisis management.

The adult learning disability teams did not have clear measures in place to gauge the effectiveness of interventions with service users and carers, or consistent and tangible ways of obtaining service user or carer feedback. The review team noted a reliance on the recording of interventions, with less focus on outcomes for users and family carers. There was evidence of user engagement emerging across the five trusts. Some carers raised concerns about a lack of clear information about services and frustration caused by delays in accessing some services for example day care opportunities and respite care.

A reliance on inpatient care in specialist hospitals was evident, along with the lack of effective community based alternatives, such as extended hours of service, or home treatment services. This has resulted in consequential delays in the discharge of some patients.

The change in responsibility to the local commissioning groups (LCGs) provides an opportunity for focussing on prevention and ensuring safe and sustainable services, which respond effectively to population need. Moreover the new Learning Disability Service Framework[3], launched September 2012, (DHSSPS) builds on the work undertaken by the Bamford Review[4]. It sets out guidance on the core standards applicable to all trusts. Some critical decisions are required by the HSC Board in terms of when and how these standards can be fully implemented.

The future commissioning of services needs to be undertaken within a framework of formal evidence based practice guidance about the standards and outcomes, as set out in the DHSSPS Service Framework for Learning Disability. This development would help provide a context for rebalancing the existing workforce, as well as identifying priorities for investment.

All trusts continue to report unmet needs; for respite services; dementia services; home treatment; crisis response teams and advocacy services; as set out in the HSC Commissioning Framework. This report should be used by the HSC Board to inform future commissioning of services. At the time of the review, plans were only at an early stage in relation to the targeting of investment in additional community based services. The provision of funding by 2015 to meet hospital resettlement targets and the aging profile of family carers needs to continue to be prioritised by the HSC Board.

It is critical that the HSC Board ensures that information is gathered consistently about the clinical and social needs of adults with a learning disability. The HSC Board should also complete a profile of each trust, regarding the effectiveness and efficiency of service delivery which should include a review of staff roles and team working. The level of investment in workforce skills and management of clinical networks should be reviewed by HSC Board in order to ensure a more equitable service is delivered by community staff.

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[3] Learning Disability Service Framework, September 2012. Belfast, DHSSPS.
[4] The Bamford Review of Mental Health and Learning Disability, 2007

The review team found it difficult to obtain a clear vision from trust staff about the best configuration of teams and structures to meet identified and future needs. Many of the challenges set out in this report are as a result of long-established cultures and practices. Each trust will require to develop effective partnerships coupled with determined leadership before sustainable transformation can emerge.

The review team acknowledge that a considerable number of changes and improvement may have occurred since April 2011.

1.0   Introduction

1.1   Background to the Review

The formal definition of people with a learning disability, Equal Lives (DHSSPS, 2005) is as follows:

"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."[5]

As a consequence, the individual is likely to experience difficulty in understanding new or complex information or learning new skills. The individual may also have difficulties with social and/or communication skills, with carrying out activities of daily living independently, and may have associated physical and sensory disabilities.

In Northern Ireland around 26,500 people have a learning disability, of whom about half are aged between 0 – 19 years[6] The Equal Lives report described the prevalence of learning disability in Northern Ireland as "difficult to secure" and asserted that the often quoted figure of around two per cent of the population is likely to reflect overall prevalence rather than service need. Less than four per cent of people with a learning disability are in hospitals, the majority live with family carers (66 per cent) and another 30 per cent in community-based accommodation (McConkey et al., 2003).[7]

 People with learning disabilities are more likely to experience admission to acute hospitals than the general population. This is due to higher rates of, and vulnerability to, specific health conditions, increasing longevity, with the inevitable diseases of old age, for example dementia. It has also been projected that the number of people with a learning disability will increase by one per cent each year over the next 15 years, and that the number of children and older adults with complex physical health needs will both be large areas of growth (DHSSPS 2005)[5]. This is due to increasing life expectancy, advances in medical care, more mothers giving birth later, and increased survival rates of "at risk" infants due to improved healthcare.

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

A stated objective of the Equal Lives report is to "secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services, that are as locally based as

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[5] Equal Lives DHSSPS, 2005.
[6] Bamford Action Plan, DHSSPS, 2009
[7] McConkey et al 2003. Equality and Inequalities in Health and Social Care in Northern Ireland (DHSSPS 2004).

possible and responsive to the particular needs of people with a learning disability". This objective is underpinned by 14 recommendations for service improvements. Furthermore, specific legislation, including the Human Rights Act (1998)[8] and the Disability Discrimination Act (1995) [9] have highlighted the legal requirement to ensure equality, dignity and autonomy is afforded to service users. These statutes require that reasonable adjustments are made to ensure that services do not unlawfully discriminate against people with learning disabilities, and include the provision of accessible information.

Access to primary and secondary healthcare services for people with learning disabilities has been reflected in a number of reports and inquiries. National Patient Safety Agency (NPSA) (2004) [10] report, "Understanding the Patient Safety Issues for people with learning disabilities" highlighted that care of people with a learning disability in general hospitals was a major safety concern.

Within Northern Ireland a number of research projects such as Promoting Access[11] and Patient People[12], together with research specifically into access to accident and emergency services[13], have also identified major challenges in accessing general healthcare for people with learning disabilities.

The DHSSPS response to 'Delivering the Bamford Vision' (2008)[14] stated, "the Northern Ireland Executive accepts the thrust of the recommendations", and set out proposals to take the recommendations forward over the next 10 to 15 years. This envisages a model of community based care in which no one remains in hospital unnecessarily and people with a learning disability enjoy the maximum quality of life possible, consistent with their needs.

There have been a number of drivers for the modernisation, reform and restructuring of traditional models of community learning disability services. A traditional model of service provision consists of generic social service departments undertaking specialist functions with a range of services provided by social workers, nurses, psychologists and speech and language therapists.

Transforming Your Care (TYC) 2011[15] sets out a summary of key proposals, including a commitment to closing long stay institutions. TYC states that "By 2015, anyone with a learning disability is promptly and suitably treated in the community and no one remains unnecessarily in hospital."

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[8] Human Rights Act, 1998
[9] Disability Discrimination Act, 1995
[10] The National Patient Safety Agency (NPSA), 2004
[11] Barr, O. (2004) Promoting Access: The experience of children and adults with learning disabilities and their families/carers who had contact with acute general hospitals in the WHSSB Area and the views of the nurses in these hospitals. A reported prepared for the WHSSB.
[12] Southern Health and Social Care Council (2008) Patient People: Experiences of adults with a learning disability as hospital in-patients in Craigavon Area Hospital and Daisy Hill Hospital. SHSCC, Lurgan.
[13] Sowney, M., Barr, O. (2007) The challenges for nurses within the accident and emergency care service communicating with and gaining valid consent from adults with intellectual disabilities. Journal of Clinical Nursing. 16 (9): 1678-1686
[14] Delivering the Bamford Vision DHSSPS, 2008.
[15] Transforming Your Care (A Review of Health and Social Care in Northern Ireland) DHSSPS, 2011.

This report presents a baseline assessment of the role and composition of community learning disability teams and teams for adults with a learning disability across the five trusts. It highlights the baseline level of investment in these services as at 1 April 2011. The review also provides information about access to and provision of learning disability services across community teams for adults with a learning disability and children with a disability (as at 1 April 2011). A separate report is available in respect of children with a disability. The adult report indicates the types of transitional arrangements in place for moving between adult services, the type of engagement and communication with service users and the information database systems in use. The report also provides information on unmet need for community services for adults with a learning disability.

1.2   Terms of Reference

The terms of reference for this review were agreed as follows. The review would be undertaken in two stages.

Phase 1 - (2011-12) a baseline assessment of teams for adults with a learning disability and children with a disability and service provision as at 1 April 2011.

Phase 2 - (2014-15) an assessment of the quality and effectiveness of trusts' Learning Disability Services for adults, against the DHSSPS's Learning Disability Service Framework.

The review excluded services that are currently regulated by RQIA, as outlined in the list below:

- Adult Placement Agencies
- Day Care Settings
- Domiciliary Care Agencies

- Supported Living Services
- Independent Hospitals
- Nursing Agencies

- Nursing Homes
- Residential Care Homes
- Independent Clinics

1.3 Membership of The Review Team

Ashok Roy	-	Consultant Psychiatrist, Coventry and Warwickshire Partnership Trust
Theresa Nixon	-	Director of Mental Health, Learning Disability and Social Work, RQIA
Patrick Convery	-	Head of Mental Health and Learning Disability, RQIA
Audrey Murphy	-	Inspector, Learning Disability, RQIA
Jill Munce	-	Complaints Manager, RQIA
David Philpot	-	Project Manager, RQIA
Janine Campbell	-	Project Administrator, RQIA
Professor Roy McConkey	-	Advisor to the Project Organisational Team

1.4 Methodology

All five HSC trusts were asked to complete a self-assessment questionnaire to provide information on the:

- role and compositon of learning disability community services for adults
- profile of staff and the level of investment in the community teams
- provision of learning disability services, across community teams for adults with a learning disability (as at 1 April 2011)
- information database systems
- carers' assessment and direct payments
- engagement and communication with service users
- transitional arrangements between children and adult learning disability services
- information on unmet need for community services for adults with a learning disability.

For each trust, RQIA met with a team providing front line services. A second team was asked to evidence models of current good practice.

Validation visits were made to each of the five trusts. Meetings were held with members for staff who provided adult learning disability services, and presentations were made by the teams (chosen either by their specialty or locality).

The review team also met with representatives of the HSC Board with lead responsibility of learning disability services, and with the DHSSPS.

Meetings were held by the review team with service users and their families before, during and after the visits to trusts to obtain their views about service provision.

2.0 Role and Composition of Community Learning Disability Teams and Profile of Investment in Staff across the Five Trusts

The Equal Lives report[16] (DHSSPS, 2005) of the Bamford Review observed: "The concept of a Community Learning Disability Team has been a feature of learning disability services in the UK since the 1970s. Traditional models of service delivery have consisted of generic social services departments undertaking specialist functions and providing a range of health and social services.

The form and function of these teams varies widely and there has been very little research undertaken into the effectiveness of the various models, despite the fact that they are an expensive component of health and social services provision"

Since the previous DHSSPS review of learning disability services[17] in 1995, community services for those with a learning disability have evolved in response to changes in policy, legislation and identified needs.

The HSC Board, in its Commissioning Plan 2011-12[18], set out an expectation that community learning disability teams will provide community based assessment and treatment services, comprising of psychiatry, learning disability nursing, allied health professionals (AHP) and social work inputs. The HSC Board Commissioning Plan also sets out targets with regard to the resettlement of patients currently in long-stay hospital placements.

The aims and scope of community learning disability services are as follows:

- to support individuals with a learning disability
- to support the carers of individuals with a learning disability
- to support staff and other carers involved in the lives of individuals with a learning disability
- to provide information and support to the wider community, including primary care professionals

As part of the RQIA review, health and social care trusts were asked to describe their current community teams, outlining their core functions, the type of services provided, and management/leadership arrangements. Table A2 in Appendix 2 provides a summary of the responses received. A number of different structures exist for adult learning disability teams, with evidence of collaborative working.

The review team noted that the structure of community teams providing services to people with a learning disability is changing across Northern Ireland. These changes have occurred in the context of the Review of Public

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[16] Equal Lives, DHSSPS, 2005
[17] Review of Policy for people with a Learning Disability in Northern Ireland. Belfast: DHSS, 1995
[18] HSC Board Public Health Agency Commissioning Plan 2011-12. November 2011

Administration (RPA), resulting in mergers of trusts and reorganisation of service provision.

All trusts, at the time of the review, had maintained the teams which existed within the former legacy trusts, consisting mostly of social workers and learning disability nurses, with occupational therapists included as part of the teams in the Belfast, Northern and Southern trusts.

Four trusts had created challenging behaviour teams and three - the Belfast, Southern and Northern trusts, provided a specialist forensic team who work with people with a learning disability referred by the court.

The review team found that community learning disability services for adults fulfil a number of functions in relation to facilitating access to a range of services, from primary care through to the provision of highly specialised care. Service users should be able to step up or step down the care pathway according to their changing needs and in response to treatment. A stepped care model would normally consist of 1 to 4 tiers. Tier 1 services would provide the least intervention, tiers 2 and 3 providing more specialist community assessments and interventions, and tier 4 providing inpatient assessment and treatment services.

The review team noted various initiatives had taken place to develop a stepped care model of provision. However, this type of service model was not always clearly understood by staff. Transforming Your Care (DHSSPS, 2011) makes a number of recommendations in relation to the quality and accessibility of services for individuals with a learning disability in the community and states "tangible services on the ground are the touchstone by which those using the service judge its success"[19]. During the review a number of families described community services as fragmented. Some families reported having inputs from a variety of team members but did not always understand the role, task and function of the different team members.

The review team considered that trusts have a considerable way to go to ensure that the service improvements required under Transforming Your Care are fully achieved.

2.1   Profile of Investment in Staff Teams for Adults with a Learning Disability

Information was requested on the numbers of staff in post at 1 April 2011 for each grade within the various disciplines; along with the total gross salary costs (inclusive of employer's costs) (see Table 1).

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[19] Transforming Your Care (A Review of Health and Social Care in Northern Ireland) DHSSPS, 2011.

Table 1: The Total Amount of Funding across Staff Disciplines in 2010-2011 in Community Teams for Adults with a Learning Disability across the Five HSC Trusts

Discipline	Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust	Northern Ireland Total
Social workers and care management[1]	£1,288,000	£1,320,268	£893,600	£1,115,000	£728,000	£5,344,868
Community LD Nursing and Health Facilitators	£290,000	£722,292	£413,000	£650,000	£426,000	£2,501,292
Occupational Therapy	£118,000	£323,500	£83,000	£355,000	£52,000	£931,500
Speech and Language Therapy	£180,000	£252,000	£251,000	£216,000	£83,000	£982,000
Physiotherapy	£121,000	£245,000	£49,000	£183,000	£79,708	£677,708
Clinical Psychology	£115,000	£215,800	£234,000[4]	£141,789[4]	£70,500[4]	£824,352
Challenging Behaviour Services	£342,000	£391,889	£129,000[4]	£177,117[4]	£133,500[4]	£1,232,545
Psychiatry	£139,000	Not supplied	(£158,000)[3]	£106,785[4]	£218,000	£499,380[5]
Other specialist services[2]	£250,227	£99,000	-	£174,920	-	£524,147
Community support workers	£128,000	Included in Social Work	-	£293,899	-	£421,899
Management and Administration	£254,487	£133,477	£118,297	£144,084	£189,554	£839,899
Total reported by trust	**£3,225,714**	**£3,703,226**	**£2,170,987**	**£3,557,594**	**£1,980,262**	**£14,637,693**

A blank cell indicates that the trust made no report but it does not necessarily mean that no service of that type is provided. (Details of whole time equivalent (WTE) staffing is contained in Appendix 1 of this report)

[1] Social work costs includes team leaders and care management. Some trusts reported separately on these categories of staff.
[2] Certain trusts had developed other specialist services such as forensic psychology and for mental health and learning disability.
[3] The South Eastern Trust provided this as an estimate although the budget is with the Belfast Trust through Muckamore Abbey Hospital. (This arrangement also applies to the Northern Trust although no estimate of costs was provided). This amount is not included in the trust's total costs.
[4] For the South Eastern Trust and the Western Trust these costs have been apportioned 50/50 with Children's services and in the Southern Trust the apportionment is 75% adult: 25% children. However, the monies may sit within one budget within the trust.
[5] These costs would rise to £821,725 if the estimate cost for South Eastern Trust is included in the total and a pro rata amount of the average costs across four trusts in added in for the Northern Trust.

Figure 1: The Percentage Total Spend on Professionals Providing Community Services for Adults with a Learning Disability across the Five HSC Trusts
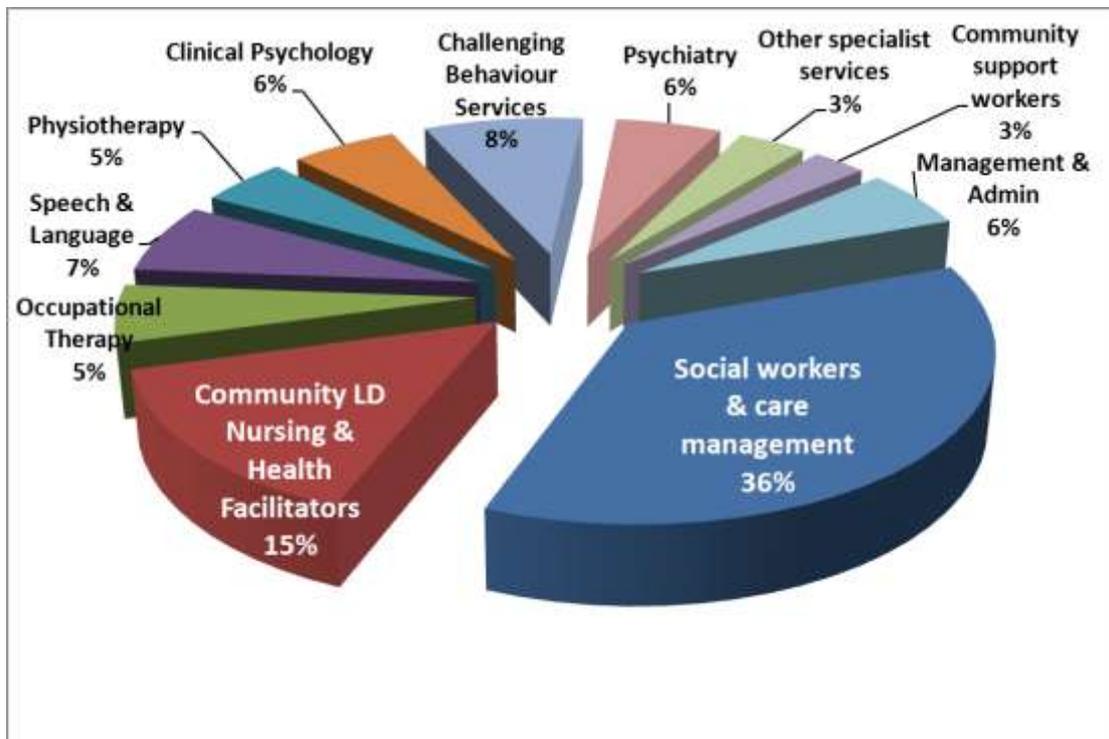

Figure 1 illustrates the percentage of total spend by discipline for Northern Ireland as a whole. (NB the costs for psychiatry have been calculated on a pro rata basis across the five trusts). This indicates that social workers accounted for over one third of the spend, followed by community learning disability nursing at 14 per cent. The three allied health professional therapists along with clinical psychology and challenging behaviour services, account for a further 33 per cent, with four per cent is spent on other specialist services and community support workers. The psychiatry costs, at three per cent, may be an underestimate of the amount expended in direct community services, as a component may be included within specialist hospital costings. Likewise, the management costs (at six per cent) are related to the direct management and administration costs of community services and do not include other support service such as human resources and finance.

2.2   Comparisons across the Trusts

Spending on services for adults with a learning disability across the five HSC trusts was calculated as an amount per adult (aged 20 to 64 years inclusive) within the overall trust population (see Appendix 2 Table A3). The adult populations are the actual numbers from census data and are not weighted populations based on deprivation indices. These calculations are based on 2010 mid-year estimates.

Table A3 in Appendix 2 illustrates the variation in terms of gross expenditure by disciplines within trusts. The total per capita spend on adult learning disability services is highest in the Southern and Belfast Trusts and lowest in the South Eastern Trust.

The review team made the following observations from the analysis of this data:

- The Belfast Trust spends proportionately more on social workers and care managers per head of population, whereas the Southern Trust concentrated its investment more heavily in community nursing staff with a learning disability specialism or community learning disability nurses.
- All of the trusts spend more on social work and nursing staff than all the other disciplines combined.
- The South Eastern Trust had a higher spend on speech and language therapy services per head of adult population than other trusts, nearly three times more per capita than the Western Trust, which had the least expenditure on speech and language therapy services to support adults with communication needs.
- Trust expenditure on occupational therapy funding was variable, with the Western Trust at less than half of the Belfast Trust and less than a fifth of that spent by the Southern Trust.
- The Belfast and Northern trusts spend significantly more on challenging behaviour services, with the South Eastern Trust spending least on this service, although this is compensated by a higher spend on clinical psychology which is highest in the South Eastern Trust and lowest in the Western and Northern trusts.

These calculations can be further refined by considering the distribution of adults with a learning disability reported by the trusts to be in receipt of services from community teams in 2010-11. This is given in Table 2 along with the percentage of the overall adult population (aged 20 to 64 years inclusive). The table also gives the total per capita spend for each person with a learning disability reported by the trust to have received services.

Table2: The Number of Adults in Receipt of Services from Community Learning Disability Teams in 2010-11 and the Total per Capita Spend per Person.

	Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust	Northern Ireland Total
Number of adult persons with a learning disability	1609	1989	1551	1660	1156[1]	7965
Adult population of trust	198,119	268,698	203,794	210,587	176,799	1,057,997
Number of persons with LD per 1,000	8.12	7.4	7.61	7.88	6.54	7.53
Total spend on LD	£3,225,714	£3,703,226	£2,170,897	£3,557,594	£1,980,262	£14,637,693
Per capita spend for persons with LD	£2,004	£1,862	£1,400	£2,143	£1,713	£1,838

[1] An additional 104 cases were known to the trust but were unallocated. If included in the total this would bring the rate per 1,000 to 7.13.

Table 2 denotes the range and variation between trusts in terms of the expenditure per capita for each person with a learning disability. The Belfast Trust provides a service to the highest number of individuals per capita; 25 per cent more than the Western Trust with the lowest ratio of 6.54 persons. It is unlikely the differential is explained by a higher prevalence of learning disability in the population of the Belfast Trust. This is more likely due to variations in the criteria used by trusts in assessing a person as having a learning disability and in the availability of access to these services, especially as the Western Trust reported knowing of around 1,700 adults with a learning disability in their area.

Moreover, there is marked variation in the average spend per person with learning disability across the five trusts, with over a 50 per cent difference between the South Eastern Trust (with the lowest spend) and the Southern Trust (the highest spend).

2.3 Structure of Community Learning Disability Teams - Adults: Model of Service Delivery and Outcome Measures

Each trust was asked for a range of information in relation to:
- the profile of its adult learning disability service
- referral criteria
- information database systems in place, and how they evaluated effectiveness
- information about carers' assessments and direct payments
- engagement with service users
- information on models of good practice
- unmet need
- specific challenges facing the services.

The review team noted that the existing community support teams for adults with a learning disability deliver a traditional model of service provision. Adults with a learning disability receive services provided by community nurses and social workers for learning disability, combined with services from allied health professionals and psychologists. The review team found no evidence of a tiered model of service provision similar to CAMHS, offering services such as crisis response or home treatment teams. Services were, in the main, delivered on a weekday basis.

2.3.1 Belfast Health and Social Care Trust

The Belfast Trust has four community learning disability teams (in North, South, East and West Belfast), which offer assessment and intervention to people with a learning disability and advice and support to their carers. The teams have a key responsibility in coordinating care planning and they sign-post people to appropriate services. In addition, the trust has a forensic service to support community teams to work effectively with people with offending behaviours and a specialist behaviour support service (PROMOTE) for people with learning disabilities and diagnosed mental health needs.

The review team met with the West and South Belfast community learning disability teams. Both teams comprised of social workers, community learning disability nurses and an assistant care manager. There were no occupational therapy and physiotherapy team members present; they are not part of the core team but are attached to the teams and located with them. The teams reported individual caseloads of 48 - 50 service users, and an increase in referrals was noted.

Referrals by Source and Access Criteria

Referrals to adult services may be made from schools, children's services, and from primary care services. Referral criteria are set by the trust's learning disability psychology services. All new referrals are assessed against eligibility criteria. Once deemed eligible for services, all referrals are allocated to a community team member for an initial assessment, which involves

service users and carers as appropriate. Multidisciplinary inputs are sought, as noted in the care plan. Caseloads were reported to range from 30 to 70 service users but there was no reported caseload weighting system and few case closures, reflecting a long term commitment of service provision for families. Adults requiring palliative care receive this in accordance with the trust's end of life care strategy. A learning disability carer representative was on the trust's palliative care steering group.

The trust has arrangements for responding to out-of-hours contacts, including a case alert system.

The teams reported good links with the trust's forensic services. There were less well developed links with mental health services; in particular, mental health crisis response services do not become involved with individuals with a learning disability. The review team noted that there was no clear plan to develop a stepped care model of intervention, with no crisis response provision available to individuals living in the community. People with a learning disability are largely excluded from mental health services for adults.

Psychiatry input is provided by three psychiatrists across three localities, covering children and adult services (combined total of 0.9 whole time equivalent). Concerns were raised by the trust staff in relation to the resettlement of patients without the transfer of funding for a community psychiatric service from Muckamore Abbey Hospital.

Staff reported a need for more forensic psychology and forensic psychiatry services for dealing with patients with offending histories.

Information Database Systems

The trust described a range of electronic systems for recording service user information. A range of disciplines were reported to have access to these systems. The trust reported limitations in relation to SOSCARE[20]. The PARIS[21] information database was reported to provide trust staff with current information quickly and accurately, and to promote better information flows between disciplines.

Evaluation of Service Effectiveness

The trust stated that service evaluation is undertaken on a case by case basis, and through the process of supervision and audit.

Carers' Assessment and Direct Payments

The trust reported that 297 carers had been advised of their right to a carer's assessment and that carers are routinely advised of this right at the point of

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[20] SOSCARE: Social Services Client Information System
[21] PARIS: Patient Record Information System in the Belfast Trust

referral, at first assessment and reassessment points. The trust reported that this is monitored through staff supervision and audits of files.

The trust reported that 243 carers had requested an assessment of their carer's needs over the preceding 12 month period and that 265 people with a learning disability over 18 years received an assessment of their needs during this period. The trust reported that 102 carers received an assessment and a care package in respect of their identified needs.

There were only 71 adults with a learning disability receiving direct payments at the time of the review. This figure is low in relation to the adult learning disability population of the trust (four per cent of adults with a learning disability known to the trust).

Engagement with Service Users

The trust reported that service users' views are captured using different methods, including invitations to carers to attend senior trust management meetings on occasions. Workshops are organised by the trust for service users and carers, carer support groups are in place and, service users are involved in drawing up their care plans. Efforts are being made to provide information in a user friendly accessible format.

The trust reported that accessible documentation is being developed by behaviour support services and speech and language therapy teams. Community teams have developed information packs in relation to a wide range of services and the trust has engaged with a TILII (Telling it Like it is) group in the design of a 'Lost for Words' service for individuals with communication needs.

Model of Good Practice

An area of good practice in the South Eastern and the Belfast trusts was the development of information packs by speech and language therapy staff referred to as communication passports. These passports provide essential information for community care staff, secondary healthcare staff and acute hospital services. These were reported by service users and carers to have been beneficial.

The review team met with the trust's specialist PROMOTE team which was described as the only team of its kind in Northern Ireland. This team was established in 2005, led by a clinical psychologist to provide services for persons with a diagnosis of learning disability and mental health. There are inputs from speech and language therapy, psychiatry and therapeutic input from a social worker. The team's rationale is to address the prevalent mental health needs in the learning disability population. The PROMOTE team was described as part of a stepped care model (tier 3) and works alongside services for challenging behaviour and forensic services.

The review team was advised of the links between the community teams and the specialist PROMOTE team. Prior to the development of the PROMOTE team, it was reported that service users would receive mental health input from community learning disability team members who were skilled in this area.

The community teams act as the first point of contact and referrals are screened at weekly referral meetings. At the time of the review the PROMOTE service was in receipt of two new referrals per week and there were 80 - 100 service users known to the team.

The review team was advised of links between mainstream mental health services, the PROMOTE team, and of links with dementia services. It was acknowledged by PROMOTE team members that the trust's operational policies do not facilitate integration across mental health and learning disability services.

The PROMOTE team reported measuring effectiveness against an adult wellbeing scale, where service users are asked to identify objectives for improvement in their wellbeing goals. However, the review team noted there was no quality of life or engagement outcome measures developed within the service.

The review team considered that the PROMOTE team provided helpful training programmes to independent and residential sector staff and noted that the team often have to provide outreach services to individuals placed outside trust boundaries.

The link between tier 3 and tier 4 services was discussed. The PROMOTE team reported their role in the prevention of unnecessary hospital admissions. The service is operational during office hours. However there were no arrangements in place for out-of-hours support. Team members attend monthly resettlement meetings with hospital staff to review admissions, the times patients are admitted and any service failures.

The review team considered that further clarity is required in the provision of tier 3 and tier 4 services.

It was difficult to establish evidence of the psychiatrists acting as full members of the community teams, apart from their clinical role. The review team expected that consultant psychiatrists would be providing clinical leadership in developing and influencing a tiered model of service delivery, but found they were operating more at a day to day operational level with patients in hospital or in the community.

There was a lack of clarity about the vision for the infrastructure required for resettlement of people in the community by 2015, or of the specialist seven day week services that are required. There was also little evidence of outcome measurements being used to assess clinical effectiveness, of the

efficiency of teams, or services, with the exception of the PROMOTE behaviour support services.

Challenges Facing the Service

The requirements to respond to the growing numbers of service users known to teams, and maintaining the constant level of staffing presents a challenge to the trust, as does the increase in safeguarding vulnerable adult referrals. Other challenges noted by the trust were the timely availability and funding of community based packages of care, accommodation for young people with complex needs, and the planning for the resettlement of hospital patients to the community.

2.3.2 Northern Health and Social Care Trust

The Northern Trust had the highest population of adults with a learning disability (1,989) at the time of this review. Spend per person with a learning disability was just above the Northern Ireland average. The Northern Trust had the least expenditure on administration and management; less than half of the expenditure in this area, compared to the Belfast and Western trusts.

The review team met with the Magherafelt Locality Team which comprised social work, nursing, occupational therapist, forensic practitioner, clinical psychology, behaviour planner and a safeguarding officer. The trust reported that the community learning disability teams for adults were in transition. At the time of the review the traditional locality model of service delivery, consisting of generic social services departments undertaking specialist functions, was under review.

The adult learning disability community services are provided by three integrated specialist multidisciplinary teams which currently compromise social work, occupational therapy and nursing. Those teams have close links with other specialist professional teams, including psychiatry, psychology, speech and language therapy and physiotherapy. Older service users with a learning disability do not transfer to older persons services. However there are some informal arrangements in place in each locality to work with colleagues in the older persons' programme of care, where the person is assessed as requiring domiciliary care or other specialist resources. On a regional basis there is a drive to encourage this development by the HSC Board. There was no evidence of opportunities for knowledge/skills transfer between mental health and learning disability staff to enable them to deliver services in an integrated manner.

The review team met with a large community team, which comprised nurses, social workers, psychology, speech and language and an occupational therapist. Investment in community nursing was below average, but there was a significantly higher expenditure noted on clinical psychology services.

The community forensic mental health and learning disability multidisciplinary team supports the transition of adults with a learning disability from secure service provision to the community accommodation. In addition, an adult autism spectrum disorder (ASD) link service has been provided for older adolescents and adults with a diagnosis of ASD.

Referrals by Source and Access Criteria

The trust reported the main sources of referrals as coming from schools, primary care services, psychiatrists as well as self-referrals. All new referrals are allocated to a social worker who will arrange assessments and care planning, as required.

Information Database Systems

Northern Trust makes use of a range of electronic systems to record client information. These include SOSCARE, LCID[22] and a number of standalone, unidisciplinary systems. The trust acknowledged limitations with regard to SOSCARE, particularly in relation to the sharing of information across disciplines and recording of specific conditions. LCID was reported to be used by nursing and speech and language therapists.

Evaluation of Service Effectiveness

The Northern Trust reported positively on face-to-face contact with service users. Services are evaluated by seeking views from service users, and from complaints highlighted at its Governance Audit and Effectiveness Committee. Other methods of monitoring effectiveness include performance management, audits, supervision, and monitoring of waiting lists. There was no evidence of the trust having developed key performance indicators (KPIs) to measure effectiveness.

Carers' Assessment and Direct Payments

The Northern Trust advised that all carers of adults with a learning disability have been advised of their right to a carers' assessment. The trust reported the use of Northern Ireland Single Assessment Tool (NISAT) and social work assessment documentation to record needs.

In adult services, outcomes are monitored during professional supervision sessions. Information about carers' assessments are collated across the trust on a quarterly basis and in the annual discharge of statutory functions report for the HSC Board.

The trust reported that 73 carers' assessments were requested during the 12 month period prior to the review (April 2010 - March 2011). Fifty carers' assessments were undertaken during this period.

The trust reported that 55 service users were in receipt of direct payments, (three per cent of those adults with a learning disability known to the trust). On 9 January 2012, the trusts reported that due to the Girvan judgement[23] about gaps in direct payments, there had been no new direct payments made to service users who lack capacity. The trust retains a waiting list of those assessed who require direct payments.

Engagement with Service Users

The Northern Trust outlined the practice of involving service users in the assessment process and in care planning. The trust had engaged

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[22] LCID; Local Community Information Development Database
[23] Gap in care payments legislation. http://www.courtsni.gov.uk. 7 March 2011

independent advocacy services, in particular for individuals being resettled from long stay hospitals.

The trust reported having little written information available to service users to outline the role specifically of community learning disability teams. The trust has however developed a range of products which include CDs and leaflets to provide information on complaints/comments, direct payments and day opportunities. There are also leaflets about supported living, adult placement and respite care. Information on the trust website and a range of referral forms provide contact details for specialist services. Some disciplines have been involved in educating acute service providers on the needs of individuals with a learning disability, e.g. accident and emergency staff. The trust acknowledged that this is an area requiring further improvement.

Model of Good Practice

The Adult Challenging Behaviour Service (ACBS) is managed and clinically led by a consultant clinical psychologist. This team offers behaviour intervention, advice, consultation and training for staff in the management of challenging behaviour.

Challenges Facing the Service

Challenges include the need to demonstrate efficiency savings, demographic changes in relation to prevalence of learning disability and other conditions, including dementia, service users living longer and individuals with complex needs. Ageing carers; meeting resettlement targets; higher expectations from service users and carers in relation to day service provision was also a significant challenge. The Home Treatment and Crisis Response Team available to those in mainstream mental health services, 24 hours per day, is not available to adults with a learning disability. Access to an intervention diversion bed in a community facility would assist in the prevention of hospital admissions for adults with learning disabilities. This service was available previously and has since been withdrawn.

2.3.3 South Eastern Health and Social Care Trust

The South Eastern Health and Social Care Trust had recorded a population of 1,551 adults with a learning disability receiving services at the time of the review.

There are three adult teams for learning disability which cover the Down, Lisburn and North Down/Ards area. Each multidisciplinary team provides an assessment, care planning and support service. A behaviour support service provides assessments, intervention and support to people with challenging behaviour, both adults and children. The review team met a large community learning disability team based at Thompson House, Lisburn. The team includes a team leader, social workers, assistant care manager and community learning disability nurses. The resettlement manager, lead clinical speech and language therapist, and epilepsy nurse specialist are trust wide posts. There is a health facilitator whose role focuses on the development of General Practitioner led services for persons with a learning disability. The team reported not having access to appropriately trained sensory integration staff. The health promotion message is reinforced by an enhanced service with GPs; Healthwise scheme; links with councils in relation to keep fit; aerobics; 'Health for Life' programme and a 'Cook It' programme. The learning disability service has a health development forum and there are audits of health development activity and training of staff. Partnership arrangements are in place with the Family Planning Association in relation to sexual health.

The trust is involved in a community integration project which aims to support 30 patients who will be resettled from long stay hospitals. The team reported good links with community groups and the development of health passports to facilitate better access to mainstream services. The team is co-located with the trust's behaviour support team which is helpful for staff communication.

Palliative care arrangements offered to people with a learning disability are similar to those provided to the general population and consist of GP, district nursing and AHP input. Additional support is available from community learning disability nursing and psychology services, as required.

Referrals by Source and Access Criteria

Referral sources are mainly from children's services and from other trust professionals. The speech and language therapy team and other allied health professionals may receive referrals from families and other services. Criteria used for access to services include use of ICD-10[24] and DSM IV[25] Referrals are allocated by locality, following case load weighting. An out-of-hours arrangement is available through Emergency Duty Team (EDT), which provides the services of an approved social worker (ASW), as required.

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[24] ICD-10 10th revision of the International Statistical Classification of Diseases
[25] DSM IV Diagnostic and Statistical Manual of Mental Disorders 4th ed.

The review team also met the trust's behaviour support service which covers the whole catchment area. The team is nurse led and delivers services alongside psychology, with input from consultant psychiatry as required. Most referrals come from social workers as well as schools. Eligibility criteria for the service include aspects of Emerson's definition of challenging behaviour: "culturally abnormal behaviour(s) of such intensity, frequency or duration, that the physical safety of the person or others is placed in serious jeopardy, or behavior which is likely to seriously limit or deny access to the use of community facilities".[26]

While team members do not take on key worker responsibilities they reported undertaking a key worker role. It was reported that most contacts with the service were short term. The team reported having an educational role within day and respite services, and a role within resettlement planning in the hospital setting. Outcome measures were described by the team in the context of the reduction in frequency, duration and intensity of challenging behaviours.

The behaviour support service is operational during office hours. While a pilot has been undertaken to extend these hours, there were no plans to fully implement this arrangement. The trust indicated that the future configuration of the service will involve significant change to meet complex needs. The trust reported that a senior manager has been appointed to take forward the development of a complex needs service. Part of this work will be to develop opportunities for delivery of new community support services. Staff referenced a high number of people with autism on caseloads.

The review team considered that, in general, community staff are continuing to provide a traditional model of service delivery. Service users with a learning disability are currently unable to access mainstream mental health or services for older people. The review team would encourage the trust to move towards a care pathway model of intervention involving the development of step up / step down services. A resettlement post has been funded to provide the team with the opportunity to engage with hospital services to profile service user needs, inform service planning, and enable a person centred approach to resettlement from long stay hospitals to the community. This helps to improve user's experiences by shaping the care pathway. This in turn informs service development.

There were no waiting lists for services at the time of the review.

Information Database Systems

The South Eastern Trust reported the use of a number of electronic systems to record client information. These included SOSCARE, LCID, Trojan[27] and Microsoft Office programmes. A range of professionals and administrative staff are involved in the use of these systems. The trust outlined a number of

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[26] Emerson, E. (1995) Challenging Behaviour. Analysis and Intervention in People with Learning Difficulties. Cambridge.
[27] An electronic systems to record client information

advantages and disadvantages associated with each system and made suggestions for improvements, including adding new fields to SOSCARE to capture more information. The trust reported a lack of uniformity across systems since legacy trusts merged in 2007. The review team considered that all trusts need to be able to link with each other. Further training is required for relevant staff using the systems.

Evaluation of Service Effectiveness

Outcomes are evaluated through service user engagement groups– e.g. Telling It Like It Is (TILII) group, service users' reviews, team action plans, team meetings; supervision; service level agreements; audit activity; and a reduction in recorded incidents and complaints.

The trust agreed that further work is required to develop effective outcome measures with service users.

Carers' Assessment and Direct Payments

The trust did not specify the breakdown between children and adult services.

In the period prior to the review, (April 2010 to 31 March 2011) the trust identified that 117 carers' assessments were offered and 75 completed. The trust reported that 206 carers have received services or a care package in respect of their assessed needs.

The trust reported that staff routinely advise carers of their right to a carer's assessment. This is monitored through supervision of staff. Respite care services are not allocated without a carer's assessment being completed.

The trust reported that 55 adults were in receipt of direct payments during the reporting period (9 January 2012) (four per cent of those with a learning disability known to the trust). The uptake of direct payments is still low for adults with a learning disability.

Effectiveness of direct payment is evaluated through supervision, complaints and adverse incident reviews, the use of the trust risk register, feedback from service users and carers, and staff, and through the audit of individualised management plans. The team reported using feedback from service users as an indicator of carer satisfaction. The trust has a range of formal measures for evaluating outcomes, including service level agreement contract reviews, which are convened quarterly. The trust completes a balanced scorecard, reports monthly on vulnerable adult activity, carers' assessments and direct payments.

Engagement with Service Users

Information available to adults with a learning disability and their carer's disability is limited. Front line staff at the point of assessment provide information. The trust reported on the development of service leaflets and advised that information is available on the trust's website, on direct

payments, complaints, compliments and comments. The trust reported positively on close links with a carers' forum in the Lisburn area and of the skills of learning disability team members in communicating with service users. The trust also reported on the development of software packages to promote the provision of information and service plans for service users. The trust has implemented essential lifestyle planning principles in the preparation of person centred plans with service users, who are encouraged to sign their plan and are provided with a copy.

The trust outlined a number of methods for consulting and involving service users in the design of community services. Examples included a peer advocacy and training group Telling It Like It Is (TILII), a carers' forum, individual advocacy service (Bryson House), person centred reviews and service user forums.

The trust reported holding a number of public meetings in relation to the modernisation of adult disability services and a number of meetings with carers to discuss future planned changes in service delivery.

Models of Best Practice

A number of steering groups with representatives, including adults with learning disability, were referenced, and an example of the reconfiguration of a day care service was cited as an example of innovation. The trust has also engaged with University of Ulster at Jordanstown and service users to promote the Bamford principles in their design of supported living services.

Challenges Facing the Service

The South Eastern Trust reported that funding challenges are impacting on the effectiveness of the delivery of adult services for respite care. There is a lack of specialist accommodation for individuals with complex needs, including forensic needs. Other challenges included the cost of transport, staffing resources within facilities and inequalities of access to day services.

The learning disability community teams continue to face problems in accessing mainstream services, particularly mental health services for adults with a learning disability and difficulties in developing partnership working between adult learning disability services and other mental health services, for example older people.

The trust reported a lack of community infrastructure to address the range of needs of individuals with learning disability, including meeting the forensic needs of people who have committed offences. The management of challenging behaviour and complex health needs, without step up / step down beds to avert inappropriate hospital admissions and facilitate earlier hospital discharges presents a challenge. Other challenges include demographics, ageing service users and carers, increased activity in adult safeguarding, variation in quality of trust commissioned services, with limited availability of specialist services outside of the trust.

2.3.4 Southern Health and Social Care Trust

The Southern Trust has the second highest number of adults with a learning disability (1,660) and has the highest expenditure on community learning disability services for adults in Northern Ireland.

The Southern Trust reported having three learning disability teams for adults that cover the areas of Newry and Mourne, Armagh and Dungannon and Craigavon/Banbridge. There is also a specialist service which offers a range of tertiary and support services.

The review team met members of the trust's specialist autism team. The trust reported having links and informal service level agreements with the South Eastern Education and Library Board. The trust operate in accordance with Regional Autism Spectrum Disorder Network and stated they measure effectiveness by consultation with carers and service users, and by monitoring readmission rates to hospital.

The review team met with one of the trust's community teams for adults with a learning disability (Newry and Mourne). The team consists of a team leader, social workers, nursing and care management staff, based within one office. Team members reported that sharing a base helps to enhance collaborative working and communication. Team members' caseloads were estimated to be in the region of 55 for social workers and 100 for care managers. The team was described as an 'integrated team' with easy access to allied health professionals. The team refers individuals to the behaviour support team and psychology services, as necessary, and can access inpatient services through consultation with psychiatry. The team reported involvement in discharge planning from hospital and attendance at ward based meetings.

The trust reported that service users have a designated key worker and there is a single point of entry into the service, and all newly referred individuals have a comprehensive assessment. Care plans and individual cases are reviewed on an annual basis. Community learning disability services are not provided out-of-hours.

The trust reported 10 – 15 adults with a learning disability who are parents of children under the age of 16. The trust indicated that joint working between adult and children's services is undertaken where there are recognised child support/safeguarding needs.

Health promotion is undertaken by two health facilitators who work alongside general practitioners. A health screening tool is drawn up for each service user, with an annual review of health needs undertaken. Other agencies involved in health promotion include community access officers who promote projects such as the Healthy Minds programme and have funding applications prepared for the PHA Investing for Health programme. Fit Futures[28] and FIT

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[28] Fit Futures, Investing for Health DHSSPS, 2006

4 U[29] programmes have also been undertaken. The trust has developed guidelines for staff working in the area of sexual health with individuals with learning disability, however acknowledged that there are no formal procedures for this.

Palliative care is provided by multidisciplinary team members and links are made with Macmillan nursing and other palliative support services available in the community.

Referrals by Source and Access Criteria

Referrals are received mainly from children's disability teams, GPs, other disciplines or from carers. The trust's operational policy sets out referral criteria to include age (over 18), and the individual must be resident within the trust area to meet the criteria for a specialised service.

Referrals are allocated at referral meetings by the team leader. Out-of-hours arrangements are in place for social work services and on-call psychiatry, as required.

Information Database Systems

The Southern Trust outlined a range of information systems which are used to record client information and information about services received. These included SOSCARE and COMCARE. These were reported to be used by a range of professional and administrative staff. A number of disadvantages have been identified by the trust, which included complexities in the use of systems and the inability of systems to share client assessments and treatment plans.

Evaluation of Service Effectiveness

Outcomes are evaluated through service user engagement groups.
There was no evidence of the community teams having developed key performance indicators (KPIs) to measure the effectiveness of interventions.

Carers' Assessments and Direct Payments

The trust reported that all carers of children and adults with a learning disability are offered a carers' assessment in accordance with trust policy. The trust team managers regularly monitor assessment offered and report monthly to the HSC Board on the uptake of assessments.

The trust stated that carers do not usually request assessments of their needs but that 235 were offered during the April 2010 – March 2011 period. During this period, 126 new assessments were completed and 115 new or increased care packages were provided. The trust did not break down how many of

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[29] Fit 4 U Project is funded by the Public Health Agency and led by the Southern Health and Social Care Trust

these were undertaken in respect of carers of children or adults with a learning disability.

The trust reported that 115 adults with a learning disability were in receipt of a direct payment (as of 9 January 2012) (seven per cent of those known to the trust). The uptake of direct payments is low for adults with a learning disability.

Engagement with Service Users

The Southern Trust stated that information leaflets and operational protocols are available to service users and carers on request. The leaflets outline the role of community learning disability teams/services in providing information to adults with a learning disability.

The trust reported using a number of methods for consulting and involving service users in the design and delivery of services, including carer's involvement in planning meetings, workshops and a carers' consultation group and autism forum. The trust also reported having a day opportunities and community access service user group.

Service users are encouraged to sign their person centred plans, but do not receive a copy of the plan, although they were reported as being available on request.

Other methods of consulting and involving service users include the use of an independent advocate, user forum, as well as the assessment, care planning and review processes.

The trust has produced an information pack for young people who are in transition from children's to adult services. This outlines the role and range of services available. Information is also available to service users in relation to regulated services and behaviour support services.

Model of Good Practice

The Southern Trust reported that behavioural services and specialist forensic practitioners were involved in risk assessment and management of a sex offender programme. The team is also involved in providing awareness-raising sessions, undertaken with carers, service users and the independent sector.

Challenges Facing the Service

The Southern Trust reported a need to make continued efforts to develop supported living and more suitable respite arrangements. An outreach team or crisis response team in the community would assist in preventing hospital admissions.

2.3.5 Western Health and Social Care Trust

The Western Trust has the smallest number of adults with a learning disability (1,156) and its spend per capita for adults with a learning disability receiving services from community teams is below the Northern Ireland average. The review team was advised that the prevalence of learning disability in Fermanagh is the highest of any county in the UK. The trust reported significant levels of deprivation recorded in Londonderry and Strabane. The trust also reported historical difficulties in recruiting learning disability community nursing and psychology staff.

The trust has two community learning disability teams. The teams described their role in the context of assessing needs and planning for service users to access day services and respite care. The trust reported challenges regarding the disaggregation of expenditure in children's disability and adult's learning disability services.

The review team met with the northern sector community learning disability team. The team comprised a team leader (nursing), social work, speech and language therapy and psychology staff. Input from psychology spans both children and adults with a learning disability in both hospital and community settings.

Speech and language therapy input was reported to be trust wide, with two therapists providing a service limited to eating and drinking assessments (dysphagia). At the time of the review there was no specific service to meet communication needs of people with a learning disability. Adults with palliative needs would have their needs met within the regional generic standard on palliative care. There was no evidence of inclusion of people with learning disability from mental health and other services. Learning disability team members acknowledged that a number of areas could be further developed. These included a single point of access, to speech and language therapy working with individuals with communication issues.

Referrals by Source and Access Criteria

Referral sources are mainly from children's disability services, primary care (GPs), social services, paediatric services and families. The adult programme reported the development of referral criteria likely to include diagnosis of learning disability through psychiatric and clinical psychology, following assessment. The service user is only referred to the team when agreement on the diagnosis of learning disability is confirmed. Referrals are allocated by the team leader to a key worker or care manager, on the basis of information provided in the referral and in terms of caseload capacity of staff. Individual caseloads are in the region of 35 to 40 cases.

The review team met with the trust's behaviour support team which was comprised of four behaviour therapists. Team members have a background in social work, nursing and applied behaviour analysis. The vision of the team

is to maintain service users in their own home and provide services to support patients discharged from hospital.

Children and other adult behaviour support services are provided by this team who work in parallel with community teams. At the time of the review, the behaviour support services were managed by a children's services manager. Team members reported that the behaviour support team is trying to move to the development of a tiered model of intervention and a more specialist team structure for adult services.

Information Database Systems

The Western Trust referred to a number of electronic systems used to record information including: SOSCARE, ePEX, and Understanding the Needs of Children in Northern Ireland (UNOCINI). The trust highlighted the limitations of SOSCARE and the plans to move to the ePEX information system for all disciplines across adult services.

Evaluation of Service Effectiveness

Team effectiveness is evaluated through monitoring, direct observations, and baseline and post intervention models.

The review team considered that there was over reliance on informal networking rather than the use of clear clinical pathways between services. There was little evidence provided relating to social or outcome measures of clinical effectiveness of teams or services. Further work is required to ensure adherence to pathway intervention following assessments of clinical needs of the population, in order to demonstrate improvement.

Carers' Assessment and Direct Payments

The Western Trust reported that all carers are advised of their right to a carers' assessment and that this is monitored through team leaders. There were 29 carer's assessments for carers of an adult with a learning disability having been offered during the 12 months prior to the review period (1 April 2010 to 31 March 2011), and 19 assessments were undertaken. The trust did not collate information in respect of services or care packages provided following the assessment of carers' needs at the time of review.

The trust reported that 61 adults with a learning disability were in receipt of direct payments (January 2012) (five per cent of those known to the trust). This figure remains low for adults with a learning disability.

Engagement with Service Users

The trust did not highlight any specific written information available to service users and their carers in relation to the role of community learning disability services / teams for adults with a learning disability. Individual service leaflets were reported to be available in respect of behaviour support services, speech

and language therapist, carers' assessments, direct payments, and financial assessments. The trust also referenced its website as an information source.

The trust referred to an established carers' network in the northern sector and of engagement with carers in relation to new service developments. The trust reported its intention to establish a similar network in the southern sector. The trust is developing a statement of purpose defining the role and function of the community team. This will be used to inform carers and service users of the services the team offer. The trust did not indicate a timescale for the completion of this work.

The trust reported that some staff within adult services have received training in person centred planning and that all service users are encouraged to sign their person centred plan and to retain a copy of the plan.

The trust acknowledged the need to review the guidance in relation to social and personal development for adults with a learning disability. A trust health improvement department is reported to be developing a sexual health workshop for staff working in learning disability services; at the time of reporting, sex education was being provided on a case-by-case basis.

Model of Good Practice

The trust is currently implementing a direct enhanced facilitation service in partnership with primary care, to ensure adults with a learning disability have ease of access to health promotion strategies.

Challenges Facing the Service

Challenges reported include complex needs, ageing population with no graduation to older person's services, increasing administrative requirements with reduced clerical input, and insufficient safeguarding designated officer capacity within the programme. The trust also reported not having a dedicated forensic service for adults with a learning disability referred by the courts and the challenge this presents to the community teams.

3.0   Management of Transitions and Interface Between Services

The review team focused attention on each trust's transition arrangements, to ensure that adults with a learning disability receive appropriate assessment and support throughout their lives. The review team used the standard set out in the DHSSPS Service Framework for Mental Health and Wellbeing[30] to assess the effectiveness of the trusts' transition arrangements.

The framework states that persons with learning disabilities experience four times the incidence of mental health disorders, compared to their non-disabled peers, and yet have limited access to generic mental health services. The framework sets out the need for individualised care plans and care pathways for individuals with a learning disability and mental health needs, and a coordinated approach to service provision. For an example of the components of a pathway of care see Appendix 4.

Standard 56 of the framework states: "A learning disabled person with mental health needs should have access to appropriate mental health support for their needs."

Trusts were also asked for information about any formal and informal arrangements in place to meet the transition needs of people with a learning disability and of any joint working arrangements across other disciplines for people with a learning disability.

Transitions to adult services for young people with a learning disability, were cited by trusts as a continuing concern both for young people and carers. The review team was told of significant difficulties on transition from school and from child to adult health and social care. Trusts reported that there are no statutory obligations to support young people with learning disabilities on transition into further education and from further education into employment. There are variations across Northern Ireland in terms of supported employment opportunities and available work placements. Furthermore, part time working can impact on entitlement to social security benefits. Young people with learning disabilities and their families do not always receive appropriate information about support available to young people on leaving school.

Parents of adults who have attended further education courses expressed concerns about the lack of support for the young adult settling into further education, and a lack of genuine options and subsequent opportunities for progression once a training course comes to an end.

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[30] Standard 56 of Service Framework for Mental Health and Wellbeing. DHSSPS, October 2011

Belfast Health and Social Care Trust

The Belfast Trust had no formal arrangements for adults with a learning disability to access older persons' services, in terms of any planned transition. Staff reported having occasional joint working arrangements, which were agreed across services but only on a case by case basis for individuals with a learning disability who also have mental health needs.

The trust highlighted having links with dementia care services, palliative care, sensory support services, mental health services, employment services and with services in the private and voluntary sectors, including leisure services and further education. The trust had developed links across a range of acute healthcare providers and other specialisms including epilepsy, diabetes, and, ear nose and throat services. The trust has a health facilitation nurse who is involved in promoting direct enhanced services by GP practices, including accessing health checks and screening.

The trust's PROMOTE Service has developed protocols for securing access to services relating to self-harm, psychosexual or eating disorder.

Access to the Muckamore Abbey hospital for assessment or treatment is determined by the multidisciplinary team in accordance with the Mental Health (Northern Ireland) Order 1986, regardless of diagnosis. The trust reported that community staff remain in contact with all individuals in the inpatient setting throughout their admission and are involved in any discharge planning arrangements.

Northern Health and Social Care Trust

The Northern Trust has agreed arrangements for referring adults (with a learning disability) to a learning disability hospital for assessment or treatment. They are supported by learning disability community staff throughout their admission and discharge phase. Individuals who remain in hospital after one month are assessed for discharge from the adult challenging behaviour service. Long stay patients are considered for a preliminary behaviour assessment prior to their discharge. The trust reported that these arrangements work well. However, consideration by the trust is being given to a dedicated link worker to formalise transitions arrangements between hospital and community. The trust has not developed a step down arrangement to improve the individual's transition from hospital to the community and the review team considered this should be a priority in the future.

The trust reported that older persons with a learning disability do not transfer to older persons' services. Informal arrangements exist for joint working across localities and across teams in dementia care, palliative care, sensory support, mental health, employment and leisure services. However, people with a learning disability do not access mainstream mental health services.

The trust reported positively on the appointment of three health facilitators who liaise directly with GPs within their locality areas, and play an active role in health promotion and education.

South Eastern Health and Social Care Trust

The South Eastern Trust reported no formal joint working across mental health and learning disability services for adults. Adults with a learning disability do not transfer to older persons' services. Joint working arrangements have been developed within palliative care, sensory support services and employment and leisure services, through service level agreements.

The trust reported that the majority of GP practices have signed up to a direct enhanced service providing health screening for adults with a learning disability. A health facilitator has been organising health promotion and early intervention services. The trust identified a number of areas requiring improvement in relation to health care education for carers and staff, and raising awareness of mental health issues.

The trust has arrangements for accessing learning disability hospital services for adults, achieved through planned admissions with the consultant psychiatrists in Muckamore Abbey Hospital. The community based key worker maintains contact with the patient during admission and contributes to the discharge planning arrangements. The trust made a number of suggestions for improving transitional arrangements between hospital and community. These include improved information sharing and adequate notice given to community staff in relation to the discharge of hospital patients.

Southern Health and Social Care Trust

The Southern Trust reported that health facilitators have formal working relationships with GPs. However, joint working arrangements in respect of mental health, palliative care, sensory support, or dementia services were not well developed. Access for adults to the inpatient assessment and treatment unit is made through the GP and in conjunction with the consultant psychiatrist. There are arrangements in place, including post-admission and pre-discharge meetings, for community teams involved in the admission of an individual to the specialist unit.

Joint working arrangements have been established with a number of private and voluntary services. A link service exists between the community teams and leisure, further education and employment services.

Western Health and Social Care Trust

In the Western Trust some informal joint working arrangements are in place across services and providers. These included dementia, sensory support and palliative care services, and are negotiated by teams on a case by case basis. However, individuals with a learning disability do not routinely have

their mental health needs assessed or met by frontline mental health staff. The trust advised that adults with a learning disability do not transfer to older persons' services.

The trust has arrangements for admissions for adults with a learning disability to the specialist learning disability hospital at Lakeview, Gransha, (Londonderry). Community learning disability teams remain in contact with patients and plan for their discharge.

The trust has highlighted the need for more adults with a learning disability to be able to access mainstream specialist learning disability services.

4.0   Unmet Need

Each trust was asked to describe unmet need or identified gaps in community learning disability service provision for adults with a learning disability. There is no working definition of unmet need. The term unmet need relates to the possibility that persons may, for whatever reason, fail to be provided with a service, or timely provision of a service.

The review team noted that the endeavour to provide a definition of unmet need has been ongoing since 2007 and has been subject to a previous recommendation by the DHSSPS report Standards for Adult Social Care Support Services (2008)[31] This states: "Information collected by HSC Commissioners and trusts to identify and monitor unmet need is informed by collating information from individual assessments, care plans and reviews".

Unmet need is defined and recorded by trusts in terms of the numbers of people awaiting services, rather than reflecting the complexity of identified needs. The review team found that the arrangements for recording and reporting unmet need are inconsistent. Information on unmet need in trusts is currently collected manually from various sources and locations. Trusts provided comments on difficulties in trying to address unmet need and the impact of this on service users and their carers.

Belfast Health and Social Care Trust

The Belfast Trust identified unmet need for adults with a learning disability in respite care, domiciliary care, social and leisure provision, and community treatment and support services. This is compounded by the lack of specialist expertise in provider organisations.

The trust reported that shortages in community staff are adversely impacting on its ability to improve the transition arrangements between community and hospital services. This has resulted in unnecessary and avoidable hospital admissions due to the lack of wraparound services, access to early intervention and intensively staffed accommodation to support individuals with complex needs.

The trust did not provide a detailed account of how it responds to unmet needs but stated that care plans are reviewed when needs increase or change.

The trust reported that unmet need can lead to carers' stress, and deterioration in wellbeing or the breakdown of care arrangements for the person with a learning disability. The trust reports these gaps on a monthly basis and submits an annual return on the discharge of statutory functions report to the HSC Board.

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[31] Standards for Adult Social Care Support Services, 2008

Work has commenced in the development of community services infrastructure. A critical review is being undertaken of home treatment options, particularly the trust's tier 3 services, including a behaviour support team. The trust reported the need to further develop these services and to focus on patterns of admission to hospital. The trust's PROMOTE service has established links with mental health services. However, the trust reported that there are no specific out-of-hours arrangements to support individuals with a learning disability in the community. The trust also indicated the need to undertake a review of the volume and quality of the advocacy services they commission from external agencies.

Northern Health and Social Care Trust

In the Northern Trust unmet need is reported and recorded monthly and highlighted to senior management. Waiting lists are also monitored and the trust's risk register is used to document any key concerns about the overall trends and lack of capacity to meet need where risks are identified.

Attempts to address unmet need were described by the trust in the context of resource constraints, staff sickness and vacancies. Unmet need was reported to impact on carers in terms of a breakdown of caring arrangements resulting in users requiring emergency placements; delaying the discharge of patients from hospital; and responding to higher level of behavioural difficulties, without a sufficient level of specialist staffing to meet assessed need.

The trust highlighted the resettlement needs of 42 adults with a learning disability in Muckamore Abbey Hospital and the development of supported living and adult placement services as a key priority. This is required in addition to the provision of step up/step down services, to prevent admissions to hospital. Funding for advocacy services also remain a priority.

The trust reported an identified gap in gaining access to mainstream mental health services for adults with a learning disability, in particular to the Home Treatment and Crisis Response Team, to reduce unnecessary hospital admissions. The trust reported having insufficient respite services, day services, dementia services and shortfalls in availability of specialist dental services.

South Eastern Health and Social Care Trust

In the South Eastern Trust unmet need is recorded within service user needs assessments and reviews. Monthly performance reports are provided to senior trust staff. Unmet needs are also recorded within the trust's annual statutory functions report to the HSC Board.

The trust reported the need to develop a step up/step down model of care provision supported by a seven day week crisis response team which delivers a service out-of-hours. The trust reported concerns about the lack of expertise by some independent care providers in appropriately managing people with challenging behaviours. This had led to more admissions to

hospitals whenever community care arrangements could not be sustained. Trusts reported insufficient funding for advocacy services as an unmet need.

The trust also reported a need to develop services for individuals with complex needs and for people with a learning disability referred by the courts with a history of offending. Service users' and carers' expectations of services has increased, corresponding with an increased demand for services from the trust. This has resulted in the limited resources being used to avert a crisis. The consequence of this is that less time is available to work with, for example, older carers to help them plan for a different form of service provision for their son/daughter in a community setting.

Southern Health and Social Care Trust

In the Southern Trust unmet need is captured on risk registers which are reviewed by management. The trust reported that unmet needs are discussed regularly at a senior level and with the HSC Board.

The trust highlighted the resettlement needs of a number of long- stay patients in Longstone Hospital, Armagh as a priority for investment. It also highlighted the need to further develop a range of community learning disability respite care and accommodation services, including a rapid response support service to assist individuals living in the community. The trust believes that early intervention and enhanced behaviour support staff would help reduce the need for hospital admissions and services for people referred by the courts with a history of offences. Additional funding for advocacy services is also required by the trusts.

The impact of unmet need was reported by the trust to cause stress to carers, impact on the mental health of service users, and can result in emergency admissions to hospital.

Western Health and Social Care Trust

In the Western Trust unmet needs and gaps in service provision include: forensic services for people with learning disability referred to the courts for offending behaviour, insufficient community team staff resources, limited access to psychology services and limited availability of challenging behaviour services (this is shared between children and adults services). A gap also exists in specialist accommodation required by individuals with challenging behaviours. The trust considered that admissions to hospital could be reduced by enhancing the capacity of the independent sector in responding to challenging behaviours, particularly at weekends.

The trust also identified problems experienced by individuals in making the transition from children to adult services. Some of these service users have presented with neurodevelopmental disorders, including autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD).

The trust records unmet need quarterly and reviews waiting lists of unmet needs through the annual discharge of statutory functions report to the HSC Board. The trust also referred to working closely with the regional lead on adult learning disability services within HSC Board, in relation to improving transitions for older persons with a learning disability.

Service pressures are reported to the HSC Board, and discussed at the DHSSPS the Bamford Monitoring Group, and the local commissioning group. Unmet needs is recorded in the trust's risk register.

The trust identified a number of priority areas for investment, including the development of community infrastructure to reduce the number of hospital admissions, and advocacy services. The trust is involved in a Regional Community Integration Project and reported only small numbers of individuals from their trusts who need to be resettled from long stay hospitals.

The trust reported on the impact of unmet needs on carers' ability to cope, often resulting in a breakdown of care arrangements. This pressure also can lead to ill health in carers and a need for the trusts to invest in higher cost care packages to support people with a learning disability in the community.

5.0 Conclusion on Adult Teams and Services for People with a Learning Disability

The findings of this baseline review demonstrate that a high proportion of the investment in adult learning disability teams and services is committed to a traditional model of service provision. Community learning disability teams comprise of a range of services provided by social workers, nurses, psychologists undertaking specialist functions and speech and language therapists. The review team found there were no common managerial structures across the trusts for the delivery of adult learning disability services in the community.

The current model of delivery of services by community learning disability teams is configured along the lines of the former legacy trust structures. Many of the services currently provided in institutional settings could be provided in the community or in people's homes, making them more accessible. Services should be planned on the basis of the personalised needs of people with a learning disability. The delay in changing to a new model of service delivery has been constrained by inadequate bridging finance to support new developments in the community. The percentage of funding allocated to other programmes, hospital care, mental health services restricting access to adults with a learning disability, has also been a factor in moving to a new model of service delivery.

The findings of the review team indicate that the provision of various specialist therapeutic services for people with a learning disability is variable across the five trusts. At best this represents less than 25 per cent of the total expenditure on community services for adults with a learning disability. There is a need for trusts to consider how home treatment and crisis response teams could be developed to operate on a seven day week basis. If trusts continue to deliver services as they currently do, they risk failing to adequately meet the needs of adults with a learning disability. Whilst the review noted examples of innovative practice, there is a need for more joint planning and sharing of models of effective practice across trusts.

Consideration should be given to trusts to expand the hours of operation in the community, with the goal of establishing an extended hours service for families, or residential facilities in the community with the capacity to provide outreach support. Where a seven day per week service is not required, based on evidence of assessed need, the development of alternative early prevention and intervention models of care should be delivered by integrated health and social care partnerships.

A more robust review of the multiagency and integrated nature of team working is required by the HSC Board, in terms of assessing the effectiveness of the current method of service delivery. This should include some measurement of qualitative outcomes. This is essential so that trusts can manage the demands facing their services, as the population ages and more people require to be looked after in community settings. Further discussion is

required by the HSC Board regarding the future model of service provision, to ensure it is efficient, patient centred and provides high quality, evidence based outcomes for service users. The challenge for trusts is how best to utilise their existing resources while gathering evidence to support further transformation and extension of their service provision.

The review team found from discussions with the trust staff a reliance on informal networking by teams, without any use of clear clinical pathways and interfaces between services. Trusts are at an early stage in terms of achieving the Bamford vision of true partnership working with adult mental health services and those for older people. No trust demonstrated an attempt to consider the potential for a knowledge/skills transfer between mental health and learning disability staff, to deliver services in an integrated way. Given that trusts are integrated in terms of the provision of health and social care, more could be done to develop a skill mix, between professions in the combined directorates of mental health and learning disability. This would assist in the sharing of learning and encourage equality of access to mainstream services.

The review team noted that trusts are working to develop user friendly information for service users and their carers. Service users and carers stated that public communication could be improved. A number of families interviewed by the review team stated there was a lack of clear accessible information about services in their locality on trust websites. More innovative methods of communicating with service users and carers are required to ensure adults with a learning disability are involved in the planning and reviewing of services.

The progression of carers' assessments is critical to ensuring early support is available to meet carers' physical and emotional needs. A small number of people with a learning disability and their carers have taken up direct payments. Service users and carers indicated they need more clarity about this type of option, although the lack of financial resources from the trusts may also have been a factor in promoting this choice for carers. Further promotion of direct payments is required by trusts.

Carers reported that a range of respite and short breaks are available across the trusts. However these can be based in respite units which can reduce the flexibility of the service offered. Many parents and carers expressed frustration at the delay in the implementation of the Bamford proposals and waiting lists for particular services. Access to more a flexible model of service provision in the community is required.

It is crucial that further efforts are made to promote independence and personalisation; a more person centred service. The proposals set out in Transforming Your Care should aim to deliver tangible changes for adults with a learning disability and their families. At present, the provision of advocacy services is limited and further work and investment is needed to promote both peer and independent advocacy for adults with a learning disability. This is critical in supporting individuals to make informed decisions and in promoting

rights. The review team commends the partnership that trusts have developed with the community and voluntary sector in developing new service models. The continued involvement of this sector needs to be promoted in providing a varied range of additional support services. The target to end the long term hospital residency of people with a learning disability by 2015 means that early planning is required to develop the range of personalised housing and care supports to enable people to live independently in the community.

The review team considers there is still a need for consistent outcomes in terms of access to other mainstream health care services. Disability awareness training for clinical staff in the community is needed so that they can deal confidently and appropriately with adults with learning disability.

Exclusion of people with a learning disability from mental health services for adults/older people and from the newly established autism services was particularly evident.

The recent release of the Learning Disability Service Framework, DHSSPS September 2012, aims to promote and secure better integration of service delivery along the care pathway from prevention, diagnosis, treatment and rehabilitation to end of life care. Further work is required to ensure people with a learning disability can access the full range of health promotion initiatives available to the general population. Widening access to screening programmes and public health interventions will continue to require an increased focus by the LCGs. The review team considers that the planned integrated care partnerships should ensure that clinicians are facilitated to respond appropriately to the needs of people with a learning disability.

The Bamford Review of Learning Disability set out to reform and modernise the law, policy and provision affecting people with a learning disability in Northern Ireland. The proposed Mental Capacity (Health, Welfare and Finance) Bill also proposes changes in respect of the presumption of capacity and will create additional demands on trusts. Training will be required to support trusts in effectively delivering the requirements of the new legislation.

A review is required of current data systems and technology to ensure relevant information is available to professional staff about client assessment and treatment plans. The proposals set out in Transforming Your Care should aim to deliver tangible changes for adults with a learning disability and their families.

This report highlights the requirement to develop and improve community services to ensure they meet the needs of individuals in long stay hospitals, and address the current unmet needs that within community provision. This will require a determined programme of service change and reconfiguration to meet present and future health and social care needs of this population.

The increased level of care delivered in a community setting will need to be closely aligned with demand; with outcomes evaluated for effectiveness.

Trusts should formulate development plans for community learning disability services in the period 2013-2015 in full consultation with service users and carers. This is the most promising way to ensure that investment is used in the most effective way to produce the best possible patient and client outcomes.

6.0 Recommendations for Trusts – Adult Learning Disability Services

There are a number of areas for service improvement that trusts need to consider. This will require significant leadership in the planning, implementation and transformation of service provision.

Model of Community Service Provision

All trusts should review their current model of service provision to ensure that it actively promotes the prevention, inclusion and integration of people with a learning disability, in line with the principles set out in Equal Lives, particularly in the areas of housing, leisure, training, further education and employment opportunities.

Learning Disability services should be reviewed alongside mainstream mental health services, so that the skill and expertise from both services can be utilised in order to respond to individual need.

Review of Composition of Adult Learning Disability Teams

Each team should have clear statements of purpose, which determine the membership, from a range of disciplines such as community psychiatry; learning disability nursing; social work; allied health professionals; psychology; behaviour support; specialist epilepsy nurses and practitioners with forensic knowledge and experience.

Possible Approaches to the Development of Service Provision

A number of approaches could be considered by trusts in relation to the development of a tiered model of service provision. Suggestions are outlined in Appendix 3 for consideration by the trusts.

Developing a Personalised Pathway of Care for Learning Disability

Trusts should provide an individualised pathway of care, consisting of a coordinated assessment of need, agreement of expected outcomes, provision of care and treatment. This should be followed by a joint review of achieved outcomes along with the people receiving services, and their carers. See suggestions in Appendix 4.

Assessment of Clinical and Social Care Needs

To meet a variety of individualised needs consistently, effectively, safely and in partnership, commissioners need to:

- understand the needs of the population
- plan intervention and treatment based on assessed need
- ensure/develop corresponding skills in providers

- use person centred, outcome focussed treatment plans
- provide incentives to timely achievement of agreed outcomes
- develop a range of personalised pathways of care, the core components of which are shown on Figure 3.

Trusts should gather information about the clinical and social care needs of the populations they serve, in order to service development. Community learning disability teams have a key role to play in gathering and collating this information. This is a requirement under the Learning Disability Service Framework.[32]

Delivery of an Extended Hours Service

Trusts should review access to services and ensure that effective arrangements are in place for the provision of community learning disability teams for adults with a learning disability which can provide services outside 9am to 5pm, Monday to Friday, in community settings.

Trusts should ensure that family carers receive access to appropriate of support services. This should be based on assessed need, including domiciliary care on an extended hours basis, host family schemes with trained and approved carers, social and recreational activities provided by volunteer and paid staff, and short breaks and respite services.

Development of Interfaces between Services

Trusts should agree criteria to ensure effective interfaces from children to adult services and to other services, for example, to mental health services and older people services, to achieve a seamless transition to appropriate assessment and support.

Development of a Clinical Quality Dashboard

Trusts should agree a clinical quality dashboard (an information tool) to provide clinicians with relevant and timely information to inform daily decisions to improve the quality and measurement of effectiveness of health related patient care.

Use of Best Practice Evidence and Guidelines

All care should be delivered on the basis of standard evidence, good practice guidelines and in response to identified clinical need.

Health Related Outcome Measures

All adults should receive an annual physical and mental health check from their GP practice and arrangements should be in place to enable people with

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[32] Learning Disability Service Framework, September 2012. Belfast, DHSSPS

a learning disability to access secondary care services in line with the GAIN Guidance[33].

Examples of related outcome measures for people with a learning disability that could be agreed during assessment are shown below

- reduction in level of health supports required
- improvement in functioning of persons with a learning disability so as they can live in the least restrictive environment
- shortest length of time taken to return to optimum functioning by moving through a personalised pathway of care and treatment
- reduction in levels of harmful effects of treatment e.g. medication, carer distress etc.
- maintenance of improved level of functioning
- long term impact of residual behaviours and on-going treatment.

Compliance with Standard 56 –Service Framework for Mental Health and Wellbeing[34]

Trusts should ensure that people with a learning disability, and particularly older people, have access to appropriate mental health support for their needs, in line with Standard 56, of the Service Framework for Mental Health and Wellbeing.

Provision of Specialist Care and Support Services in the Community

Trusts should liaise with housing providers to ensure effective arrangements to provide living accommodation in the community for people who currently residing in learning disability hospitals. Trusts should develop a range of partnerships to ensure that personalised supported living options are available. This is in line with the recommendations from the Bamford Review.

Development of Partnership Arrangements

Trusts in partnership with other statutory and voluntary agencies, should ensure that services are in place for people living in community settings, for example, access to day support services. Other services include further education, vocational training, supported employment and a range of day support services for people with more complex needs.

Managing Transitions

Trusts should ensure that effective arrangements are in place for adults transferring from hospitals to the community and to older people's services.

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[33] Guidelines on Caring for People with a Learning Disability in General Hospital Settings. GAIN, DHSSPS. 2010.
[34] Service Framework for Mental Health and Wellbeing. DHSSPS, October 2011

Communication with Service Users using Accessible Formats

Staff should communicate directly with the patient with a learning disability, at all times, using accessible formats.

Advocacy

Trusts should ensure that people with a learning disability have appropriate access to independent advocates as a method of promoting a person centred approach to care and treatment, and particularly in facilitating and supporting service users in using personalised budgets. Where individuals do not wish to take financial control, they should have access to advocates to act on their behalf.

Listening to Carers

All care should be provided in a manner consistent with the Standards for Improving the Patient and Client Experience, Ensuring the Provision of Respectful and Dignified Care (DHSSPS 2008)[35]. Trusts should ensure that they listen to the family/carer, recognising their knowledge of the individual with a learning disability. This contribution should be acknowledged, valued, listened to and acted upon.

Review of Needs of Older Parents

Trusts should ensure that older carers' needs for respite assessed regularly and met, to support them in their caring role.

Direct Payments

Trusts should provide clearer information to service users, carers and families about direct payments, to ensure consistency in terms of equity, access and ease of use.

Increased Staff Training and Awareness

Trusts should ensure that staff receive training that increases their awareness of learning disability. Issues such as human rights, discrimination and the importance of good communication, attitudes and values should be included. In line with best practice, awareness training on learning disability issues should include people with learning disabilities and their family/carer, as experts through experience.

Transferability of Skills between Mental Health and Learning Disability Teams

Trusts should consider the potential for a knowledge/skills transfer between staff working in adult learning disability services and other mental health

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[35] Standards for Improving the Patient & Client Experience, November 2008, Belfast, DHSSPS.

services for adults and older people, to deliver support services in an integrated way.

Information Database Systems

Trusts should review the suitability of their information database systems to ensure they are capable of informing the assessment of clinical and social care needs and the appropriate commissioning of services.

Use of Service Frameworks as a Tool for Improvement

Trusts should ensure that the learning disability service framework and agreed performance indicators are developed, as well as feedback from users and carers is used to inform a system of continuous improvement.

7.0 Recommendations for HSC Board - Adult Learning Disability Services

Review of Expenditure in Community Learning Disability Services

The HSC Board should ensure that the data in relation to expenditure on community learning disability teams is examined in terms of equity of investment in community staffing across the Board area. This should be compared with the guidelines that different professions have produced per 100,000 of the population.

Review of Effectiveness of Community Learning Disability Teams

The HSC Board should review the current membership of community learning disability teams to ensure they include psychiatry and experienced forensic practitioners.

Review of Availability of Specialist Support Services

In view of the low numbers of behaviour therapists, specialist support workers and psychiatric sessions available in the community, the Board should review the concept and effectiveness of specialist support services, their membership, functions, working protocols and the availability of services on an extended hours basis.

Development and Agreement of Performance Indicators

The HSC Board should inform the trusts of their requirements with respect to reporting on agreed performance indicators using the Learning Disability Service Framework and the arrangements the HSC Board has in place for auditing the adherence to these standards, set out in this framework.

Development of a Skilled Work Force

Commissioning of learning disability services should be needs led so that planned interventions are evidenced based and lead to the development of a skilled workforce in all tiers of the service delivery in the community.

Review of Additional Expenditure Required in Community Learning Disability Services

The HSC Board should plan to rebalance the community based investment in psychiatry, psychology and therapy services, as a consequence of hospital resettlement, by March 2015. New service provision should include appropriate step up/step down services and robust assessment and treatment services in the community.

Local Commissioning Groups (LCGs)

All LCGs should review the capacity of existing resources to deal with the needs of people with a learning disability, children with a disability and aging carers and develop support options in partnership with local housing, further education and leisure providers.

Evaluation of Outcomes

All services commissioned by the HSC Board should focus on outcomes and these should be monitored to ensure they are reducing health and social inequalities. The HSC Board should measure the quality of services from the perspective of the individual and their family carer, clinical effectiveness, outcomes and safety.

Training

The planned integrated care partnerships in consultation with the HSC Board, should ensure that clinicians receive appropriate training to assist them in communicating and responding appropriately to the needs of people with a learning disability.

List of Abbreviations

ADHD	Attention deficit-hyperactivity disorder
AHP	Allied health professions
ASD	Autism spectrum disorder
Assertive outreach	Term used for intervention that targets people with a learning disability with a mental health condition but have not been engaged with mental health services
Belfast Trust	Belfast Health and Social Care Trust
CAMHS	Child and adolescent mental health service
CFMHS	Community forensic mental health services
CMHT	Community mental health team
COMCARE	A community care client management system
CRIS	Clinical research information systems
CRHTT	Crisis response home treatment team
DHSSPS	Department of Health, Social Services and Public Safety
DPs	Direct payments involves the provision of funding directly to patients and clients who then directly purchase the services they feel best meet their needs.
DOLS	Deprivation of liberty safeguards
DSM IV	Diagnostic and Statistical Manual of Mental Disorders fourth edition
ePEX	Electronic information database
GP	General practitioner
ICD-10	Tenth revision of the International Statistical Classification of Diseases
LCID	Local Community Information Development
MDT	Multidisciplinary team
MH & LD	Mental health and learning disability
NISAT	Northern Ireland Single Assessment Tool
Northern Trust	Northern Health and Social Care Trust
OT	Occupational therapist
PARIS	Patient Record Information System
RCPsych	The Royal College of Psychiatrists
PROMOTE	The team that provides behaviour support services for persons with diagnosis of learning disability and mental health
RQIA	Regulation and Quality Improvement Authority
RPA	Review of Public Administration
SLT	Speech and language therapy
SOSCARE	Social Services Client Administration and Retrieval Environment
South Eastern Trust	South Eastern Health and Social Care Trust
Southern Trust	Southern Health and Social Care Trust
TROJAN	Electronic systems to record client information
UNOCINI	Understanding the Needs of Children in Northern Ireland
WHSCT	Western Health and Social Care Trust

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Appendix 1: Table A1: The Number of Whole Time Equivalent Staff Within the Major Disciplines in Community Services for Children with a Disability and Adult Persons with a Learning Disability Across the Five HSC Trusts.

Discipline	Service	Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust	Total
Social workers and care management	Child		21.6	22.3	29.84	18.6	**>92.34**
	Adult	26.19	34.15	21.09	25.64	16.5	**123.57**
Community Learning Disability Nursing and Health Facilitators	Child			6.0		4.0	**10.0**
	Adult	9.0	17.2	10.1	14.85	11.0	**62.15**
Occupational Therapy*	Child	16.31	4.0	5.1	12.5	10.77	**48.68**
	Adult	3.5	6.5	2.0	8.66	1.0	**21.66**
Speech and Language Therapy*	Child	20.36	20.5	7.37	33.09	17.7	**99.02**
	Adult	3.34	7.3	5.81	4.0	3.0	**23.45**
Physiotherapy*	Child	23.75	13.97	3.7	14.58	9.58	**65.58**
	Adult	5.5	7.63	1.16	4.0	0.0	**18.29**
Clinical Psychology (NB Working across child and adult services)	Child						**0.0**
	Adult	2.1	4.0	11.3	7.5	5	**29.9**
Challenging Behaviour Services (NB In some trusts, these personnel work across child and adult services)	Child		5.4			5	**10.4**
	Adult	5.8	10.9	6.16		2.6	**25.46**
Psychiatry (Sessional time only reported for children)	Child						**0**
	Adult	2			2.8	2.0	**6.8**

*Trusts may have included all therapy staff involved with children and not just those with a disability
(Note: A total in excess of 637 whole time equivalent (WTE) staff are currently employed in these services).
>The true figure is larger than 92.34, as the value for Children was not given.

Appendix 2: Table A2: The Teams Providing a Service to Adults with a Learning Disability, as Reported by Each Trust

Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust
Community Learning Disability Teams - North	Multi-disciplinary Team (Social Work; Occupational Therapy; Community Nursing for Learning Disability) – Mid-Antrim	Down sector multi-disciplinary team	Newry & Mourne Community team	Community Learning Disability Team - Northern Sector (1 team leader; 6 social workers; 6 community nursing staff)
Community Learning Disability Teams - South	Multi-disciplinary Team for Adults with Learning Disability - Loughside	North Down & Ards sector multi-disciplinary team	Armagh & Dungannon Community team	Community Learning Disability Team - Southern Sector (1 team leader; 9 social workers; 3 community nursing staff)
Community Learning Disability Teams - East	Multi-disciplinary Team for Adults with Learning Disability - Causeway	Lisburn sector multi-disciplinary team	Craigavon & Banbridge Community team	
Community Learning Disability Teams - West				
Behaviour Support Service	Adult Challenging Behaviour Service (ACBS)	Behaviour Support team (across three sectors)	Behaviour Support	*Behaviour Support managed by Childrens Service (see page 34)*
Forensic Service	Community Forensic Mental Health & Learning		Forensic service	

	Disability Multidisciplinary Team.			
PROMOTE (service for people with LD and mental health needs)				
Complex Health Service				
	Adult ASD Link Service			
	Speech & Language Therapy			
	Physiotherapy			
			Epilepsy service	
			Community access	

Appendix 2: Table A3: The Amount of Expenditure per Head of Adult Population Spent by the Five HSC Trusts in 2010-2011 in Community Disability Services for Adults with a Learning Disability

Discipline	Belfast Trust N=198,119	Northern Trust N=268,698	South Eastern Trust N=203,794	Southern Trust N=210,587	Western Trust N=176,799
Social workers & care management	£6.50	£4.91	£4.38	£5.29	£4.12
Community LD Nursing & Health Facilitators	£1.46	£2.69	£2.03	£3.08	£2.41
Occupational Therapy	£0.60	£1.20	£0.41	£1.69	£0.29
Speech & Language	£0.91	£0.94	£1.23	£1.02	£0.47
Physiotherapy	£0.61	£0.91	£0.24	£0.86	£0.45
Clinical Psychology	£0.58	£0.80	£1.15[1]	£0.67[2]	£0.40[2]
Challenging Behaviour Services	£1.73	£1.45	£0.63[1]	£0.84[2]	£0.76[2]
Psychiatry	£0.70	Not supplied	(£0.78)[3]	£0.51[2]	£1.23
Other specialist services[2]	£1.26	£0.37	-	£0.83	-
Community support workers	£0.64	-	-	£1.40	-
Management & Admin	£1.28	£0.50	£0.58	£0.68	£1.07
Total reported by trust	**£16.28**	**£13.78**	**£10.65**	**£16.89**	**£11.20**

1 These costs have been apportioned 50/50 with Children's services although the monies may sit within one budget within the trust.
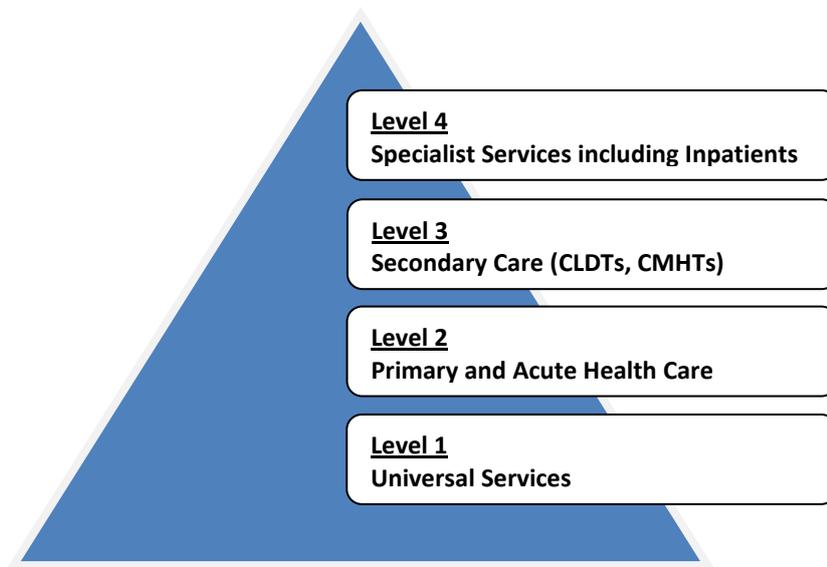2 These costs are apportioned 75 per cent adult: 25 per cent children services.
3 The South Eastern Trust provided this as an estimate although the budget is with the Belfast Trust through Muckamore Abbey Hospital. (This also applies to the Northern Trust). This amount is not included in the trust's total costs but if it were the costs would rise to £9.79 per head of adult population.

Appendix 3: Key Service Components in a Tiered Model of Service Provision

The whole population is eligible to receive universal services. A proportion will need additional secondary services and a minority will require the full a range of specialist services.

Figure 2 – Proposed Tiered Model for Service Provision to meet the needs for people with learning disabilities

Level 4
Specialist Services including Inpatients

Level 3
Secondary Care (CLDTs, CMHTs)

Level 2
Primary and Acute Health Care

Level 1
Universal Services

Level 1 - Universal Services

These services are primarily focussed on improving the health of the whole population of people with learning disabilities. Good access to housing, leisure, education and employment are known to have a positive impact on mental health. Other priorities include neonatal screening, early detection and treatment for conditions such as congenital hypothyroidism and phenylketonuria.

Level 2 - Primary and Acute Health Care

Trusts should ensure that people with learning disabilities have good access to mainstream health services. In primary care, this means regular health checks, advice and support on lifestyle factors such as diet, exercise, alcohol consumption and sexual health. Other services include health facilitation to improve access to primary care and health liaison to improve access to acute hospital based care. Training and support for carers should be made available.

Level 3 - Secondary Care by Community Learning Disability Teams / Community Mental Health Teams

Community and mental health learning disability teams need to provide assessment, treatment and some on-going support for people with moderate degree of mental health need (significant anxiety and depression, psychotic disorders, and cognitive impairment). These teams need to have expertise in

dealing with behaviour problems associated with these conditions with the whole range of learning disability and coexisting autism and ADHD. Improving Access to Psychological Therapies (IAPT) services is within this level.

Level 4 - Specialist Services including Inpatients

These services need to have expertise in dealing with people who are a severe risk to themselves and others, often with chronic severe treatment resistant mental illness, behaviour problems and offending behaviour. Services at this level include community based assessment and treatment using a combination of crisis and home treatment teams, behaviour support services, forensic teams and experts in autism, ADHD, eating disorders, dementia and epilepsy. Inpatient services may also be required where 24 hour assessment and treatment would enable a safe return to well-resourced community based packages of care. The appropriate role for psychiatric hospital services for people with learning disabilities lies in short-term, highly focused assessment and treatment of mental illness. This implies a small service offering very specifically, closely defined, time-limited services.

The relationship between these key components of the service are represented in Figure 2.

Appendix 4: Components of Pathway of Care

Figure 3 – Components of Pathway of Care
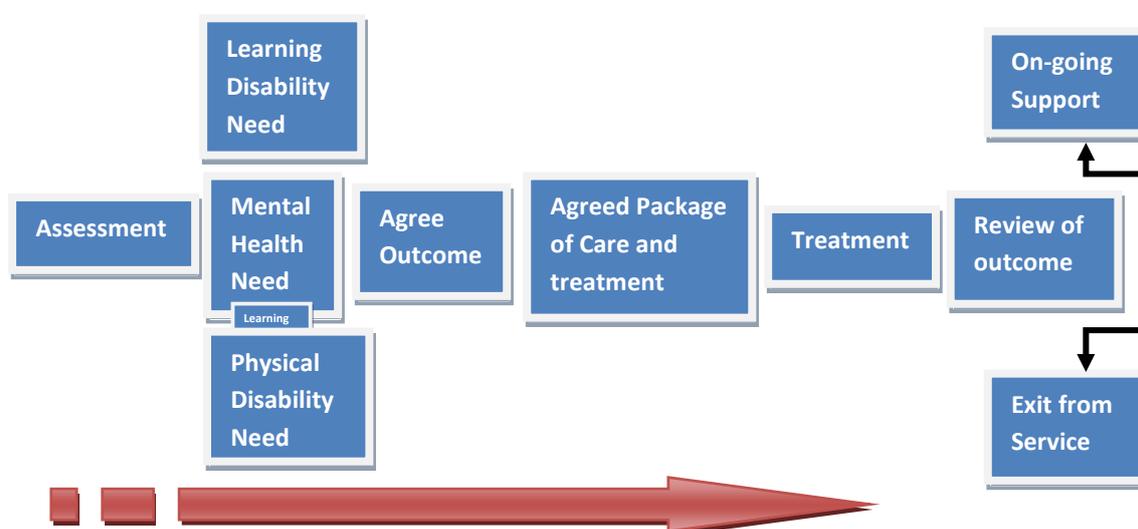
Such a model of service provision relies on an integrated approach between learning disability and other services. There should be a single point of entry after which the assessment of need commences. This would clarify the range of skills best able to meet assessed need and achieve better outcomes. The agreed care package is provided by professionals with the appropriate skills to support the individual to achieve agreed outcomes effectively and safely, regardless of which service or agency they work for. In some instances the skills may be available wholly in the mental health service or in the learning disability service. In other cases there may be a need to share skills and work jointly across services. When care and treatment is provided by a team, a named person must coordinate the delivery of treatment. This process requires a defined leadership role with responsibility for making and communicating decisions to the team.

This would clarify the range of skills best able to meet the assessed need and achieve mutually agreed outcomes. The agreed care package is provided by professionals with the appropriate skills needed to support the individual to achieve agreed outcomes effectively and safely regardless of which service or agency they work for. In some instances the skills may be available wholly in the mental health service or in the learning disability service. In other cases there would be a need to share skills and work jointly across services. In complex care when several individuals provide care and treatment an agreed individual must coordinate the delivery of treatment.

People with learning disabilities must be able to access other specialist services, such as eating disorder, substance misuse, personality disorder services as well as early intervention, crisis and home treatment, and assertive outreach.

Planning ahead is crucial. Advocacy services should be available, and individuals should have proper person-centred plans for the services they need now and in the coming years. Planning ahead also implies building in some capacity in the system to cope with demand as it emerges, rather than waiting until crises occur. The relationships between these key components of the service are represented in Figure 2.

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