



The **Regulation** and
Quality Improvement
Authority

A Baseline Assessment and Review of Community Services for Children with a 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 reviews are carried out by teams of independent assessors, most of whom are either experienced practitioners or experts by experience. Our reports are submitted to the Minister for Health, Social Services and Public Safety and are available on 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.

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Executive Summary

RQIA, as part of its 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 review concentrated on children with a disability as the five trusts indicated they could not provide, from their existing databases, information solely in respect of community services to children with learning disability.

Almost 15,000¹ children in the 0 – 15 age range were identified by the Northern Ireland Statistics and Research Agency (NISRA) as being multiple disability benefits recipients, in 2012. Trusts reported that at the time of this review there were 3,570 children with a disability known to the service within Northern Ireland. This figure is likely to be an underestimate as not all children with a disability will be in receipt of health and social services.

This report presents a baseline assessment of the role structure and composition of disability teams for children across the five trusts. It highlights the level of investment in these services as at 1 April 2011, and the models of service delivery in each trust. The report provides information about provision of and access to services. It describes the transitional arrangements, engagement and communication with service users, and their carers, and provides information on database systems in use. The report also highlights information on unmet need. It identifies the challenges facing families in accessing services for children with a disability.

The review team met with the Department of Health, Social Services and Public Safety (DHSSPS), the Health and Social Care Board, the five HSC trusts and with voluntary and charitable bodies involved in providing services.

The review team also met with a number of service users and their families. Families of children with autism spectrum disorder in particular, raised concerns about access to, coordination of and continuity of services.

The review team found it difficult to obtain clear and accurate data from trusts in relation to specific expenditure on children's services, as staff often work across both services.

There was considerable variation in the range and quality of services provided to children with a disability. Children with a disability should be able to access a child centred, seamless community service, in the right place, at the right time.

The overall model of community services for children with a disability was delivered mostly by teams of social workers and specialist community learning

¹ Multiple Disability Benefits Recipients, Northern Ireland Statistics and Research Agency, 2012.

disability nurses, assisted by allied health professionals and clinical psychology staff.

The review team commented on the variation in team structures across each trust, the multiplicity of job roles delivering similar services, and variations in the way individual professionals are deployed within teams.

All trusts had an excessive reliance on informal networking rather than using clear clinical pathways and well developed interfaces between services. There was limited evidence of information sharing between trusts or between teams within individual trusts with regard to innovative practice.

There was evidence of the use of key performance indicators and outcome measures to assess the clinical effectiveness of services. This was particularly evident in smaller specialist teams, led either by clinical psychologists or speech and language therapists. There was limited evidence of the use of caseload weighting or benchmarking across community teams. All of the teams visited reported high levels of bureaucracy and crisis management.

The review team was impressed by the commitment of staff delivering services but were concerned by the absence of a clear vision about future roles, relationships and configuration of team structures to meet identified and future needs. Trusts are at an early stage in their development of a four tiered model of service provision similar to that delivered in the child and adolescent psychiatry service.

A number of issues and areas of unmet need have been raised by the five trusts for consideration by the HSC Board who plan and commission services. A reliance on inpatient care in the Iveagh Unit was noted, along with the lack of effective community based alternatives, such as a 24 hour crisis response teams. This runs the risk of readmission to hospital-based assessment and treatment units with consequent delays in the discharge of children.

There was evidence of user engagement across the five trusts. However, some carers complained of a lack of access to information about the availability of services and a frustration, caused by waiting lists for some services, for example respite care.

The review team noted a reliance on the recording of interventions, with less focus on the recording of outcomes, following interventions with disabled children and their carers. Trusts did not have clear measurements in place to gauge the effectiveness of their interventions with service users and carers, or consistent and tangible ways of obtaining service user or carer feedback.

There are a growing number of examples available in Northern Ireland of new model of service provision, particularly behaviour support teams which following evaluation, should be shared across trusts for learning.

In order that investment is prioritised appropriately in the future, it is critical that the HSC Board ensures that information is gathered about the health and social care needs of the population served. The HSC Board should identify ways to improve the profiling of the service provided by each HSC trust, in terms of the effectiveness and efficiency of service delivery, and the impact of staff roles and team working. The level of investment in workforce skills and managed clinical networks should be reviewed by the HSC Board, to ensure a more equitable service is delivered by community staff. This would provide a context for rebalancing of the existing workforce, as identifying priorities for additional investment. At the time of the review, plans were at an early stage in relation to targeting investment in additional community based disability services.

The future commissioning of services needs to be carried out in accordance with the DHSSPS service frameworks such as the learning disability service framework, and the proposed framework for the Health and Wellbeing of Child and Young People. The local commissioning groups (LCGs) provide an opportunity to deliver safe and sustainable services, which respond effectively to population need.

The work being undertaken by the regional group on disabled children, and the by the Children's and Young People's Strategic Partnership, to plan for service provision, should enable trusts to provide improved services in future.

Many of the challenges set out in this report are as a result of long-established cultures and practices. The strategic direction is clearly set out in Transforming Your Care². The challenge is to make this vision a reality. The HSC Board needs to ensure that the most suitable and equitable range of service provision is put in place to meet current and future needs of disabled children. The trusts must work in partnership with the parents, carers and those who represent the interests of children with a disability to make sure that services are tailored to the needs of children and their families.

The review team acknowledges that a number of changes and improvements to services may have occurred since April 2011.

² Transforming Your Care, DHSSPS, December 2011

1.0 Children with a Disability - Introduction

The vast majority of children with disabilities live at home and are supported by their natural families, with others living with foster or adoptive parents. A small number of children with a disability, mostly adolescents, live in residential care settings.

Service for children with a disability operate under the principles of Every Child Matters (DHSSPS, 2004)³, The Strategy for Children and Young People in NI: “Our Children & Your Young People – Our Pledge 2006-16”,⁴ DHSSPS ‘A Healthier Future: A 20 Year Vision for Health and Wellbeing in NI 2005-25’⁵, DHSSPSNI Priorities for Action 2010-11⁶. The Equal lives Report of the Bamford Review, Chapter 4, also outlined recommendations for children, young people and families.

The UNCRC Article 23⁷ states that ‘Children who have any kind of disability should have special care and support so that they can live full and independent lives’. Children with a disability need early access to responsive and high quality services. Trusts reported increasing numbers of children with complex physical health needs, including those who are dependent on assistive technology, or who require 24 hour care.

Families of young people with disabilities provide care and support well beyond what is normally expected and over a longer period of time. Support for families is critical, particularly at times of transition, such as birth, hospital to home, getting ready for school, leaving school and when moving to live independently.

Children with disabilities experience a greater incidence of health problems requiring access to primary health care, for example respiratory and cardiovascular problems, and mobility difficulties. A Children and Young People’s Health and Wellbeing Service Framework was under development at the time of the review. It is anticipated that the framework will have a section devoted to children with disabilities.

During school years it is critical that health, social care and education services work collaboratively as the key agencies providing support to children with disabilities, to ensure appropriate planning, coordination and commissioning of services.

Effective services for children and young people with a disability and their families are characterised by:⁸

- provision of clear information and transparency of decision making
- putting families in control of the design and delivery of their care

³ Every Child Matters DHSSPS, 2004

⁴ The Strategy for Children and Young People in NI, Our Children & Your Young People – Our Pledge, 2006-16

⁵ ‘A Healthier Future: A Twenty Year Vision For Health and Wellbeing in Northern Ireland 2005-25 DHSSPS

⁶ Priorities for Action 2010-11 DHSSPS

⁷ Article 23, The Convention on the Rights of the Child. (1989)

⁸ Children with Disabilities Strategic Alliance Manifesto Review and Update (2012)

- ensuring services are responsive and provide timely support
- early intervention through good prioritisation of needs
- provision of joined up care across services
- provision of high quality short breaks
- provision of wheelchairs and equipment
- sufficient investment to meet the assessed needs of children and young people with a disability and their families.

Children's disability services require a focus on prevention, early intervention and specialist support in the community. The Children and Young People Strategic Partnership (CYPSP) had been established to ensure that the needs of children and young people are reflected in the planning, commissioning and provisions of health and social care. This includes a focus on children with a disability. Agencies involved in supporting children with a disability must develop a more consistent and person centred approach to transition planning.

It is estimated 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 with complex physical health needs will be an area of significant growth (DHSSPS 2005)⁹. This is due to increasing life expectancy, advances in medical care, mothers delaying childbirth and increased survival rates of 'at risk' infants due to improved healthcare.

The Autism Act 2011 places a statutory duty on the trusts to provide DHSSPS with data on the prevalence of autism in their respective areas. Trusts, at the time of the review, were examining how processes and mechanisms to gather data on prevalence of autism could be adapted to provide useful data on a wider range of disabilities and conditions. From April 2011, the review team were advised that no child should wait longer than 13 weeks, for assessment of autism following referral, and a further 13 weeks for commencement of specialized intervention.¹⁰

A Children and Young People's Health and Wellbeing Service Framework is under development by the DHSSPS. This will include a specific focus on children with disabilities, including early intervention, inclusive ethos, multidisciplinary teams, participation in education, respite, equipment, transition and palliative care. There have been a number of drivers for the modernisation, reform and restructuring of traditional models of community learning disability services and other services for children with autism. Transforming Your Care (TYC) 2011 sets out a summary of key proposals for services for children with a disability.

⁹ Equal Lives. DHSSPS, 2005

¹⁰ HSCB, PHA, Draft Commissioning Plan 2011-12

1.1 Background to the Review

RQIA, as part of its three year review programme 2012-15, undertook a review of learning disability community services. The Bamford Review of Mental Health and Learning Disability Services¹¹ sets out guiding principles for the development of community services. These promote person centred and needs-led approaches to service delivery.

The Bamford Review stated the needs of children with a learning disability were “a footnote, an afterthought” within health and social service (HSS) programmes of care. Such programmes were dominated by the needs of adults and lacked initiatives to improve services for children.

It became apparent in the early stages of the review that trusts were providing integrated services for children with physical disabilities and children with a learning disability. Trusts were unable to disaggregate information about services for children with a learning disability. The review team sought and received approval from the DHSSPS to extend the scope of the review to include all children with a disability.

The reasons for focusing on children with a disability and not just children with a learning disability were as follows:

- 1) All trusts provide integrated services for children with a disability in common with other regions in the United Kingdom. It is extremely difficult for trusts to disaggregate the information by a learning disability label only.
- 2) The inclusion of all children with a disability would further validate the extent and style of work of the community services teams across the region. This type of information would also be very helpful in informing the future service framework for children’s services and hence may be more useful to the DHSSPS.

The review examined the source of referrals; access criteria; the evaluation of service effectiveness; the provision of services; unmet need; transitional arrangements; engagement with carers; and challenges facing the service.

1.2 Terms of Reference

It was agreed that this review should be undertaken in two stages.

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

¹¹ The Bamford Review of Mental Health and Learning Disability. DHSSPS. 2007

Phase 2 - (2014-15) to provide an assessment of the quality and effectiveness of trusts' disability services for children, against the DHSSPS's Learning Disability Service Framework, and other frameworks, as agreed.

The review team excluded services for children with a disability that are currently regulated by RQIA, as outlined below:

- Children's Homes
- Domiciliary Care Agencies
- Residential Family Centres

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 composition of community services for children with a disability
- profile of staff and the level of investment in childrens' disability community teams
- core functions, services provided and management/leadership arrangements
- referral and access criteria
- information database systems in use by each trust
- evaluation of service effectiveness
- carer's assessments and direct payments
- engagement and communication with children and young people with a disability
- models of good practice
- transitional arrangements between children and adult learning disability services
- information on unmet need for community services for children with a disability and challenges facing the service.

RQIA met with a team in each trust which included representation from management of front line services. The trust was requested to select a second team to demonstrate current practice.

Meetings were held with members of staff who provided children's disability services. Presentations were made by children's disability teams (chosen either by their specialty or locality).

Meetings were also held with representatives from the HSC Board, with responsibility for children's disability services, and with the DHSSPS.

A number of consultations were undertaken by the review team with young people and their families before, during and after the visits to trusts.

2.0 Profile of Investment in Staff

The five HSC trusts were requested to provide details of the staffing profile for the Community Services/Teams for children with a disability. Information was requested on the working time equivalent (WTE) staff numbers in post as at 1 April 2011 for each grade of staff, along with the total gross salary costs (inclusive of employer's costs). For simplicity it is the latter that are reported in this section of the report - see Table 1. (Details of WTE staffing are in Appendix 1).

It is not clear the extent to which trusts disaggregated the services provided to children with a disability from those provided to all children by the various disciplines, notably in terms of the therapies, as there are variations in the information provided.

Table 1: Total Expenditure in 2010-11 in Community Services for Children with a Disability across the Five HSC Trusts

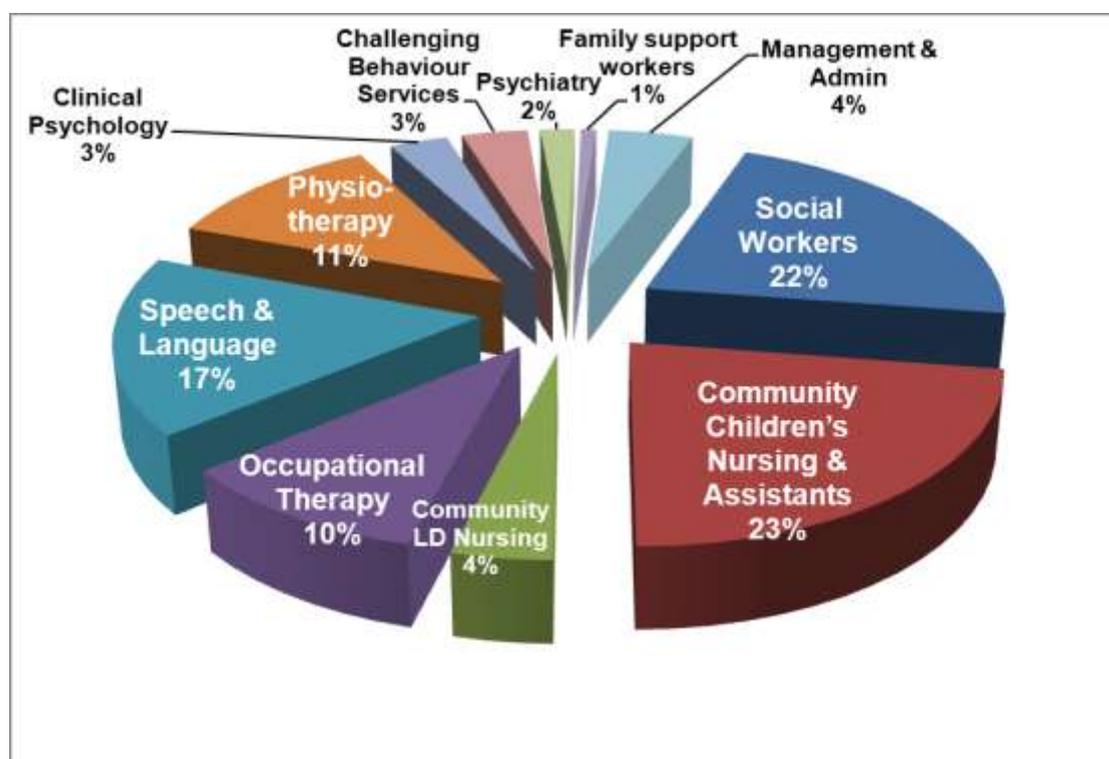
Discipline	Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust	Total for five trusts
Social Workers	£652,475	£677,043	£874,000	£602,634	£800,986	£3,607,138
Community Children's Nursing & Assistants	£604,307	£1,507,000	£744,891	£309,696	£592,184	£3,758,078
Community LD Nursing	£165,640	£86,314	£206,000	See CCN	£178,545	£636,499
Occupational Therapy	£522,000	£119,000	£218,000	£330,062	£457,434	£1,646,496
Speech & Language	£744,515	£682,000	£289,000	£386,524	£676,241	£2,778,280
Physiotherapy	£496,978	£530,000	£129,000	£358,413	£387,226	£1,901,617
Clinical Psychology ¹	£37,321	£107,900	£234,000	£47,263	£70,500	£496,984
Challenging Behaviour Services ¹	£39,064	£203,083	£129,000	£59,039	£133,500	£563,686
Psychiatry ¹	£24,937	-	£104,000	£35,595	£128,000	£292,532
Family support workers	£13,472	-	£118,000	-	-	£131,472
Management & Admin	£142,193	£207,000	£202,951	£90,525	£79,775	£722,444
Total reported by trust	£3,815,970	£4,119,340	£3,248,842	£2,219,751	£3,504,391	£16,535,226
RBHSC regional social work ²						£373,068
Total Northern Ireland						£16,908,294

¹ The South Eastern and Western Trusts provide these services from a joint budget that covers children and adult services. A 50-50 apportionment has been applied. The Southern Trust apportionment is 75% adult: 25% children.

² The Belfast Trust manages a regional social work service at the Royal Belfast Hospital for Sick Children (RBHSC). The cost is included in the total costs for Northern Ireland.

Figure 1 illustrates the proportion of spending in children's services across the various disciplines for NI as a whole, *without any pro rata adjustments for missing information*. Hence community nursing accounts for just over one quarter of the spend, followed by social work at 22 per cent. The three allied health professionals (AHP), i.e. speech and language therapy, occupational therapy and physiotherapy account for 38 per cent of the spend, with clinical psychology and challenging behaviour services accounting for a further six per cent. The psychiatry costs are an estimate of those spent in direct community services. Likewise the management costs relate to the direct management and administration of community services and do not include support services such as human resources and finance.

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



Comparisons Across the Five Trusts

Spending within each discipline was calculated as an amount per child (aged 0 to 18 years inclusive) within the trust, based on 2010 population statistics (mid-year estimates). Table 2 presents the findings and illustrates the variations between trusts, as well as the differential spending across disciplines within trusts. There would appear to be significant variations across trusts in the range and extent of community services available to children with a disability; notably in social work, community children's nursing and AHPs.

Table 2: The Number of Children with a Disability in Receipt of Services from Community Learning Disability Teams in Financial Year 2010-11 and the Total per capita Spend for Each Child

	Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust	Northern Ireland Total
Number of children with a disability	730 (estimated 65% have a learning disability i.e. 474)	481 ¹ (of whom 331 had a learning disability)	604 (including 86 with sensory disability)	959 (services to children and young people including those with sensory impairment)	796 (inclusive of those with a physical disability)	3,570
Child population of trust	85,226	120,588	89,256	101,481	84,347	480,898
Number of children with disability per 1,000	8.56	3.99	6.77	9.45	9.43	7.42
Total spend on Children's Disability	£3,442,902	£4119340 ²	£3,248,842	£2,219,751	£3,504,391	£16,908,294 ³
Per capita spend for child with a disability	£4,716	£8,564	£5,379	£2,315	£4,402	£4,736

¹ Recorded on SOS CARE

² Includes total cost of children's community nursing

³ Includes the cost of RBHSC regional social work service

Table 2 provides an analysis of expenditure. It is likely that the Northern Trust has under-estimated the number of children, due to reliance on SOS CARE returns.

The five trusts have reported a combined spend of nearly £17M per annum on community services for children with a disability, with an average per capita spend of £4,736 per child. The table does not include the full cost of psychiatric services provided in community settings to children, nor the apportionment of management and administrative costs.

As detailed in Appendix 1, around 650 WTE equivalent staff are deployed in the services provided to children with a disability and to adults with a learning disability.

3.0 Structure of Community Disability Teams – Children: Models of Service Delivery and Outcome Measures

Trusts were asked to describe the role and composition of community services for children with a disability. Table A2 in Appendix 2 summarises the responses received.

Each trust was asked for a range of information in relation to:

- the profile of children’s disability services
- referral criteria
- database systems and how team effectiveness is evaluated
- carers’ assessment and direct payments
- engagement with service users
- models of good practice
- management of transitions, assessment and recording of unmet need
- challenges facing the service.

3.1 Belfast Health and Social Care Trust

The Children’s Disability Service consists of six teams working in partnership with the voluntary sector, to deliver a flexible service responsive to local need. The service aims to help families to meet the specific needs of children at home, with appropriate support when necessary. A trust service request panel for children’s disability services was reported to meet monthly to prioritise need and respond to unmet need. The trust reported on a wide range of multi-disciplinary inputs in relation to the provision of children’s disability services, review arrangements and care planning. The trust reported a number of approaches to preparing child centred plans, including liaising with service users, schools, families and other professionals.

Community learning disability nursing take the lead in health promotion and relationship building. Sex education is provided in partnership with the Family Planning Association (FPA) and Health for Youth through Peer Education (HYPE). Access is available to a health facilitator nurse whose role is to maintain links with palliative services, epilepsy and diabetes specialists in mainstream services. Trust staff were reported to have received training in personal relationships and local champions act as a resource within services.

The review team enquired about the interface between the community adult learning disability team and staff at Iveagh Unit (specialist treatment unit for children with a learning disability). The trusts identified the main reasons for hospital admissions, including mental health issues and families inability to deal with children with challenging behaviour. Admissions to hospital were often triggered by a crisis at home or the breakdown of care arrangements at home. The trust reported difficulties in making adequate arrangements for the timely discharge of children from hospital, due to the lack of appropriate Tier 3 community assessments and interventions.

The community learning disability teams described links with the trust's out-of-hours duty team and the sharing of information in relation to risk assessments and emergency management plans. The Adult Challenging Behaviour Support Service (ACBS) planned out-of-hours work with individuals in regulated services but this was not routine practice. At the time of the review, the trust had no plans to develop a crisis response or home treatment model of service provision in the community.

Palliative services are provided to children in partnership with NI Hospice and children's community nursing.

The trust reported an annual £1M spend on community self-help groups, including mainstream parents' support groups and an autism post-diagnosis support group.

Referrals and Access Criteria

Referrals are received primarily from children's services/schools, GP or primary care or through probation services. The current criteria, which is currently the subject of both local and regional review is:

1. A child (aged 0-18) has a diagnosed learning disability.
2. A child with a significant physical disability, health condition or sensory impairment.

New referrals are allocated to the community teams on a locality basis.

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 SOS CARE¹². A Patient Record Information System (PARIS) 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

Service evaluation was reported to take place through the process of audit, feedback from service users and carers, and through supervision of staff and monthly monitoring reports.

¹² SOS CARE; Social Services Client Administration and Retrieval Environment

Carers' Assessments and Direct Payments

The trust reported that there were 86 direct payments being received by children at the time of the review (9 January 2012); 12 per cent of children known to the trust.

Engagement with Service Users

The trust referred to information on children's disability services being available on its website and of work being undertaken by the trust to update leaflets, in relation to direct payments and autism intervention services. The trust is also involved in the Children's and Young Peoples' Strategic Partnership.

The trust reported that service users' views are captured during the Looked After Children (LAC) review process. The voluntary agency Voice of Young People in Care (VOYPIC) provides insight into the effectiveness of services. The trust reported positively on their Children's Interdisciplinary Schools Team which communicates information to children. Frontline staff were reported to have liaised with speech and language therapy colleagues to promote more effective communication, particularly for children with a learning disability.

Model of Good Practice

The Leicester model¹³ of home based assessment and treatment was referenced as an example of good practice. However, the trust had no plan to move to the Leicester model, at the time of the review.

Challenges Facing the Service

Challenges include the availability of appropriate placements or support packages for children and young people leaving care or leaving hospital. The trust also referred to higher public expectations of carers for additional services in light of the autism legislation¹⁴.

The trust reported challenges in relation to developing local services for children to prevent hospital admissions or admissions to residential care. The development of community based treatment services and the lack of tier 3 specialist intervention services were also described as a challenge. The trust had produced a strategy on partnership working with other agencies to assist in the process of change and improvement.

¹³ http://www.leicspart.nhs.uk/_OurServices-ChildrensDisabilityService.aspx

¹⁴ <http://www.official-documents.gov.uk/document/cm84/8438/8438.pdf>

3.2 Northern Health and Social Care Trust

The Northern Trust reported having four locality teams and a range of residential and shared care services for children with a learning disability.

The trust described a range of services provided to carers of children with a learning disability. These included sponsored child minding, Article 18 payments, domiciliary support, respite care/short breaks. Palliative care needs are met by children's community nursing staff and there is a children's palliative care forum with input from the Northern Ireland Hospice. The team reported working with service users with a number of co-existing conditions including autism and complex physical health needs. The review team noted that autism figures are not being compiled, but a database was reported to be under development.

Emergency out-of-hours arrangements are in place and reflect the geographical spread of the trust area, with a case alert system for high risk cases.

The review team met with the children's challenging behaviour service team which consists of a planner, programmers, consultant clinical psychologist and an educational psychologist. The team is jointly funded by NSHCT and North Eastern Education and Library Board and is managed through the clinical psychologist. This team operates across three trust sectors. The team reported that 75 per cent of time is spent in schools, assessing and undertaking interventions. There is also input into service users' homes and into respite placements.

Referrals by Source and Access Criteria

Referrals to services for children with a disability come, in the main, from social workers, relatives/families or from paediatric staff. All newly referred service users have a social work assessment which includes service user and carer involvement. Multi-disciplinary inputs are noted in the care plan. The trust reported that all meetings concerning children with a disability, such as child protection, LAC¹⁵ and family support meetings are multi-disciplinary in nature, with emphasis placed on the involvement and participation of the service users and family.

Access to the service is defined by use 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"¹⁶ and refers to the individual's long term future as likely to lie in learning disability services. There was no waiting list for access to the service at the time of review. There were 72 service users, with the average length of contact with the service being approximately one year.

¹⁵ LAC; Looked After Children

¹⁶ Emerson, E. (1995) *Challenging Behaviour. Analysis and Intervention in People with Learning Difficulties*. Cambridge

Information Database Systems

The Northern Trust reported on a range of electronic systems. These include SOS CARE, LCID¹⁷ and a number of standalone, uni-disciplinary spread sheets. These databases are used by a range of professional staff. The trust acknowledged limitations with regard to Social Services Client Administration and Retrieval Environment (SOS CARE), particularly in relation to the sharing of information across disciplines and in the recording of specific conditions. The Local Community Information Development (LCID) was reported to be used by nursing and speech and language therapy professionals.

Evaluation of Service Effectiveness

The evaluation of effectiveness by professionals is outlined in the monthly data collected in relation to referrals, Looked After Children (LAC) targets, and the annual discharge of statutory functions report. Supervision procedures are also used as a means of checking outcomes, along with feedback from service users.

Carers' Assessments and Direct Payments

The Northern Trust reported that all parents and carers of children with a disability are advised of their right to a carers' assessment. In children's services, monthly and quarterly monitoring is undertaken in relation to advice given to carers. The trust reported that information about the outcomes of carers' assessments is not routinely collated by the trust.

The trust reported that 49 clients were in receipt of direct payments (children's nursing reported 11 clients) during the April 2010 - March 2011 period; 10 per cent of children known to the trust.

Engagement with Service Users

Nursing, community paediatrics and speech and language therapy have developed information leaflets about their roles. The trust highlighted the valuable role of speech and language therapy services in providing augmentative communication systems for children and adults, including the use of Makaton and visual strategies.

The trust uses its website as a source of information for service users, carers and GPs. The trust outlined that parents and service users are asked to comment on services and particularly within the LAC/child protection processes. The trust acknowledged at the time of the review there were limited opportunities in relation to consultation on the design of services.

¹⁷ LCID; Local community information development

Models of Good Practice

Children with a disability who require social work input have one social worker allocated from the children's disability team with responsibility for all statutory responsibilities for that child. This differs from other trusts where children have a number of social workers from different teams responsible for different aspects of their needs. The model within the Northern Trust ensures that the child's needs are viewed and addressed holistically and consistently.

Challenges Facing the Service

The trust referenced challenges to decision making, following a judicial review; time spent responding to Freedom of Information requests; budgetary constraints; high expectations of families; retention of staff; strict referral criteria and insufficient resources allocated to specialist services.

The trust identified the needs of children with challenging behaviour and complex physical health needs as a priority for development at the time of the review.

3.3 South Eastern Health and Social Care Trust

The South Eastern Trust children's disability service is part of the overall cared for children's service. The trust has teams for children with disabilities, which cover geographical catchments under the supervision of the senior manager for children with disabilities and a senior practitioner for transitions and volunteering. The children's disability service had participated in a trust review process to assist in service reform and safe practice.

The trust reported the use of essential lifestyle planning principles in the preparation of person centred plans. Service users are encouraged to sign their person centred plan and are given a copy of the plan.

Out-of-hours support for children with a learning disability is provided by the trust's emergency duty team.

Referrals by Source and Access Criteria

The main sources of referral are through paediatric services, schools and through gateway teams. Referrals are allocated to either a social worker, community learning disability nurse or to the behaviour support team. Referral criteria apply and individuals must have a diagnosis of a learning disability. ICD 10¹⁸ and DSM IV¹⁹ criteria must apply.

There were 604 children in receipt of a service during the reporting period; 86 of these were receiving services in respect of their sensory needs.

Information Database Systems

The South Eastern Trust reported the use of a number of electronic systems. These included SOS CARE, PROCARE, LCID, Trojan and a range of Microsoft Office programmes. A range of professionals and administrative staff are involved in the use of these systems. The trust outlined a number of advantages and disadvantages associated with each system and made suggestions for improvements, including adding new fields to SOS CARE to capture specific information. The trust reported at the time of the review, a lack of uniformity across systems since the legacy trusts merged. Further training was required for relevant staff using the systems.

Evaluation of Service Effectiveness

The South Eastern Trust reported that effectiveness of service delivery is monitored through complaints/comments processes, LAC reviews, and through monitoring and contracts meetings with voluntary organisations, and audits. Recent work with the community learning disability nursing service has resulted in the development of a better skill mix and enhanced multidisciplinary team working. A family support resource panel has been

¹⁸ ICD-10; Tenth revision of the International Statistical Classification of Diseases

¹⁹ DSM IV; Diagnostic and Statistical Manual of Mental Disorders Fourth Edition

established to maximise equity of access and service provision across the trust. Appropriate standards for supervision are in place for all social work staff.

Carers' Assessments and Direct Payments

Staff routinely advise carers of their right to a carers' assessment. Additionally, respite care services are not allocated without a carer's assessment of need being completed. At the time of the review, 117 carers' assessments were offered and 75 completed.

The trust reported there were 87 direct payments being received by children with a disability; 14 per cent of children known to the trust.

Engagement with Service Users

The trust reported a number of methods for consulting and involving service users and their carers. These include parents' groups, community access workers and feedback from VOYPIC. The trust highlighted some methods of communication with children, including a booklet on a respite care service, complaints leaflets for children, sharing documentation from LAC reviews and the role of VOYPIC in providing advocacy services.

The trust acknowledged that the provision of written information for service users and their carers is an area requiring further improvement and described a plan for achieving this. The trust website provides information about services. The trust had appointed new community access workers who will develop literature for service users and carers. They also had appointed an autism coordinator to help signpost families to services.

Models of Good Practice

The South Eastern Trust has drawn up a proposal to establish an intensive therapeutic, rapid response service to reduce the need for admission to the Iveagh Unit in Belfast and to support disabled children in the community.

The trust has been involved in a HSC regional disabilities group which has undertaken work on team structures and referral processes. A paper has also been developed on short breaks.

Challenges Facing the Service

The trust reported challenges such as; responding to increasing numbers of looked after children, pressures from increased referrals in relation to autism and children presenting with severely challenging behaviours. Gaps were also cited in access to specialist forensic services for young people with a learning disability. Difficulties were also cited in recruiting foster carers for children with complex physical health needs. The lack of a tiered model of service intervention, including therapeutic intensive supports, was also a challenge for trust staff.

3.4 Southern Health and Social Care Trust

The Southern Trust reported the ongoing development of three integrated care teams for children with a disability with a single point of entry. These teams are based in Newry, Armagh and Craigavon. There is a multidisciplinary children's support service, in addition to an autism support service including a diagnostic and intervention team.

Out-of-hours arrangements include emergency social work and psychiatry service. The trust reported that extended services for children's community nursing provision is currently under development.

Children living in residential or foster care have their transition needs met through the LAC processes; core group meetings and use of Understanding the Needs of Children in Northern Ireland²⁰ (UNOCINI). Trust transition coordinators become involved at age 14. Adult services are also invited to attend LAC reviews for young people aged 17. The trust reported positively on its involvement of children in the LAC process, in person centred planning and transition work, and highlighted these areas as examples of good practice in relation to communication with children. The trust reported the processes of case planning meetings and core group meetings in which key professional staff involved in the child/family's life meet together. Other meetings included school reviews, hospital review/discharge meetings.

Children with life limiting conditions who require palliative care are referred to the relevant professions including allied health professionals, children's community nursing, Children's Hospice, social work, who can provide the appropriate care including end of life care supported by Horizon House and Hospice at Home.

Referrals by Source and Access Criteria

The trust acknowledged that referrals to community teams come from a range of sources, but are mainly from community paediatricians, health visitors and parents/carers. The referral criteria reflect the requirements of trusts as set out in Children's Order²¹ to undertake an assessment of a child in need. Referrals are screened by line managers and, if appropriate, allocated to social work staff. Allied health professions (AHP) referrals have admission criteria which are applied at the screening/triage stage. The trust reported that all newly referred individuals have a comprehensive assessment and care plan and are reviewed on an annual basis. The trust referred to the use of essential lifestyle planning and to person centred Planning Alternate Tomorrows with Hope (PATHs), and 'Listen to Me' booklets. Service users are encouraged to sign their person centred plans and are given copies.

²⁰ UNOCINI, DHSSPS. 2008

²¹ The Children (Northern Ireland) Order 1995

Information Database Systems

The Southern Trust outlined a range of information data systems including SOS CARE, Clinical Research Information System (CRIS), and Community Care Client Management System (COMCARE) used by a range of professional and administrative staff. A number of disadvantages have been identified by the trust in relation to these systems including the inability of client assessments and treatment plans to be shared electronically across disciplines.

Evaluation of Service Effectiveness

The trust reported that service evaluation is undertaken through supervision, feedback from service users and their parents, regular audits and through discussions, involving carers at a Wraparound²² forum, established by the trust.

Carers' Assessment and Direct Payments

The trust reported that all carers of children and young people with a disability are offered a carer's assessment, in accordance with trust policy. Team managers regularly monitor and report on the uptake of assessments. During the reporting period the trust completed 126 new assessments for carers of children and adults.

The trust reported as at November 2011 there were 130 children with a disability in receipt of direct payments; 14 per cent of children known to the trust.

Engagement with Service Users

The trust referred to written information explaining the role of the community learning disability services team for children. Information sources include team leaflets, information packs for parents about shared care, respite care and the out-of-hours social work service. The trust's website provides information to carers, service users and GPs.

The trust involves Sixth Sense²³ service users and their carers in the design of services in children's services planning. There is also a parent's council as part of the Children's Strategic Partnership²⁴. Parent's support groups are involved with respite care services. The trust has developed partnerships with a network of organisations including a range of voluntary organisations.

²² Wraparound enables children with disabilities to have access to information, assessment and, where appropriate, services which provide the social, health and educational support

²³ Sixth Sense – a group of children and young people who advocate for children with a disability in Southern HSC Trust area

²⁴ A advisory reference group of parents who are consulted by Southern Trust about the needs young people with a disability

Model of Good Practice

A Wraparound service has been developed, which seeks to improve the quality of life for children with disabilities and their families. Wraparound specialises in developing new ways of working in partnership with carers of children with a disability. Families have access to information, assessment and, where needed, services to enable the child/young person to live socially included lives. Services are designed to support or wrap around the child and his or her family and to prevent hospitalisation.

Challenges Facing the Service

The trust reported challenges in accessing psychological therapy, medium and long term service provision for children with disabilities, and difficulty in accessing behaviour support for children over 12. There was also a lack of services to meet the transition needs of children moving from hospital to the community.

The trust identified a number of priority areas for investment. These included palliative care services, the provision of a step down facility for children with complex physical health needs leaving hospital. The trust proposed developing integrated care teams for under 11 and 12+ age groups.

3.5 Western Health and Social Care Trust

The Western Trust has three children's disability teams: in Derry/Londonderry, Omagh and Fermanagh. Each team consists of social workers and a community nurse for learning disability. In addition, children with a learning disability have access to behaviour support, psychology and psychiatry inputs. There are two behaviour support services, one located in the northern sector of the trust, covering the Derry/Londonderry area and the other located in the southern sector covering Omagh and Fermanagh. The psychology and psychiatry services are located in Derry/Londonderry and cover the entire trust. The behaviour support and psychology services are shared between children's and adult learning disability directorates.

The review team was advised that a home assessment and treatment service has been established, led by a consultant psychiatrist and operationally managed by a lead nurse. The trust reported organising services to children with a learning disability around a four tier model, and had adopted the Leicester model for the provision of home based assessment and treatment.

Referral Criteria and Access to the Service

Criteria for referrals include ICD 10²⁵, to establish the presence of learning disability. Psychiatry and clinical psychology staff assess referrals using a range of assessment tools, including the Adaptive Behaviour Assessment System (ABAS)²⁶ and the Wechsler Intelligence Scale for Children²⁷ (WISC). Referrals are received from GPs, paediatricians/social workers, consultant psychiatrists from carers.

Children's community nursing services operate an open referral system. Referrals are allocated by team leaders within the geographical areas. Out of hours arrangements include social services for disabled children and on-call psychiatry.

The trust reported that all staff within children's community disability services had 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.

Sex education with children is undertaken by children's community nurses. The trust reported links with the Children's Hospice and children's community nursing for children with palliative care needs. Children were reported to be accessing Horizon House, the children's hospice in Belfast. A new four bedroomed children's hospice has opened since the review, March 2012, to provide a local palliative care service. There is no provision for children's community nursing to operate out-of-hours, and there are many constraints in relation to the provision of care at home on a 24 hour basis.

²⁵ Tenth revision of the International Statistical Classification of Diseases

²⁶ Adaptive behaviour includes the age-appropriate behaviours necessary for people to live independently and to function safely and appropriately in daily life

²⁷ individually administered [intelligence test](#) for children between the ages of 6 and 16

Children residing in residential or foster care were reported to have their transition needs managed in accordance with trust guidance for the transition of disabled children who are looked after. This process was also reported to be monitored by the trust's Disability and Looked After Children Services Joint Forum.

Information Database Systems

The trust referred to a number of electronic systems including: SOS CARE, ePEX²⁸, and UNOCINI. The trust highlighted the limitations of using SOS CARE as an information database.

Evaluation of Service Effectiveness

Service effectiveness is evaluated through trust management arrangements in the Women and Children's Directorate and the Children's Disability Team. Service user feedback is sought during LAC processes and at family support panels. Caseload analysis, analysis of unmet need, monitoring of delegated statutory functions and team health checks are used to evaluate effectiveness of outcomes.

Carers' Assessments and Direct Payments

The trust reported that all carers are advised of their right to a carer's assessment. One hundred and fifty-five carers' assessments were offered for carers of children with a disability. Of these, 94 assessments were taken up.

The trust reported that 58 children were receiving direct payments during the reporting period: seven per cent of children known to the trust.

Engagement with Service Users

The trust reported having a range of leaflets for service users and their families in relation to the role of community learning disability teams. The trust also distribute information packs, which provides a range of information on transitions and respite services. The trust's website is a further source of information.

The trust's consultations and involvement of service users and their carers was reported to have focussed on the development of a respite facility in 2011. Service users and carers were represented on a commissioning group. The trust also referred to an advocacy project which had taken place in 2009-12 and from which the 'Choices and Voices' Advocacy and Participation for Disabled Children and Young People Guide was developed. The trust reported on contractual arrangements for the independent sector to incorporate service user involvement in the design and delivery of services provided.

²⁸ Electronic information database

The trust also reported the promotion of carers' assessments and direct payments by team members and the use of LAC processes, and UNOCINI to promote service user and parental participation.

Model of Good Practice

The development of the intensive treatment team within the children's health and disability service provides therapeutic interventions with particular emphasis on family support within the home. This also supports children with a learning disability who require inpatient psychiatric care. This model ensures that children receive multi-disciplinary specialist acute psychiatric care within their own home and community, while also reducing the difficulties faced in receiving treatment in a hospital setting. This service also helps families and communities to build skills to support and care for children in their local area. It is anticipated that this service will reduce the number of children requiring admission to hospital for psychiatric care.

Challenges Facing the Service

Challenges impacting on services for children with a disability include the provision of services for children with complex physical health needs; high cost of care packages; and care supports required to facilitate discharge from hospital.

Lack of funding for hospice at home services had increased pressure on the service, as disability teams needed to cover the shortfall. End of life care was cited as difficult to provide, as symptom management necessitates 24/7 nursing cover, which the teams are not resourced to provide at the time of the review.

There is an increasing demand to provide short break/respice care for families.

The trust highlighted a number of priorities for investment in their Women and Children's Directorate Development Plan, 2012-13.

4.0 Management of Transitions

Introduction

Transition is a term used to refer to the time in a young person's life when plans are made with the young person leaving full time education and becoming an adult. Successful transition is contingent on a number of factors. Core to this process are five C's, communication, coordination, comprehensiveness, continuity and choice (Heslop, P. et al 2002)²⁹ It is important that services are responsive to a range of assessed needs in the transition stage, including transition from education to employment.

Young people with a learning disability, should have a transition plan in place before their 18th birthday and arrangements made for the transition to adulthood, following their 14th birthday. The review sought to assess the individual trusts' arrangements for ensuring that children with a disability receive appropriate assessment and support throughout their lives.

Arrangements for joint working across disciplines and agencies were reviewed, including information about any formal and informal working arrangements.

Management of transitions to adult services for young people with a learning disability, in particular, was cited by trusts as a continuing challenge. Young people and carers reported significant difficulties on transition from school and from child to adult health and social care services. 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 is also variation across Northern Ireland in terms of supported employment opportunities and available work placements. Part-time working can impact on entitlement to social security benefits. Families of young people with learning disabilities indicated that they do not always receive appropriate information about options and supports available to young people when leaving school.

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

The availability of age appropriate, flexible day care and short break services are limited and vary across trusts. Some parents said they do not always have access to detailed information on the real options available, including information on the range of accommodation choices, alternative sources of support and on eligibility or entitlement to services.

²⁹ Heslop, P., et al (2002) Bridging the Divide at Transition. Kidderminster: British Institute of Learning Disabilities

The Autism Act³⁰ places a statutory duty on the health and social care trusts to provide the DHSSPS with data on the prevalence of autism in their respective areas. At the time of the review health and social care trusts had begun to examine how processes and mechanisms to gather data on prevalence of autism could support, inform and guide the gathering of data on a wider range of disabilities/conditions. A regional network for children with autistic spectrum disorders and a regional reference group for carers was established to inform planning and service delivery. Area based approaches should ensure that geographically dispersed populations such as children with disabilities and their families are given fair and equal consideration in the planning and commissioning of services, and in delivery resources.

Belfast Health and Social Care Trust

The trust reported having effective transition planning arrangements and good collaborative working across children's and adult services to help young people bridge the transition to adult services.

The trust provided information in relation to joint working arrangements with a range of other services including education, mental health, employment, educational psychology, leisure services and further education. The trust indicated that information about the roles and responsibilities of staff working in these services could be clarified and improved.

The trust described regular liaison between children's disability services and child health services and referenced a range of professionals involved, including social work, nursing and medical staff. Transition work for individuals with complex physical health needs is supported by community nursing, paediatrics, social services, AHPs and education services.

Transition work with looked after children in residential or foster care is a trust performance management target. Transition planning for children in residential and foster care is undertaken by children's disability teams in consultation with adult services from the age of 14. Admissions of children to the Iveagh Treatment Centre are considered at multi-disciplinary referral meetings and community team members remain in contact with children admitted to the centre throughout their placement. The trust reported that reducing the number of children admitted to this specialist assessment and treatment centre could only be achieved through further investment in alternative community based support. The priority areas were identified as home treatment services, development of short breaks, respite and shared care services.

Northern Health and Social Care Trust

The trust reported that there is a clear and documented strategy and transition planning across services and pathways. The trust highlighted established links between the children's disability team and health visitors, community

³⁰ The Autism Act (Northern Ireland) 2011

paediatric nursing, clinical psychology, children's challenging behaviour services and a range of allied health professionals.

The trust undertakes transition work with children with a moderate to severe learning disability from the age of 16, when it is clear that they require adult learning disability services. The trust has arrangements for team members from adult services to attend review meetings and gather information in relation to assessment and future involvement. Six months prior to the individual's 18th birthday a social worker, from adult services, is appointed to co-work with the young person's social worker. The trust has agreed arrangements within disciplines to assist in improving the transition from children to adult services.

The trust outlined a number of joint working arrangements between the trust and education services, sensory support, mental health, private and voluntary sector providers. Children's services were reported to have limited links with further education or leisure services. The trust has identified a number of areas for improvement in terms of transition arrangements between these services.

The referral for children to specialist assessment and treatment services is made by the child's GP. Social work staff can refer to children's challenging behaviour services and to a specialist residential facility for children with challenging behaviours. Trust staff retain links with children during their admission to the specialist unit and are involved in discharge planning with the community team.

The trust reported that admissions to inpatient assessment and treatment units could be reduced by the provision of community based assessment and treatment services.

South Eastern Health and Social Care Trust

The South Eastern Trust reported that a draft protocol had been developed for the transition of looked after children (LAC) to adult services.

The trust described a number of joint working arrangements with education, private and voluntary organisations and further education. The trust also reported on a number of community based clinics in which nursing, behaviour support, psychiatry and psychology services can be accessed. These clinics are not trust wide and the trust identified this as an area for improvement.

The trust reported that children's access to the specialist assessment and treatment unit (Iveagh Unit) in Belfast was through the consultant psychiatrist and that children are reviewed through the LAC process. The increased availability of intensive therapeutic support services and the flexible use of residential care home beds were highlighted as possible methods of reducing the need for children to be admitted to the Iveagh specialist unit. The trust compiles figures on the prevalence of children with autism.

Southern Health and Social Care Trust

The Southern Trust reported having a transition protocol for children with a disability transferring between children and adult services which includes a person centred transfer meeting.

The trust has a range of joint working arrangements with providers of education, sensory support, employment, private and voluntary providers, leisure services, and further education.

Transition planning between community teams and primary care are provided by all professionals involved with the child/young person and his/her family.

The needs of young people with autism were highlighted and, in particular, the need for alternative methods of testing IQ, in order to determine the most appropriate transition pathway. The trust has developed creative partnerships with voluntary and private agencies and promotes direct payments.

Children have access to the Iveagh specialist assessment and treatment unit through their GP and relevant consultant, and this decision is based on assessed need. Children using the specialist unit maintain contact with their community social worker and have input in relation to their needs on discharge.

The trust identified gaps in service provision which result in unnecessary admissions to the specialist assessment and treatment unit. These included access to appropriate residential and long term accommodation. The provision of early intervention and intensive behaviour support and increased access to psychology services is also required.

Western Health and Social Care Trust

The Western Trust referred to a range of protocols and procedural guidance in relation to the transition arrangements for looked after children (LAC) moving from children's to adult services.

The trust referred to its adherence to The Good Practice Guidance on Transition Planning for Young People Leaving Care with a Disability³¹ (Western Trust, Looked After Children Disability Forum).

The children's disability team had established joint working arrangements with education psychology, further education, and children have access to leisure services and sensory support services. Mental health services are provided mainly by learning disability teams and CAMHS³² were reported to exclude referrals from children with an IQ less than 70.

³¹ A good practice guide produced by the Western HSC Trust, Looked After Children Disability Forum on Transition Planning on Young People Leaving Care with a Disability

³² Child and Adolescent Mental Health Service

There are established links with primary health care staff in relation to children with complex physical health needs and bi-monthly meetings between children's disability teams and children's community nursing staff.

There are arrangements in place for referring children to the trust home assessment and treatment service. The trust also reported on accessing specialist assessment and treatment services in Belfast for children with complex physical health needs.

The trust identified gaps in existing services which if remedied could reduce the need for hospital admissions. These included more training for staff working in specialist assessment and treatment services, co-ordinated input from behaviour support and psychology into tier 3 services, emergency respite provision and therapeutic supports within tier 2 services.

The trust reported that there were ongoing service improvement arrangements in place in respect of refining pathways across CAMHS and autistic spectrum disorder (ASD) services. The trust is committed to refining these processes. This includes improving information systems to provide prevalence data.

5.0 Assessment and Recording of Unmet Need

Introduction

The arrangements for recording and reporting unmet need were assessed. Trusts provided comments on difficulties experienced in trying to meet unmet need and the impact of this on service users and their carers.

Belfast Health and Social Care Trust

The trust completes a statutory function report annually, and reports on a six monthly basis through the trust's Corporate Parenting Report, on unmet need. These formal processes are supplemented by internal trust reviews of potential unmet need by the governance leads.

The trust reported ongoing efforts to improve and develop family support services including respite, short breaks and shared care. The trust outlined a need for additional investment in specific service areas, as follows:

- accommodation and intensive support for individuals in transition from children to adult services, including young people in residential care
- domiciliary care and family support, to reduce unnecessary hospital admissions.

The Autism Act 2011 and the absence of adequate funding was cited by the trust as a challenge, given the growing public expectations of service providers.

The impact of unmet need has led to some dissatisfaction, as families experience increasing pressures in their role as carers.

Northern Health and Social Care Trust

The trust referred to weekly case returns of unallocated cases, resource panel records and waiting times. The trust also reports on unmet need through the risk register. The trust has established a Children with Disability Task Force which was reported to be undertaking a root and branch review of unmet need. Difficulties in responding to unmet need were reported to result in:

- extended stays in residential care
- accommodation of a child in a respite bed on a full-time basis
- the emergency use of respite beds for children who require a full-time placement in a crisis, pending care planning.

The impact of unmet need was described by the trust as placing additional pressure on families which has resulted in an increase in formal complaints.

The trust identified a growing demand for direct payments, shared care and full time placements for children. The trust also referenced the needs of

children with complex physical health issues and nursing care needs and inpatient beds for children with severe learning disability/challenging behaviour. Psychology services reported on the needs of children with milder forms of learning disability not necessarily having their needs met by children's disability services.

South Eastern Health and Social Care Trust

Unmet needs are recorded in monthly monitoring and governance records and through the statutory functions report. The trust also maintains records of unallocated cases, refers to the risk register, collates information in relation to unmet needs and forwards this to the trust board.

The trust highlighted a range of actions taken in response to unmet need. These included:

- the establishment of a children's residential home
- joint working with Belfast Trust to meet the accommodation needs of children young people leaving Iveagh
- development of a monthly resource panel
- development of enhanced domiciliary care
- more signposting to other agencies
- provision of support and training for parents and carers.

The trust also reported gaps in specialist skills in residential care settings, a lack of psychiatry input within community settings and a gap in forensic service provision. A therapeutic intensive intervention service would reduce the need for admissions to Iveagh specialist assessment and treatment unit.

The impact of unmet need was reported by the trust as potential family/placement breakdown and risks to other family members/carers when caring for a child with challenging behaviours.

Southern Health and Social Care Trust

The response to unmet need is reported in terms of individual responses, complaints procedures and sharing of information with HSC Board and DHSSPS. Difficulties in attempting to address unmet needs were described in the context of waiting lists for respite services and lack of access to appropriate residential and fostering placements for young people. Other areas of unmet need for children included; access to medium/long term residential care for children with challenging behaviour; gaps in clinical psychology support, and skilled staff to work with children who present with challenging behaviour.

The trust identified the impact of unmet needs on carers and service users experiencing additional stress, and undermining of carers' ability to care. The trust also referred to the additional pressures on frontline staff.

Western Health and Social Care Trust

Unmet need is reported within teams and through trust management structures. The trust's statutory functions report and meetings with HSC Board are also used to report unmet need, alongside professional and clinical accountability arrangements within the trust for highlighting unmet needs.

The trust identified a number of areas of unmet need and gaps in service provision including:

- tier 2 key workers not having capacity to engage in therapeutic work with children or parents
- tier 3 - children not able to access autistic spectrum disorder (ASD) assessments and limited input from speech and language therapy and occupational therapy in relation to ASD intervention
- a gap in service provision for under 5's presenting with developmental delay
- inadequate clerical and administrative infrastructure
- hospice at home services.

The trust reported experiencing significant financial pressures when attempting to address unmet need and the impact of this on service users and carers.

6.0 Conclusion on Community Teams and Services for Children with a Disability

The trusts reported a combined spend of over £17 million per annum on community services for children with disabilities, at the time of the review. This does not include the full cost of psychiatric services provided in community settings nor the full management and administrative costs. The extent to which all trusts split the costs of services provided to children with a disability from those provided to adults was unclear. Specialist behavioural teams continue to work with both children and adults. Trusts rely more on unidisciplinary teams in children's services rather than the multi-disciplinary community teams found in adult services.

Half the costs in children disability services are spent on social work and nursing staff, with proportionately more spent on allied health professionals compared to adult learning disability services. By contrast, there has been much less investment in clinical psychology and challenging behaviour services.

Whilst the range of support provided through community services has grown, the staffing figures presented illustrate marked variation across trusts in the range and extent of staff working in children's disability services. Nonetheless, this represents a considerable investment when averaged over the number of children and families known to the trusts.

However, the lack of suitable community support services for children with a learning disability, may give rise to inappropriate admissions to the regional inpatient facility, Iveagh Unit. Delays in discharge from this service was commented on by trusts. Moreover, some children with complex physical health needs may not survive into adulthood. The resources to undertake preventative work with children and teenagers is limited; a situation that all trusts commented on.

In terms of clinical practice, community teams continue to practice in fairly traditional professional roles. The model of service provision presented was mostly that of generic social service departments undertaking specialist functions, with a range of services provided by social workers, nurses, psychologists and AHPs. Little evidence was presented by trusts of a vision of future roles, relationships, or the reconfiguration of services required to manage the service differently, in terms of Transforming Your Care³³. There is a requirement for trusts to review the duplication of effort by community disability teams. They should consider how best they can reform and modernise service provision in the community, in order to meet the needs of all disabled children.

The failure of agencies and departments to work in a holistic manner, or in partnership with each other, appears to have compounded the barriers faced by disabled children and young people. The establishment of the disability

³³ Transforming Your Care, DHSSPS, December 2011

subgroup as part of the Children and Young People's Strategic Partnership should assist in ensuring that the needs of disabled children are reflected in the planning, commissioning and provision of health and social care.

The proposed new service framework for the Health and Wellbeing of Children and Young People should also help improve the quality of care and outcomes for young people and their families.

Transition Planning

While there is improved communication and cooperation between education and health and social care overall, in effect, two separate planning and delivery processes for transition remain, which often occur at different points in time in a young person's life. The review team was made aware that this issue is currently under review by The Children and Young People's Strategic Partnership (CYPSP) Transition Group. An opportunity therefore exists to provide more meaningful information and guidance to ensure that these young people have their rights of equal access to health, social care and education upheld, to enable them to develop to their full potential.

Views of Service Users and Families

Trusts revealed a complex and varied picture of how services are commissioned and provided to children with a disability, their families and carers. The review team spoke to a number of carers about their experience of service provision. Many experienced frustration in not receiving the support they needed, services not being joined up and a lack of communication and concern about the effectiveness of service provision.

Article 2 of the Convention on the Rights of the Child³⁴ requires provision to be made for all young people with disabilities, without discrimination. Children with disabilities and their families face many additional barriers. Children with disabilities are much less likely to avail of training and employment opportunities. They often encounter difficulties in accessing services, or simply having their voices heard.

Young people with disabilities, in particular children with learning disabilities, encounter difficulties on transition from school and from child to adult health and social care services. The systems for planning for transitions are complex and require negotiation with a range of agencies. It is important that interfaces are managed. Staff said that it is difficult to transfer cases, particularly when there are no secondary behaviour teams to deliver the services required. There is a necessity for a review of the configuration of service provision for disabled children. The integrated nature of work undertaken by teams to manage the transition from hospital to home and from children to adult and other services requires review. Some significant improvements have begun to occur, including the appointment of a Transition Coordinators Service in some HSC trusts.

³⁴ Convention on the Rights of the Child, Office of the High Commissioner for Human Rights, 1989

Some carers of disabled children expressed concerns about the absence of accessible information for young people with a disability. Service users and carers are seeking access to more flexible respite care packages. These appear to be better developed in some trusts than in others. The delay in accessing respite care arrangements can cause stress and anxiety for service users and their parents.

It was difficult to access accurate data on how many disabled children are awaiting access to specialist services across trusts, or how many children/young people with autism there are in any trust. Without a basic awareness of the needs of the local population, it is hard to understand how the Health and Social Care Board or the trusts can be assured that services are being commissioned appropriately. The HSC Board, as commissioner, needs to review the quality of information about the needs of young people with disabilities, including autism.

Commissioning of services in the future needs to be carried out within a framework of formal and evidence based guidance about standards and outcomes, as set out in the service framework for learning disability and the principles of:

- 'Every Child Matters (DHSSPS) (2004)'
- The Strategy for Children and Young People in NI: "Our Children & Your Young People - Our Pledge 2006-16"
- DHSSPS 'A Healthier Future: A Twenty Year Vision & Wellbeing in NI 2005-25', DHSSPSNI Priorities for Action 2010-11
- Transforming Your Care 2011.

The purpose of the review was to provide a baseline review of community services for children with a disability. The findings highlight the challenges facing the trusts and what needs to be done to improve services. The review team considered that the development of stronger partnership arrangements by trusts with other providers of care, and a drive for modernisation based on the principles of Transforming Your Care, will help to bring about sustainable transformation. The local commissioning groups (LCGs) provide an opportunity for the system to focus on improvement and the development of innovative models of service provision, that should help meet the needs of disabled children and their families.

7.0 Recommendations for Trusts - Children with a Disability

The review team appreciates that the new organisational arrangements for disabled children's services within trusts require time to become fully established. As part of that process, there are a number of areas for service improvement that need immediate consideration. These echo some of the issues identified in the review of adult learning disability services. Common approaches may well be found to tackling them. We would also urge greater sharing of information across trusts with respect to innovative practices. The review team note the value derived from such initiatives to date.

The per capita spend on community services for children with a disability exceeds that of the adult population with a disability. Hence it is even more crucial that trusts critically review the efficiency and effectiveness of the services currently provided to children to address current challenges and unmet needs.

Review of Investment in Children's Disability Services

Trusts should review investment in models of support services for children and young people with a disability and their families, including access to specialist advice on:

- information and financial entitlements
- entitlements to a named key worker around the time of diagnosis
- support for siblings
- support for other families/parents in a similar situation
- support that recognises lifelong caring responsibilities /information and access to direct payments.

The goal is to empower parents and to ensure that specialist services are targeted to those most in need.

Review the Current Model of Service Delivery by Children's Disability Teams

Trusts, in view of the variation in the range and skill mix of staff, should review all aspects of service delivery for disabled children and young people to ensure that the current configuration of children's services meets their needs in an effective integrated, holistic and child and family centred manner.

Involvement of Children/Parents/Carers in Assessment and Care Planning

Trusts should ensure that the child and their parents/carers are involved in all assessments, discussion about care planning and discharge processes.

Managing Transitions and Related Care

Every disabled child leaving full time education should have a care and support plan, based on the young person's identified needs, wishes and known preferences. They should be encouraged to ask questions and receive relevant information in a format they can understand. Trusts should ensure that effective arrangements are in place, involving children, to plan for their transition to adulthood from age 14 and prior to leaving school.

Trusts should ensure that attention is given at particular transition points for example, the transition from hospital to community services and transition from children to adult services. Key standards for these circumstances are available in the document "Integrated Care Pathway for Children and Young (People with Complex Physical Healthcare Needs" DHSSPS (2009))³⁵.

Data Collection on Prevalence of Autism

The Autism Act 2011 has placed a statutory duty on the health and social care trusts to provide the DHSSPS with data on the prevalence of autism in their respective areas. Health and social care trusts should examine how the prevalence of autism could inform and guide the gathering of data on a wide range of disabilities/conditions. Trusts should ensure that due regard is given to ensuring that geographically dispersed populations such as children with disabilities and their families are given fair and equal consideration in the planning and delivery of services.

Partnership Working

During school years, health and social care and education staff should seek to ensure that appropriate coordination, collaborative commissioning and planning of services for disabled children is shared by all agencies.

Development of Tiered Model of Service Provision

Given the lack of an agreed tiered model of service provision, each trust has developed services differently. A number of approaches could be considered by trusts in relation to the development of a tiered model of service provision (see Appendix 3).

³⁵ People with Complex Physical Healthcare Needs" DHSSPS (2009)

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 services for disabled children, which can respond, as necessary, outside 9am to 5pm (Monday to Friday in community settings).

Family Support Services

Trusts should review the level of family support, short breaks and child care routinely available to children with a disability to ensure access to a flexible range of family support services.

Services should be based on assessed need, including domiciliary care; host family schemes with trained and approved carers; social and recreational activities provided by volunteer and paid staff; and a range of short breaks and respite care services.

Communication with Children with a Disability and their Carers

Trusts should ensure that staff develop accessible easy to read information for children and young people with a disability. The HSC Board should consider the types of information, advice and support available for parents and carers, the types of support offered to families, and eligibility for services provided by trusts.

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 the ease of use.

8.0 Recommendations for HSC Board - Children with a Disability

Future Configuration and Commissioning of Children's Disability Services

The HSC Board, in view of the findings of this report, should review the future configuration and commissioning of services in order to ensure they can appropriately meet the assessed clinical and social care needs of children with a disability, taking account of the priorities set out in Transforming Your Care.

Value for Money

The HSC Board should review the outcomes of different service models for children and young people whose behaviour presents a challenge. The HSC Board should seek evidence that any new investment is linked to significant reform and service improvement, as a condition of approving new service developments.

Eligibility and Access Criteria

The HSC Board should ensure that procedures and systems which define, map and determine eligibility for services reflect the needs and circumstances of disabled children, young people and their families across Northern Ireland, to ensure equality of access.

Evaluation of Service Frameworks

The HSC Board should discuss with the trusts the development of evaluation frameworks for family support initiatives and interventions. The views of children and young people with a disability and their families should be reflected in the evaluation framework.

Review of Information Database Systems

The HSC Board should review, with trusts, the range of information systems to record client information and information about services received, given the number of disadvantages identified by trusts in relation to current systems of data capture. The continuing use of a learning disability register by trusts should be reviewed by the HSC Board.

Development of Outcome Measurement of Clinical Effectiveness

The review team found little evidence apart from specialist teams of the use of clinical or social care outcome measurements linked to service efficiency and effectiveness. This should be reviewed by the HSC Board and discussed with trusts to ensure that outcomes can be demonstrated effectively.

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

- reduction in level of health supports required
- improvement in functioning of children with a disability so as they can live in the least restrictive environment
- shortest length of time taken to return to optimum functioning, when possible, 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.

Access to Training and Employment Opportunities for Young Disabled People

The HSC Board should commit to the introduction of a specific programme to address the needs of disabled young people in relation to access to training and employment opportunities. The HSC Board should work in partnership with schools and Department of Employment and Learning recognising that training and employment opportunities can impact on the health and social care needs of young people and their carers.

Development of a Skilled Workforce

Commissioning of services for children with a disability should be needs led and planned interventions should be evidenced based and lead to the development of a skilled workforce in all tiers of the service delivery in the community.

List of Abbreviations

ADHD	Attention deficit-hyperactivity disorder
AHP	Allied health professions
All About Me	Communication book recording the preferences of a child with a learning disability
ASD	Autistic spectrum disorder
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
ePEX	Electronic information database
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
DSM IV	Diagnostic and Statistical Manual of Mental Disorders fourth edition.
GP	General practitioner
HSC Board	Health and Social Care Board
ICD-10	Tenth revision of the International Statistical Classification of Diseases
LAC	Looked After Children
LCID	Local Community Information Development
MDT	Multidisciplinary team
MH & LD	Mental health & learning disability
Northern Trust	Northern Health and Social Care Trust
OT	Occupational therapist
PARIS	Patient Record Information System
RBHSC	Royal Belfast Hospital for Sick Children
PROMOTE	The team that provides behaviour support services for persons with diagnosis of learning disability and mental health
RQIA	Regulation and Quality Improvement Authority
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
VOYPIC	Voice of Young People in Care
WHSC	Western Health and Social Care Trust
Wraparound	A service in Southern Trust that enables children with disabilities to have access to information, assessment

and, where appropriate, services which provide the social, health and educational support.

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

Appendix 1

Table A1: The number of WTE 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	12.47	21.6	22.3	29.84	18.6	104.81
	Adult	26.19	34.15	21.09	25.64	16.5	123.57
Community LD 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 & Language Therapy*	Child	20.36	20.5	7.37	33.09	17.7	99.02
	Adult	3.34	7.3	2.4	4.0	3.0	20.04
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 (Working across child and adult services)	Child						0.0
	Adult	2.1	4.0	8.4	7.5	2.6	24.6
Challenging Behaviour Services (In some trusts, these personnel work across child and adult services)	Child		5.4			2.5	7.9
	Adult	5.8	10.9	6.16		2.5	25.36
Psychiatry (Sessional time only reported for children)	Child		Provided BHSCT	Provided BHSCT		1.0	1.0
	Adult	2	Provided BHSCT	Provided BHSCT	2.8	2.0	6.8

*Trusts may have included all therapy staff involved with children and not just those with a disability. Also trusts may have included all bands of staffing such as therapy assistants which would further inflate the WTEs. The number of staff working in Community Children's Nursing was provided by only two trusts (Northern and Western) – over 70 WTEs in both and thus probably over 150 in all trusts. NB. A further 7 WTE social work staff are employed at the Royal Belfast Hospital for Sick Children. (Note: A total of around 650 WTE equivalent staff are currently employed in these services).

Appendix 2 Table A2: The teams reported by each Trust working with CHILDREN with a Disability
(NB Teams are grouped to show similarities and differences across trusts).

Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust
NW Belfast Community Team – Social and Nursing	Children with Disabilities Social Work Teams	Social Work services – Ards Team	Social Work Team - Newry	Disabled Children’s Team – Derry (Social Worker, CNLD, psychiatrist, psychologist, paediatric social work and hostcare).
SE Belfast Community Team – Social Work and Nursing		Social Work Services – Down team	Social Work Team - Armagh	Disabled Children’s Team – Omagh (see above)
		Social Work Services – Lisburn team	Social Work Team - Craigavon	Disabled Children’s Team – Fermanagh (see above)
		Community Nursing Team - Ards	Community Nursing Team -Newry	
		Community Nursing Team - Down	Community Nursing Team - Armagh	
		Community Nursing Team - Lisburn	Community Nursing Team - Craigavon	

Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust
	Child Development Team - Consultant Paediatrician, specialty grade doctor, SLT, OT, physio, dentist, orthoptist			
	Causeway Child Development Team - Consultant Paediatrician, physio, SLT, OT, dietician, dentist, orthoptist, community children's nursing, SW, Ed psych			
	Children's Challenging Behavioural Services (CCBS)		Children's Behaviour Support Service: multi-disciplinary	Behaviour Support Teams (Children and adults)
	ASD Diagnostic Service - paediatrician, SLT, OT, Ed psych variable composition		Autism Support Service – Diagnostic & Intervention team (SWs, Autism support workers, clinical psychology and OT):	

Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust
Children's Interdisciplinary Schools Team (CIDS Service)				
	Community Children's Nursing Teams			Community Children's Nursing (specialist nursing services – epilepsy, diabetes, continence, respiratory)
				Home Treatment Team (Nurse led).
Speech and Language Therapy Services	Speech and Language Therapy (SLT) Children with Disability Service		Speech and Language Therapy team	
OT teams – Special Schools: Cedar, Lodge, Greenwood, Oakwood, Glenveagh, Tor Bank, Segal House	Children's OT		OT team	
Physiotherapy Children's Community and Educational team	Paediatric Physiotherapy		Physiotherapy Team	

Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust
Royal Jubilee Maternity Hospital/ Royal Belfast Hospital for Sick Children – Social Work team				
	Podiatry			
	Dental			
			Sensory Disability Team	
				Transition Team (Managed within MD team).

Appendix 2 Table A3: Expenditure per Child by the Five HSC Trusts in 2010-11

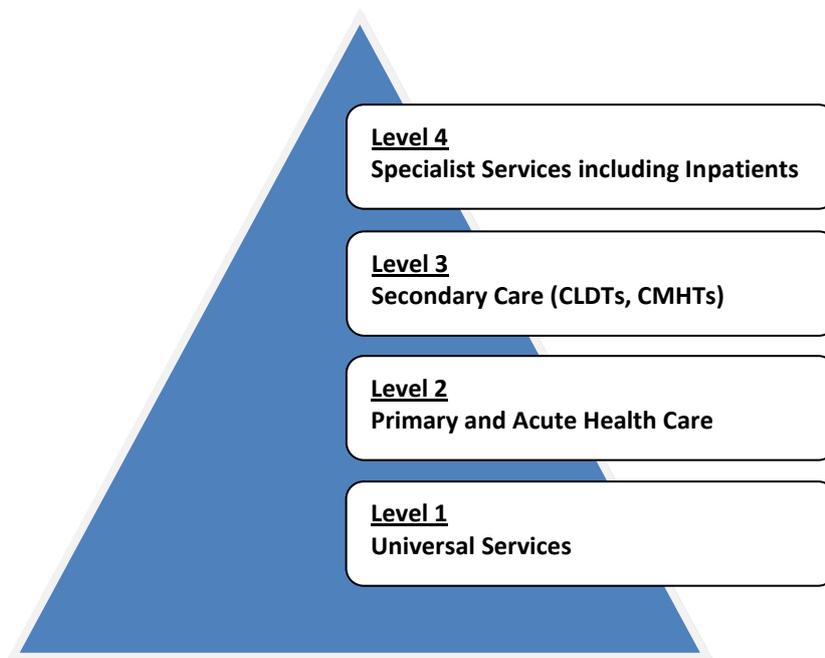
Discipline	Belfast Trust	Northern Trust	South Eastern Trust	Southern Trust	Western Trust
	N=85,226	N=120,588	N=89,256	N=101,481	N=84,347
Social workers	£7.65	£5.61	£9.79	£5.94	£9.50
Community Children's Nursing (CCN)	£7.09	£12.50	£8.35	£3.05	£7.02
Community LD Nursing	£1.94	£0.72	£2.31	Included CCN	£2.12
Occupational Therapy	£6.12	£0.99	£2.44	£3.25	£5.42
Speech & Language	£8.74	£5.66	£3.24	£3.81	£8.02
Physiotherapy	£5.83	£4.40	£1.46	£3.53	£4.59
Clinical Psychology	£0.43	£0.89	£2.62	£0.47	£0.84
Challenging Behaviour Services	£0.46	£1.68	£1.46	£0.58	£1.58
Psychiatry	£0.29	Not supplied	£1.17	£0.35	£1.52
Family support workers	£0.16	-	£1.32	-	-
Management & Admin	£1.67	£1.72	£2.27	£0.89	£0.95
Total reported by trust	£44.40	£34.17	£36.43	£21.87	£41.55

Table A3 takes no account of the variation in the numbers of children with a disability. Trusts were asked to report on the number of children with a disability in receipt of services in the financial year April 2010 to March 2011.

Appendix 3 Key Service Components

All children with a disability are eligible to receive universal services. A proportion will need additional secondary care services and a minority will require the full range of specialist care assessment and treatment services.

Diagram 1 - Service organisation for meeting the needs of children with disabilities.



The relationships between these key service components are represented in Diagram 1.

Level 1

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

Level 2

Children with disabilities should 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

Children's disability teams should provide assessment, treatment and some on-going support for children with moderate degree of mental health need (significant anxiety and depression, psychotic disorders, and cognitive impairment). These teams would need to have expertise in dealing with behaviour problems associated with these conditions with the whole range of learning disability and coexisting autism and Attention deficit-hyperactivity disorder (ADHD). Access to Improving Access to Psychological Therapies (IAPT) services also falls under this heading.

Level 4

These services need to have expertise in dealing with children with a disability 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, specialist forensic practitioners 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 specialist psychiatric hospital services for children 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



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