# Agenda Item 48 Appendix 1



# Review of Therapy Services for Brighton and Hove Children's Trust

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A division of



November 2009

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#### The College of Occupational Therapists

The College of Occupational Therapists (COT), a registered charity is a wholly owned subsidiary of the British Association of Occupational Therapists. It is primarily involved with the setting of professional and educational standards for occupational therapy together with the promotion of research activity, evidence based practice and the continuing professional development of its members. The College represents the profession on a national an international level and has 11 accredited Specialist Sections supporting expert practice in key areas. The British Association of Occupational Therapists is the professional body and trade union for occupational therapy staff in the UK with a strong country based regional and local membership structure.

#### The College of Occupational Therapists Consultancy Service

The Consultancy Service, a not-for-profit division of the College of Occupational Therapists provides confidential, expert advice on the delivery of multi-disciplinary and occupational therapy services. The service offers a wide range of services including: multi-disciplinary and occupational therapy service reviews, effective recruitment solutions, service integration, disability consultancy, interim management and supervision, and training.



# Review of Therapy Services for Brighton and Hove Children's Trust

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# **EXECUTIVE SUMMARY**

- 1. A review of children's therapy services was commissioned by the PCT commissioners and the Head of the Integrated Children's Development and Disability services.
- 2. The purpose of this document is to provide recommendations on the therapy services to provide the best service for the best value, in terms of:
  - current performance and capacity,
  - the effectiveness of current pathways across health and education
  - the development of further integration.
- 3. The extent of the brief was to work closely with service providers and consult as many stakeholders as possible within the limited timeframe of the project.
- 4. The review draws heavily on the wealth of existing information referring to the Trust strategy, various consultations with parents/carers and recent preparation for a business case.
- 5. The review was also based on information obtained from detailed questionnaires completed by providers and stakeholders and interviews with providers and available stakeholders.
- 6. The agreed timeframe precluded a full representation of stakeholders and an assumption was made that the views contained in this document are broadly representative.
- 7. The review has taken direction from the following seminal documents:
  - Commissioning a World Class Service. (DH 2007)
  - Every Child Matters(DH 2003)
     Parliamentary Disabled Children's Review (SO 2007)
  - Improving the Life Chances of Disabled People (DWP/DfES/DH 2005)
  - Removing Barriers to Achievement (DfES 2004)
  - National Service Framework for Children, Young People and Maternity Services, especially Standards 6 and 8. (DH 2004)
  - Palliative Care Services for Children and Young People in England. (DH 2007)
  - Aiming High for Disabled Children; Better support for Families (DfES 2007)
  - The Bercow Review of Services for Children and Young People (0-19) with Speech Language and Communication Needs (DCSF 2008).
- 8. Local policy drivers which have influenced the review include:
  - Draft Commissioning Strategy 2005/6
  - The Disability Strategy three years on A stock take. July 2009
  - Background papers from parent/carer consultations December 2008 to present
  - Business Case and Options Appraisal 2009.



- 9. The review established that the Trust has made considerable progress towards achieving integrated services.
- 10. Education Health and Social Care have been combined in a single structure with a vision and purpose to improve life chances for all children
- 11. There is commitment to disabled children as evidenced by the Trust as a signatory to the Every Disabled Child Matters charter and the integrated care pathway in the disability service.
- 12. There is further scope for integrating and co-ordinating therapies outside of the Child Development Centre.
- 13. Further development and the formal implementation of the principles of the Early Support Programme and the Common Assessment Framework (CAF) will assist in extending the ethos of the 'team around the child'.
- 14. The role of keyworker or lead professional will also ensure that families have a point of contact and assistance in navigating services and contribute to the efficiency of services by reducing duplication.
- 15. Parents are well organised and enthusiastic partners and wish to bring their expertise to all appropriate strategic and operational meetings to ensure that services have a child and family focus.
- 16. Anomalies in the equity of provision have been raised and need to be addressed to make the system fair for all.
- 17. Funding issues relating to the Chailey School impact on the ability of community therapists to provide a service to children with complex needs now included in local mainstream schools.
- 18. Training has been an iterative theme for providers and stakeholders. There is concern in terms of ensuring that therapists are appropriately skilled and updated, that parents are empowered through the requisite training for them to manage their children's needs and that the wider children's workforce are skilled up to include complex children in universal settings.
- 19. A decision is needed about a cost effective way of progressing this, whether through additional recruitment of therapists or buying in defined training from outside providers.
- 20. Therapy services are working to capacity and they should explore different working practices and collaboration with other teams e.g. advisory teachers to maximise resources. Speech and Language Therapy is pursuing this course of action.



- 21. Physiotherapists are to be transferred to the community team in February and this presents a fresh opportunity to examine the interface of the physical therapies to stretch resources.
- 22. Occupational Therapy is struggling with long waiting lists and times.
- 23. Therapy services should be looking to work more closely across issues such as clinical governance where many examples of good practice appear in individual services.
- 23. Therapy services still appear to be working in parallel rather than in an integrated way.
- 24. Although there is no benchmarking standard for number of therapists, the services do not appear to be obviously under-resourced by comparison with similar services.
- 25. Other services are increasingly looking to skill mix to provide additional capacity and provide direct intervention under supervision of qualified therapists. This has the potential to provide transformational change and is recommended in the NSF standard 8 as the development of a para-professional workforce.

# **Key recommendations:**

- 26. Twelve recommendations have been made encompassing the following:
- 26.1 Data collection and records management.
- 26.2 Information about services
- 26.3 Capacity and Best use of Resources
- 26.4 Skill mix
- 26.5 Training
- 26.6 Access
- 26.7 Parent Participation
- 26.8. Child and Family Centred Services
- 26.9 Outcome focused Services
- 26.10 Equity
- 26.11 Gaps in services
- 26.12 Fundamental Principles for inclusion in Service Specifications.



#### TERMS OF REFERENCE

- A review of children's therapy services was commissioned by the PCT Commissioners and the Head of the Integrated Children's Development and Disability Services.
- 2. The purpose of this document and the requirements for the review are:
  - To make an analysis of current performance and capacity issues and to examine current care pathways across health and education and,
  - to make recommendations to develop further integration to provide the best service for the best value.
- 3. The terms of reference required the Advisor to work closely with service providers and to consult with as many other key stakeholders as possible within the available timeframe.
- 4. The review draws heavily upon the wealth of existing service information and papers made available to the reviewer including the views of parents/carers through the various consultations facilitated by Amaze, the local voluntary parent organisation.

#### **METHODOLOGY**

- This review was conducted through questionnaires for providers and stakeholders

   In addition a series of in-depth interviews was held with all providers and
   available stakeholders including parents.
- 2. In view of the tight three week timeframe there are gaps in stakeholder representation, however every effort was made to ensure that key stakeholders were included. Fieldwork visits consisted of in-depth interviews with providers and stakeholders, all of whom completed preparatory questionnaires and were generous with their time and knowledge.
- 3. The interviews allowed for a frank exchange of views and the opportunity to 'showcase' services and also to identify gaps in provision.
- 4. Providers, users and stakeholders wished their views to be reflected in the report and the author has made every attempt to encapsulate the themes and the exceptions that were highlighted.





- 5. In the short timeframe it was not possible to gather a full range of views and an assumption is made that the opinions and recommendations are broadly representative.
- 6. The list of interviewees is in appendix A





#### NATIONAL CONTEXT

- 1. The review has taken direction from "Commissioning a World Class Service (DH 2007) which indicates that therapy services should deliver quality services and health outcomes, provide value for money, meet the needs of children and focus on outcomes rather than historical provision.
- 2. Other significant **national drivers influencing the shape of children's services** include:
- 2.1 2003 **Every Child Matters** (DH 2003), encompassing better co-ordinated and integrated services.
- 2.2 The creation of **Children's Trusts** bringing together statutory agencies to work together in the best interests of children and families. Brighton and Hove is well recognised as a trailblazer in this respect.
- 2.3 **The Parliamentary Disabled Children's Review** (SO 2007), recognised that disabled children are likely to have poorer outcomes across a range of indicators compared to their non disabled peers and more difficult transitions to adulthood with poorer employment and social prospects. This may have the consequence of preventing them integrating into and contributing to their communities. Their families are more vulnerable to breakup due to the pressures of providing care.
- 2.4 **Improving the Life Chances of Disabled People** (DWP/DfES/DH 2005) sets the challenge of achieving equality for disabled people by 2025.
- 2.5 **Removing Barriers to Achievement** (DfES 2004) promotes action to improve Special Educational Needs (SEN) provision in mainstream schools and encourage inclusion.
- 2.6 The National Service Framework (NSF) for Children, Young People and Maternity Services (DH 2004)sets standards for children's health and social care services especially around co-ordinated and integrated services with a special emphasis on the contribution of therapists and the role of the 'para-professional'. Standards 6 and 8.
- 2.7 Palliative Care Services for Children and Young People in England DH 2007) has highlighted the needs of the many disabled children and young people who have life limiting and life threatening conditions.
- 2.8 **Aiming High for Disabled Children** (DfES 2007) presents imperatives for disabled children and their families to lead lives like their non disabled peers, The three priority areas for action arising from this White paper are:
  - Access and empowerment.



- Responsive services and timely support
- Improving quality and capacity.
- 2.9 **The Bercow Review** of services for Children and Young People 0-19 with Speech, Language and Communication Needs (DCSF 2008) determined 5 key themes:
  - Communication is crucial.
  - Early identification and intervention are essential.
  - There needs to be a continuum of services designed around children and young people.
  - Joint working is critical.
  - The current system is characterised by high variability and a lack of equity.

These themes are central to providing quality therapy services across the disciplines.





#### LOCAL POLICY DRIVERS

# 1. Draft Commissioning Strategy 2005/6

- 1.1 Following the Children's Trust service redesign process, a review was launched in November 2004 resulting in a strategy, which included the vision that by 2010 the life chances of all children in Brighton and Hove would be improved, so as to maximise their individual potential.
- 1.2 The standard for disabled children and young people and those with complex healthcare needs was that they should receive co-ordinated high quality child and family centred services based on assessed needs which promote social inclusion and where possible enable them and their families to live ordinary lives.
- 2. The Disability Strategy three years on A stock take, July 2009
- 2.1 This review was undertaken to examine what has been achieved and to identify the key strategic issues.
- 2.2 There was evidence that some of the ambitions from the 2005 strategy had been fulfilled.
- 2.3 It was felt that developments in the integrated care pathway and in the integrated service represent significant achievement, while recognising that further challenges remain.
- 2.4 There is a need to clarify pathways for mild and moderate disabilities and complex medical needs.
- 2.5 The occupational therapy service is integrated across health and social care under one line manager and this should facilitate equipment issues across the homeschool divide.
- 2.6 There is an effective integrated equipment store provided in house.
- 2.7 There was recognition of the importance of identifying specific targets and in having a clear evidence base.
- 2.8 The Children's Disability and Complex medical needs Partnership Board has been formed and is co-chaired by the Director of Amaze and a Head of Service.
- 2.9 The strong partnership with parent carers together with robust support and payment is a good example of partnership working.
- 3. Review of waiting lists.

A review of waiting lists for therapies was undertaken in June/July 2009 and



submitted to the PCT. As a result £50,000 was made available for 6 months to reduce waiting times for physiotherapy and occupational therapy from referral to initial assessment.

#### 4. Review of Therapies

- 4.1 From July-September 2009 a review of therapies was undertaken resulting in proposals to support a development programme in the following areas.
  - Training and development for practitioners and parents/carers
  - Communication and information sharing protocols and standards setting.
  - Development of service specifications.
  - Ongoing work to evidence equity of provision in therapies and to highlight shortfalls.
  - Enhancement of therapy provision for direct and indirect therapy.
- 4.2 There is a need to interpret national guidance from Aiming High for Disabled Children and Healthy Lives, Brighter futures to meet local requirements and establish key performance indicators. (DfES 2007)
- 4.3 Identification of significant issues were identified in relation to data collection, both in relation to the functionality of the integrated service (how data is collected and shared about individual families receiving services) and for strategic planning.
- 4.4 Brighton and Hove have a database for Children with Special Needs, known as the Compass and maintained by Amaze, the local voluntary parent organisation. The quality of information collected has improved significantly in terms of informing future commissioning.
- 4.5 Currently information is held on 1500 children and young people, with updated information (collected in the last 2 years) on 1000 families.
- 4.6 The integrated service and integrated care pathway have greatly improved the experience of parents and professionals in simplifying some of the previous complexities of navigating the system.
- 4.7 There is an integrated management structure with a single operational head of service with commissioning responsibilities for disability services.
- 4.8 The referral form to the service is based on the CAF and seeks to ensure consistent information is received regarding the needs of individual children.
- 4.9 The ICP provides a more planned and holistic model of assessment considered by a multidisciplinary team and each child has a single plan which co-ordinates different interventions and professionals and engages with parents and carers.
- 4.10 The range of support and/or intervention is dictated by assessed need, not age or address.



- 4.11 There remain different waiting lists for intervention/treatment and these continue to vary.
- 4.12 The Seaside View Child Development Service now houses most of the integrated team with the exception of the pre-school team (PRESENS).
- 4.13 The review recognises the need for further development of this model.
- 4.14 The issue of timely interventions highlighted in the 2005 review is being scrutinised by a review group of practitioners, managers and representatives from the community and voluntary sector and some short term funding has been allocated to improve waiting times for physiotherapy and occupational therapy.
- 4.15 Much work has been done to engage with and empower parents, using the Compass to provide information, services and support.
- 4.16 Parent training is an area for future development.
- 5. Background papers from parent/carer consultations
- 5.1 Brighton and Hove Children's Trust is fortunate in having very committed and involved parents who are keen to use their experienceto inform and shape services.
- 5.2 Consultation events in December 2008 recognised the services and expertise of committed and responsive staff and highlighted examples of good practice.
- 5.3 Key findings were:
  - a) The need to listen to parents and respond to their concerns
  - b) The value of honest open and empathetic communication.
  - c) Recognising the parent as 'expert' in understanding their child.
  - d) Transparent and accountable decision-making at all levels.
  - e) Training at all levels and in all settings, including for parents.
  - f) Additional resources,
  - g) Including parents in service planning and development
- This is in concert with the focus in 'Aiming High for Disabled Children' (DfES 2007) for the development of a parent participation forum in every area to enable parents to be represented at all significant strategic meetings and to be actively engaged with commissioners and providers in shaping services
- 6. Benefits of a Multidisciplinary Therapy Service for Children and Young People in Brighton and Hove
- 6.1 Brighton and Hove Children's Trust has made considerable progress towards achieving integration.



- They have brought together Education, Health and Social Care in a single structure with a vision and purpose to improve life chances for all children, guided by the principles from Every Child Matters and subsequent Government guidelines.
- 6.3 In relation to disability they have elected to adopt an inclusive definition which includes:
  - Profound and Multiple Disabilities
  - Complex Health Needs including acquired and/or life limiting conditions
  - Severe Learning Disabilities
  - Specific Learning Disabilities
  - Mild and Moderate Learning Disabilities
  - Speech and Language Difficulties
  - Sensory Impairment
  - Autistic spectrum Disorder
- 6.4 Paediatric therapists from Occupational Therapy, Physiotherapy and Speech and Language Therapy have knowledge and skills which are critical in contributing to the development of children in all of these groups.
- 7. Local Demographic information
- 7.1 Trends and forecasts drawn from national studies indicate a consistent increase in need and demand for therapy services.
- 7.2 The prevalence of severe disability and complex needs has risen together with improved diagnosis.
- 7.3 This is due to a number of factors including increased survival of pre-term babies and increased survival of children following severe trauma or illness.
- 7.4 Children with life limiting conditions have better life expectancy due to improved treatment and support.
- 7.5 In addition, there has been a significant increase in the number of children identified with autism and a variety of special educational needs.
- 7.6 Identification of the need for therapy intervention is recognized by growing numbers of referrers across a range of agencies.
- 7.7 From the 2005 Strategy, it was estimated that, if 7% of the child population was disabled, there would be approximately 3646 disabled children in Brighton and Hove. Additionally the prevalence of autism is estimated to be 1%.
- 7.8 450 children were receiving services from the Developmental Child Health Services.



7.9 268 children were open to the Disabled Children's team.





# **NOVEMBER 2009 REVIEW OF THERAPY SERVICE**

# The provider perspective

# 1. Occupational Therapy

- 1.1 There are 5.6 WTE staff, well distributed through the grading structure from Band 6-8a for Health and similarly for Social Care with 1 WTE assistant and administrative support.
- 1.2 They have an open caseload of approximately 400 cases (Health) and 43 allocated, 11 duty cases (Social Care). This indicates s a high caseload average per therapist
- 1.3 The waiting list is 92 (Health) and 18 (Social Care) with the longest waiting time at 33 weeks (Health) and 15 months (Social Care for adaptations).
- 1.4 Although additional funding was made available to address waiting lists, the service has had unforeseen difficulties with sick leave for individuals who were working to reduce the waits.
- 1.5 The numbers of referrals are increasing (especially for developmental coordination disorder)
- 1.6 Children with physical disabilities remain 'open' to the service with episodes of high or low intervention.
- 1.7 The referral criteria are standard for similar community services.
- 1.8 Referrals are accepted from other professionals but not from parents/carers and all referrals are processed through the multidisciplinary referrals panel.
- 1.9 Children/young people are seen across a range of settings including home and mainstream/special school.
- 1.10 There is an integrated community equipment store provided in-house which works well so that the provision for equipment at home is quite smooth. There are some difficulties with the provision of equipment at school due to constraints in funding streams.
- 1.11 Wheelchair services are provided through adult services under South Downs Health and are adequate for standard items.
- 1.12 Children and young people now have an expectation of more sophisticated, state of the art wheelchairs, not provided under the current arrangements.



- 1.13 Whizzkidz are entering into partnerships with Trusts to provide children and young people with appropriate wheelchairs and may represent a way forward for children and young people to receive what they want.
- 1.14 Challenges for the service include:
  - Providing a service to an increased number of children with physical disabilities in mainstream settings. These pupils formerly attended a local independent specialist school for PD, Chailey Heritage. With increasing inclusion in local mainstream settings, the team find it difficult to meet the needs of these pupils without having received any additional increase in resources.
  - Releasing staff from casework to provide training across other settings. The
    work of Professor David Sugden at Leeds University has demonstrated the
    efficacy of empowering teaching staff and parents to provide therapeutic
    programmes. The occupational therapist's could look at devolving
    responsibility for areas such as 'handwriting' to schools, with appropriate
    training and support.
  - The need for engineering backup for equipment maintenance across occupational therapy and physiotherapy.
- 1.15 The deployment of the physiotherapy team in the integrated disability service from February 2010 provides new opportunities for increased joint working and shared policies and protocols.
- 1.16 It will also present the chance to look at discharges within the services ensuring that an open caseload refers only to those children currently receiving an episode of care and that the review process is carefully managed so as not to unnecessarily burden the system and reduce capacity for new referrals to be seen.
- 1.17 The development of skill mix across the physical therapies would provide opportunities to use assistants in a number of areas
  - Organising equipment issues
  - Assisting in running groups so as to free up a therapist for other more specialist work
  - Carrying out programmes under the direction of a qualified therapist in order to create opportunities for more direct work with children.

#### 2. **Physiotherapy**

2.1 The Physiotherapy service has been provided from the acute hospital and has not been a community service as such.



- The community team (3.467wte) is to be TUPE'd over to the integrated service from February 2010.
- 2.3 There is no designated administrative support.
- 2.4 This move represents further progress towards an integrated service and a fresh opportunity for this cohort of staff to work together with colleagues to plan a clinically co-ordinated service around the needs of children and families.
- 2.5 Current community caseload is approximately 220 with an additional 65 in special schools.
- 2.6 To date there had not been available capacity within the service to review the caseload in order to understand whether all these are active cases.
- 2.7 There appears to be a high ratio of cases per therapist (55:1) but without accurate caseload information this cannot be validated.
- 2.8 There were 128 new referrals in the last financial year, with 41 awaiting assessment as at 1.11.09.
- 2.9 Average waiting times stand at 6 weeks for preschoolers and 4 months for school age pupils, all of which falls within the 18 week waiting time target.
- 2.10 Short term additional resources have been provided to ensure reduced waiting times.
- 2.11 The physiotherapy assessment and intervention service has been based at the Child Development Centre for the past two years, where excellent working relationships have been established with other professional groups and where physiotherapy is very much part of the integrated care pathway.
- 2.12 The service is provided within the CDC, with one off visits to nursery/home for preschoolers and group sessions within the centre.
- 2.13 School age children receive an assessment and therapy service at the CDC with one off school visits to observe and/or advise. They are currently unable to provide group sessions to this age group.
- 2.14 An issue of inequitable provision was highlighted within schools, where Education fund additional hours to provide direct intervention for pupils with complex needs who have physiotherapy specified on their statements. There are other pupils who are not eligible for this enhanced provision but may have similar levels of need.
- 2.15 As with Occupational Therapy, the physiotherapists are struggling to meet the needs of those pupils who formerly attended Chailey Heritage School.
- 2.16 Physiotherapists provide direct input to Hillside, Downsview, Downsview Link College and Easthill Park Nursery, all of which are special educational settings.



- 2.17 There is a paucity of explicit protocols and policies, probably as they have been a splinter group from an acute service, so there is no explicit information regarding eligibility, packages of care, discharge criteria etc.
- 2.18 However, with the proposed move to the disability service, it is probably advantageous to be in a position to make a fresh start based on an integrated approach.
- 2.19 The referral process is through the referrals panel with any professional able to make a referral. Parents cannot refer directly.
- 2.20 The physiotherapy team has not yet been fully involved in the Early Support programme or the CAF process.
- 2.21 Clinical Governance will need to be established with the implementation of clinical supervision, service audits and the consistent use of outcome measures.
- 2.22 User feedback and parent participation in shaping services should be introduced to meet the core offer (Aiming High for Disabled Children (DfES 2007).)
- 2.23 These clinical governance issues should be managed through multidisciplinary consensus and across services.
- 2.24 Challenges for the service include:
  - Matching resources to demand when physiotherapy is seen to be a community service.
  - Urgent need for administrative support to allow efficient and appropriate use of resources.
  - Extending skill mix to allow for more direct work under supervision of qualified staff.
  - Available capacity for staff to develop policies and protocols for the service and to provide clinical supervision.

#### 3. Speech and Language Therapy

- 3.1 The service consists of 25.66 SLT's supported by 3.06 administrative staff, configured into 3 locality teams and a complex needs team. There is a senior professional lead for the service who also carries a clinical caseload.
- The current active caseload is approximately 2670 with annual referrals of around 1518.



- 3.3 Average waiting times are 6-8 weeks for preschoolers and 6-8 weeks for school age children.
- 3.4 The service provides assessment, intervention, advice and training across a range of settings including health clinics, children's centres acute hospital, educational settings, (including specialist language unit, behaviour support facility, mainstream and special schools/nurseries), family homes and the child development centre.
- 3.5 Average caseloads per therapist are high
  - Pre-school 1:68
  - School-age 1:200
  - Special school 1:122.
- 3.6 The service manages demand by providing a mainly consultative service from school age.
- There are robust policies and protocols in place and the service has recently completed the Quality Self Evaluation Tool (Q-set) set up by the professional body (RCSLT 2008). Through this, the service demonstrated a rigorous system of Quality and Clinical Governance, including the implementation of clinical supervision and the use of outcome measures.
- 3.10 Additionally the service is looking proactively at a service specification including key performance indicators.
- 3.11 The service has reflected on what the Bercow Review (DCSF 2008) means for Brighton and Hove and have developed an action plan from the relevant recommendations. They need to share that plan with commissioners to agree priorities and secure any resources that may be required to implement the actions
- 3.11 An open referral system is operated so that parents can self refer.
- 3.12 Special Needs referrals are processed through the referrals panel in the integrated service but all other referrals go to the local teams.
- 3.13 This can make it difficult to understand the totality of need for SLT across the Trust.
- 3.14 Fragmentation of the teams into localities also reduces the flexibility of the service to respond to pressures such as fluctuations of demand and makes communication challenging across the service.
- 3.15 The therapists work across agencies and enjoy excellent working relationships across multidisciplinary boundaries.
- 3.16 Challenges



- 3.16.1 The shift to inclusion for pupils with complex needs presents challenges in terms of:
  - logistics (pupils having to be seen across a number of schools),
  - skills development for staff ( supporting pupils and staff with high technology communication aids)
  - Inequity of provision(pupils with specific allocation of SLT time on statements receive a higher level of service)
- 3.16.2 Young children with identified special needs are well supported through the integrated care pathway. However there is not a comprehensive model of care for those with autism and their speech and language needs are being addressed in the community clinic settings. Therapists in these clinics may be newly qualified or inexperienced and not have the requisite knowledge and skills to meet these very complex needs.
- 3.16.3 It is felt that there needs to be a holistic approach to this condition in which SLT's would play a part.
- 3.16.4 The school service has presented challenges but the current model appears to be working well.
- 3.16.5 Pupils in secondary schools are also receiving this consultative service.
- 3.16.6 The SLT's have been working closely with the Speech and Language advisory teachers in a complementary way to provide an integrated and multidisciplinary service.
- 3.16.7 There is, however little opportunity to meet with parents, and communication is generally difficult. The idea of using telephone surgeries or drop-in's should be explored.
- 3.16.8 In the new children's hospital there has been an expansion of the beds in the neonatal unit to a maximum of 6 babies.
- 3.16.9 Together with the other responsibilities of working in an acute hospital, including services to inpatients and outpatients and the videofluoroscopy clinic, resources are stretched and this is an area of high clinical risk.
- 3.16.10 Additionally these highly specialist staff do outreach work and advise therapists in the community on complex cases.
- 3.16.11 Special schools have experienced gaps in service due to lack of cover for maternity leave and this can leave the most vulnerable children very exposed to clinical risk.



- 3.16.12 Contact and communication with parents is an issue in these settings and the service needs to address this problem which is deeply felt by parents. Telephone surgeries or home visits during holiday times may be part of the solution.
- 3.16.13 Increased training for teachers and teaching assistants is a high priority for the service so that schools can deal with low level problems in the universal and targeted groups and free therapists to work with more complex speech, language and communication needs (Bercow Review (DCSF 2008)). However there are resource implications for this.
- 3.16.14 Small teams in a number of localities pose an ongoing problem for providing an equitable service so that there is not a postcode lottery as to what a child may receive.
- 3.16.15 It is important that team leads and the professional lead are able to have their views represented at a high level to ensure best practice, access and equity.
- 3.16.16 The service is coping with considerable pressures and would want to consider further skill mix developments.
- 3.16.17 The therapists believe that SLT assistants would enhance the service to children in mainstream and special schools and within children's centres. At present much of the intervention in schools is indirect. Employing SLT assistants would enable more direct intervention where indicated.
- 3.16.18 In children's centres there is insufficient time to focus on early intervention and preventative strategies or to provide effective training and support to early years settings to enable them to support individual SLT programmes.
  - Table 1 Information from providers. See appendix B

#### **User views**

- 4. In addition to the reviewed material from earlier consultations (Dec 2008), the reviewer met with representatives from Amaze, the parent organisation that provides the parent partnership function, runs the disabled children's register and other support functions and which is fulfilling the functions of the parent participation initiative under the Aiming High directive (DfES 2007). They have parent representation on various steering groups and seek to be actively involved with service delivery issues.
- 5. In July 2009, the Parent Carers Council provided a number of case studies to illustrate the difficulties that parent carers continue to experience. The issues highlighted included:
  - Difficulties in effecting smooth transitions at key stages.
  - Understanding the model of SLT delivery to mainstream schools
  - A perceived lack of direct SLT intervention



- Lack of transparent information about what services can provide.
- Poor communication with parents
- Difficulty in understanding how the OT service works impacting on securing equipment for school.
- Delays in providing equipment resulting in frustration and distress for families
- But
- A very positive acknowledgement of the physiotherapy input received by a child and the quality of the communication with the family.
- 6. A frank and wide ranging discussion with the Amaze representatives indicated a helpful attitude that parents can bring to bear on shaping services. They would want to see:
- 6.1 A universal ethos that puts parents and children in the centre of the process (as proposed in the Early Support Programme and Aiming High (DfES 2007)), with a 'team around the child' approach
- 6.2 The appointment of 2 keyworkers and a service co-ordinator, through Aiming High funding and with a parent as part of the interview process is a positive step to enhancing this aspiration.
- 6.3 Improved communication, both with individual therapists and families, and in providing clear and transparent information about what services are able to offer (entitlement based on criteria) and referral and eligibility criteria to access therapies. (core offer as directed by Aiming High DfES 2007)).
- 6.4 Enhanced training for staff and parents.
- 6.5 Involvement of parents as co-trainers, to help therapists appreciate the family perspective and to acknowledge parents as the 'experts' for their children.
- 6.6 Parents believe that open and honest dialogue about individual children and service issues would be a positive factor in managing demand.

#### Stakeholder views

#### 7. Special Schools

- 7.1 The interview with a head teacher was supported by completed questionnaires from school staff and a view from another school
- 7.2 The work of therapists is supported in this particular school by a number of teaching assistants (TA's) who have developed expertise in specific areas, such as Makaton and hydrotherapy.
- 7.3 The therapists are seen as an asset to the school and their skills and knowledge are respected and valued.



- 7.4 There are challenges in terms of available space and time constraints in terms of the therapy allocation to the school.
- 7.5 Cover for maternity or sick leave is seen as an ongoing challenge for continuity of service.
- 7.6 Specific issues in relation to the individual therapies were reported as:

#### 7.6.1 Occupational Therapy

- The time constraints mean that Occupational Therapist's are fully occupied with equipment issues and unable to assess and advise on other recognised therapeutic areas of OT expertise such as sensory issues and hand function.
- More access to a technician to adapt equipment would be helpful
- The provision of equipment in schools is an issue in terms of funding.

# 7.6.2 **Physiotherapy**

• The issue is how to integrate the programmes in school and who should carry out the programmes.

#### 7.6.2 For Speech and Language Therapy

- The issues are time constraints and level of parent demand for direct intervention.
- 7.7 Therapists need to see themselves as a 'virtual team' who go into various setting and must be prepared to be flexible and responsive to the needs of those situations, in addition to meeting the needs of individual children.
- 7.8 The co-ordination of services is still seen as problematic and there is a need for a lead professional to lead on this process and be a point of contact for the family.
- 7.9 The issue of inequity was raised where some children may have very high levels of input determined through the Chailey school or parental demand.

#### 8. Outreach to mainstream schools

- 8.1 Expertise from special schools is shared with mainstream schools to enable pupils to be included wherever possible, or to benefit from joint placements in special and mainstream schools.
- 8.2 This service requires the services of therapists and is working well in many respects.
- 8.3 The need for a co-ordinated approach between therapies requires further development.



- 8.4 Greater transparency in determining therapy input is required so that teachers can understand the basis on which decisions are made.
- 8.5 The need for explicit models of service delivery and decision making is essential to maintain a fair and accessible system. Such models could then be presented to other providers of services to ensure equity.

# 9. Mainstream primary/infant schools

- 9.1 Similar issues were highlighted including the inequity of Chailey led provision. Services are valued and the work of individual therapists is highly regarded. Therapy resources are very limited and there is often a long delay in providing the written therapy programmes.
- 9.2 Teaching assistants are not given sufficient advice/modelling/training to be certain that they have the skills and competence to carry out programmes.
- 9.3 Some schools/teachers are more knowledgeable/skilled in relation to working with therapists and account should be taken of this when dispensing advice.
- 9.4 Thresholds for intervention and levels of therapy input should be clear, explicit and transparent so that schools can understand the decision making process.
- 9.5 Available information regarding service delivery would reassure schools that services are planned rather than reactive.
- 9.6 Schools require more timely and responsive services to ensure that identification and intervention can be put in place as early as possible.
- 9.7 With the inclusion of more complex children into mainstream settings schools need to feel that there is regular and planned support to help them meet the needs of pupils.

# 10. Community Paediatricians and the Child Development Service

- 10.1 There have always been strong links between the paediatricians, therapies, the preschool teaching service (PRESENS) and the social workers in the Disabled Children's Team, and the establishment of the Integrated Disability Service has cemented this.
- 10.2 This is complemented by the work of the specialist health visitors and the nursery nurses attached to the CDC.
- 10.3 It has enabled such initiatives as the single point of access through the multidisciplinary fortnightly referrals panel and the development of the integrated care pathway (ICP).
- 10.4 It is regarded as a strong team with many examples of good practice including the service to children with Down's Syndrome.



- 10.5 The service never formally adopted the badge of the Early Support Programme as it was felt that they had comparable processes in place.
- 10.6 However, subscribing to the Early Support brand makes the model explicit for parents and others, ensures that families receive all the excellent resources of the programme and sets in train the nationally recognised approach of the 'team around the child'. This facilitates transitions and sets the standards of child and family centred services across all working practices.
- 10.7 Parents understand and identify with these principles on which Aiming High was predicated and it can only enhance children's services across the Trust to formalize this association.
- 11. Identified challenges for the servicesThe identified challenges for the services are as follows:
- 11.1 Resource implications in terms of supporting children on discharge from hospitals, and supporting children with life threatening and life limiting conditions in the community. Therapy services are fundamental to these support packages and there needs to be a strategic view as to how this can be provided.
- 11.2 The pressures on therapy time in special schools are exacerbated by providing services to increasing numbers of pupils from other areas, notably East and West Sussex.
- 11.3 Therapy resources do not benefit from the cross charges made between education authorities but there is the expectation that all pupils in a school will have their needs met, including receipt of therapies.
- There is a piece of work to be done to estimate what percentage of therapy time is spent on pupils from other counties, and consequently how much more time might be made available to residents in Brighton and Hove if this was taken into consideration.



#### CONCLUSIONS AND RECOMMENDATIONS

- 1. Brighton and Hove Children's Trust has made significant progress toward integration.
- 2. Commitment from the top has ensured a whole system approach with structures put in place to build shared services and to focus a needs driven and holistic model around the needs of the child and family.
- 3. The children's trust has adopted integrated assessment and care pathways as core processes in the disability service.
- 4. These pathways will need to be monitored through the use of key performance indicators to achieve agreed outcomes.
- 5. The work of the Brighton and Hove Children and Young People's Trust continues to evolve and develop and the latest change in the structure for complex needs demonstrates an integrated service structure with a single head of Integrated Children's Development and Disability Services who manages all the therapies together with other key specialist services.
- 6. There is a committed workforce who are constantly striving to meet demand and provide quality services in order to contribute to the aspiration to improve life chances for children and young people.
- 7. Their individual contributions to delivering services to children and young people are recognised and valued.
- 8. There are many recognised and positive achievements in the journey to helping all young people achieve their potential.
- 9. The Trust has signed up to the Every Disabled Child Matters charter thereby pledging to fulfil those commitments.
- 10. There are a number of innovative and effective services including
  - a specialist outreach service to children with disabilities included in mainstream schools
  - Specialist services supporting pupils with Down's syndrome, all of whom attend mainstream schools
  - Many examples of multidisciplinary working practices.
  - SLT seconded into the behavioural unit (ACE) in line with ICAN recommendations regarding social exclusion.
- 11. Good practice, particularly regarding clinical governance should be shared across services and they should adopt a multidisciplinary approach to generic protocols.



12. There remain a number of challenges highlighted by providers and stakeholders and these form the basis of the following recommendations.

#### 12.1 Recommendation 1: Data collection and Records management

- Data collection and records management remain an area of difficulty in terms of strategic and operational planning and management.
- There are differing IT systems that cannot communicate with each other and this will present a medium to long term problem in securing resources to fund a satisfactory solution and in finding an appropriate IT package that will meet the requirements.
- In the meantime it is important to foster a multidisciplinary approach to records management and this might be accomplished in a low tech way by combining all therapy files (where possible) so that is only one folder for every child.

Ref. :Recommendation 78 Laming Report 'Within a given location, health professionals should work from a single set of records for each child'

#### 12.2 Recommendation 2: Information

- There should be development of the 'core offer'. This is a statement of the services and standards that families can expect in relation to their disabled children.
- Greater transparency about decision making is a theme that has been highlighted by parents and stakeholders.
- Families are envisaged to access information that is easily available, relevant and accurate to various stages in the child's life, co-ordinated across all local services and user focussed.
- This information should be developed in partnership with parents and children/young people to ensure that it meets their needs. Ref. Aiming High for Disabled Children (DfES 2007)

# 12.3 Recommendation 3: Capacity and Best use of Resources

12.3.1 In response to the requirement of benchmarking for this review, there is no valid formula for determining the correct ratio of therapists in any given area. Circumstances are so variable that needs cannot be easily matched or benchmarked. The therapy establishment will be influenced by the demography in terms of indices of deprivation, but also in terms of locally available supportive resources, eg strong teams of advisory teachers, well trained Early Years



practitioners who are able to identify developmental difficulties and provide early intervention.

12.3.2 An effective model is one where therapists empower others with skills and knowledge in order to achieve good outcomes at universal and targeted / specialist levels.

#### 12.3.3 **Occupational Therapy**

- Annual referral rate :160, compared to 116 in the previous year.
- The head of service concedes that the service is a good service establishment in comparison to geographical neighbours.
- The integration of health and social care services is a strength
- Waiting times are unacceptably long.
- The waiting list should be validated and measures put in place for a system of discharges and easy re-entry to the service to allow throughput.

# 12.3.4 Physiotherapy

- Annual referral rate around 130
- The service has estimated that each therapist holds a caseload of 55.
- Williams. J (1991) identified a formula for calculating a national caseload for physiotherapy, based on the prioritisation of severity of cases. However, a total number not exceeding 45 per 1.0 wte therapist was recommended.
- This work is quite old, predicated on direct 1:1 work and precedes the current working practice of providing advice and programmes to other members of the children's workforce.
- In light of this the current establishment is possibly adequate on current referral rates.

#### 12.3.5 Speech and Language Therapy

- Annual referral rate around 1520
- The service reports the following caseload weighting.
- Pre-school 68:1
- School age 200:1
- Special school 122:1



- Despite the high ratio the service manages demand by providing a mainly advisory and consultative service to school age pupils.
- Prevalence data (M. Harshore 2006) based on 6-10% of children having a
  persistent communication disability or a specific speech and language
  impairment would suggest that the referral rate is low for the size of the
  population
- This suggests that the processes for identification within the universal population may need to be reviewed.

Ref: World Class Commissioning (DH 2007)

#### 12.4 Recommendation 4: Skill mix

- 12.4.1 Different working practices should be explored to make the best use of available resources. These may include:
  - Increasing the use of group sessions.
  - Working in virtual teams, such as the work currently under development, where SLT's are working with Specialist advisory teachers for Speech and Language to develop a service delivery model.
  - Scrutinising the deployment of therapists in the outreach teams to create a wider spread of knowledge and skills.
- 12.4.2 The formal transfer of physiotherapy to the community service offers fresh opportunities for the 'physical therapies' to examine their practices and rationalize their services.
  - This requires a detailed analysis of referrals and new ways of working to minimize waiting times.
  - Other services have met this challenge by offering drop-in clinics for triage of concerns, joint assessment clinics, or looking to collaborate with new services such as podiatry to manage simple conditions.
- 14.4.3 Services should consider the introduction of further skill mix in their structures.
  - Physiotherapy has no administrative support. Consequently a highly skilled and scarce resource is deployed for a significant proportion of time in carrying out administrative functions.
  - The introduction and development of assistants or support workers, referred to in the NSF as 'para-professionals' could provide more direct intervention to



children, assist in running groups, thus freeing up therapists' time and be useful in areas such as providing equipment.

- There are many well established precedents for this, not least the use of teaching assistants in schools or the Occupational Therapy assistants who manage patient discharge from hospitals together with co-ordinating the equipment needs.
- Physiotherapy assistants in special schools who carry out programmes are valued in many services and SLT assistants who work similarly across mainstream and special schools.
- The recruitment of support practitioner can also mitigate the disruption to services for leave of absence including maternity leave and may provide cover to bridge the gaps.
- 14.4.5 The current establishment across the services is stretched and commissioners might consider investment in this area as 'value for money' and an innovative approach to developing a skilled workforce that can meet emerging needs. (References: World Class Commissioning (DH 2007) NSF Standard 8 (DH 2004) Bercow Review (DCSF 2008).
- 14.4.6 The proposal of such a development was received with cautious optimism by parents and stakeholders, particularly when they were told of the competency framework for SLT support practitioners that has been developed by the Royal College of Speech and Language Therapists.

#### 14.5 Recommendation 5: Training

- 14.5.1 The need for an extension to current availability of training is an iterative theme of this project.
- 14.5.2 Therapists wish to secure ongoing opportunities to extend their own knowledge and skills to provide quality services.
- 14.5.3 There is an expectation that therapists will be appropriately skilled and specialised to meet increasingly challenging complexity in the disabled population (Ref : NSF Standard 8 (DH 2004
- 14.5.4 The children's workforce needs to receive training in the key developmental aspects that therapies embrace, both in early years settings to aid early identification and intervention, and in schools who are including disabled children and the special schools with the most complex and vulnerable pupils.
- 14.5.5 Training and empowering others should be central to service delivery particularly when services are becoming increasingly advisory.



- 14.5.6 Parents are anxious to be empowered by the skills and knowledge of therapists to manage their children's needs appropriately.
- 14.5.7 A business case in the summer proposed various options to establish training as a priority.
- 14.5.8 The commissioners will wish to examine all possible options as this is an expensive initiative.
- 14.5.9 The options of increasing establishment and developing training packages were set out in the business case.
- 14.5.10 A further option is to map training requirements and buy in the necessary training when required. There are many reputable trainers and packages on the market that are able to differentiate training outcomes to the relevant groups. References: NSF Standard 8 (DH 2004) Bercow Review (DCSF 2008)
- 14.6 Recommendation 6: Access
- 14.6.1 Referrals to physiotherapy and occupational therapy can only be made by other professionals and not directly by parents. This is an historic practice and uses other professionals to gate keep services. It also serves to increase frustration and anxiety in parents who seek professional advice.
- 14.6.2 Access to services should be open and transparent.
- 14.6.3 All services should accept referrals from parents and schools
- 14.6.4 Users should be able to access published waiting times.
  - Ref: Aiming High for Disabled Children (DfES 2007)

#### 14.7 Recommendation 7: Parent Participation

- 14.7.1 The disabled children's national indicator N.I. 54 is key to the system transformation for disabled children and their families.
- 14.7.2 This is the fourth strand of the core offer and will look at parental experiences of services and the extent to which they are delivered according to core offer standards.
- 14.7.3 The initial pilot and subsequent survey across 30 local authorities (LA's) reinforce the fact that parents want to be consulted, listened to and feel more supported.
- 14.7.4 Parents in Brighton and Hove through Amaze have made these views known and have signalled their willingness to work in partnership to achieve these aims.
- 14.7.5 All efforts should be made to extend the existing good practice by ensuring parent representation at operational and strategic levels.



Ref: Aiming High for Disabled Children (DfES 2007)

#### 14.8 Recommendation 8: Child Centred Services

- 14.8.1 The model of therapy provision needs to be more child and family centred beyond the integrated care pathway in the Child Development Centre.
- 14.8.2 The implementation of the Early Support Programme and its principles and the Common Assessment Framework (CAF) will ensure that practitioners work to a 'team around the child' approach in all settings.
- 14.8.3 This also enables the appointment of keyworkers and/or lead professionals to help families co-ordinate and navigate services where appropriate.
- 14.8.4 This smooth co-ordination is particularly important at key transition stages, an area highlighted by parents as being difficult.
  - Ref. Aiming High for Disabled Children (DfES 2007)NSF Standard 8 (????)

# 14.9 Recommendation 9: Outcome focused services

- 14.9.1 Agreed outcomes should be specified in service level agreements or service specifications.
- 14.9.2 Systems for reporting on outcome measures should be agreed across services.
  - Ref : Aiming High for Disabled Children (DfES 2007) World Class Commissioning (DH 2007)

#### 14.10 Recommendation 10: Equity

- 14.10.1 The issue of high input packages determined by Chailey school or parental demand leads to a very unfair system for resource allocation. Therapists and stakeholders agree that the system should be fair to all.
- 14.10.2 A further review of services from Chailey is to be carried out in the future.
- 14.10.3 Currently Chailey is funded by local commissioners but eligible children are attending local schools.
- 14.10.4 The situation appears to be one where Chailey are given the resources but local therapists are required to meet the needs.
- 14.10.5 It is important that resources are carefully scrutinised to ensure that local provision is appropriately enhanced to provide services.
- 14.10.6 Any agreed outreach from Chailey should be specified by commissioners so that there is a common standard for service delivery.



Ref: World Class Commissioning DH 2007)

- 14.11 Recommendation 11: Gaps in service
- 14.11.1 The lack of a comprehensive strategy for autistic spectrum condition is a conspicuous absence in commissioned services.
- 14.11.2 The National Autistic Society (NAS 2009) confirms a prevalence of 1% making the identification and effective intervention of the disorder a public health priority.
- 14.11.3 For the purposes of this review, the significant contributions of OT and SLT should be factored in to any proposed whole system solution.
  - Ref: NSF Standard 8 (DH 2004) Bercow Review (DCSF 2008)
- 14.12 Recommendation 12: Fundamental Principles for inclusion in service specifications
- 14.12.1 Packages of therapy should be determined by the level of need in the child / young person.
- 14.12.2 Easy and defined access to services.
- 14.12.3 Measurable outcomes demonstrating impact of interventions.
- 14.12.4 Timely assessments and interventions.
- 14.12.5 Defined models of care/care pathways.
- 14.12.6 Child and family centred services.
- 14.12.7 Equity and consistency.
- 14.12.8 Value for money
- 14.12.9 Best possible quality, evidenced by quality measures
- 14.12.10 Compliance with national standards and direction i.e. NSF Standard 8, Aiming High for Disabled Children, Bercow Review.
- 14.12.11 Parent and child participation in shaping services
- 14.12.12 Appropriate information and training for wider workforce and parents
- 14.12.13 Provision of clear and explicit information for users in a variety of accessible forms
- 14.12.14 Multidisciplinary working with a focus on the 'team around the child'.



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#### Appendix A

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