

APPENDIX 1
“More therapies in the community”
Parent Carers’ Council Summary Report
December 2008
Combined focus group and short survey findings

Introduction

In line with the national pattern, we have firm evidence that the numbers of children with learning disabilities for example children diagnosed on the autistic spectrum, complex medical needs and physical disabilities, are increasing, with particular challenge during the years of puberty and adolescence. Modern medical intervention means that this generation of young people survive into adulthood, with the majority of their care being delivered at home by a largely untrained workforce of parent carers. During the past decade, there has been a growing need for specialist therapy intervention to assist these parents and their children to achieve their maximal communication, social and emotional and educational potential. Local parent carers have advocated for more flexible and good quality community multidisciplinary therapy to assist them in the overwhelming tasks of daily living. They were optimistic that the children’s Integrated Disability service would deliver these improvements. However, this city wide exercise with parent carers of children of all ages and from across the city indicates continuing dissatisfaction with current therapy provision and concerns about poor outcomes for both child and family.

Launch of Parent Carers’ Council, Brighton & Hove

In July 2008, at the first meeting of the Parent Carers’ Council in Brighton & Hove, parent carers voted that “More therapies in the community” was their priority issue. These services include speech and language therapy (SALT), occupational therapy (OT), physiotherapy (PT) and psychology. These therapies are provided by different statutory bodies (Brighton Hospitals University Hospitals Trust, Children and Young People’s Trust, Chailey Heritage Clinical Services) on different sites including special and mainstream schools, the children’s hospital and Seaside View which is the integrated children’s disability service based on the Brighton General Hospital site. An unrepresentative baseline survey of parents attending at the time also indicated parent carers felt unable to influence the Children and Young Peoples Trust, and local health provision and had only weak confidence in local health provision (see Appendix One).

Key findings from focus group event held on 5th December 2008

Twenty parent carers attended this event, together with five invited listeners (key local officers or managers), and two members of *amaze* staff. In the first task, fourteen practitioners from the fourteen different statutory or voluntary sector organisations were named as valued examples of local good practice. The named individuals will be sent a certificate and letter of thanks on behalf of the Parent Carers’ Council. Chailey Heritage was the only team/site nominated twice as an example of good practice. This event illuminated a range of issues concerning good and poor local practice in the co-ordination and delivery of these therapies for children. A separate focus group report records the full range of parent carers’ contributions and views that were expressed during the four different activities. A comment on a feedback form illustrated the feeling of many parent carers, “*why do we have to fight for everything that able-bodied children assume as their right, like freedom to communicate, have friends etc?*” This local finding is in keeping with national research including the Aiming High for Disabled Children Cross Party Review that took place in 2006, and other work¹.

¹ For example “Ignored and Invisible” report referenced in first report.

The key findings from focus group were:-

1. **Listening to parents, taking their concerns seriously**, and respecting their views were recognised as the hall marks of good practice and we thank those who routinely demonstrate these qualities. However, parent carers reported these basic markers as weak or absent in some local therapies provision. They also wanted practitioners to visit the child where they were, at home, nursery or school rather than taking child to multiple appointments on different sites.
2. **Communication that was honest, sympathetic, clear, timely and respectful of the parents' knowledge of the child** was identified as most important ingredients to constructive working with families. Parents also wanted different services and practitioners to communicate with each other better and to effectively co-ordinate the delivery of different services. Key working that responded to the families' views and needs was seen as one tool for better communication and co-ordination.
3. **Transparent and accountable decision-making at all levels needs to show response to parents' (and child/young person where possible) involvement** and priorities. Need for impartial, full information and support for parents making decisions and effort to "fit the service to the child and not the child to the service".
4. **Need for additional skills training at all levels and in many settings**, from basic personal skills of how to relate to both disabled/ill child and their parents carers, to highly specialist skills for intense specialist provision. Need to include parents in this training so that families' perspective consistently understood from proven evidence base. Concerns were raised that much 'therapy' was not carried out by sufficiently trained staff. Survey feedback showed that when child attended to by qualified therapists then parents were satisfied with therapy. However the over long waiting period, staffing discontinuity and insufficient amount of contact with skilled therapists were identified sources of strong dissatisfaction across ages and therapies.
5. **Workforce and resources** – not just more money invested across services for children with special needs to prevent avoidable disability, distress and social isolation, but more importantly, by involving parents in the decisions achieving a wiser use of these resources and expertise.

Short postal survey summary

During four weeks in November 2008, 47 parent carers of 49 children with additional needs, living in Brighton and Hove, completed a short postal survey. The unsolicited survey was sent to over 1,000 local parent carers registered with Amaze, the umbrella organisation supporting parents of children with any special need in Brighton & Hove. The response rate is low and entirely within rate expected from non-selected 'families in need' population. It is not possible to discern the range of levels of satisfaction from parents who did not complete the question, however the staff members from Amaze, who manage the Compass database, an active caseload and busy helpline for local parent carers concur that the findings are in keeping with their day to day contact with families.

Parent carer responses were:

6% related to children with special needs aged 0 to 4 years

40%	“	“	5 to 11 years
30%	“	“	12 to 15 years
13%	“	“	16 to 19
11%	“	“	20 – 25 years

Key messages from short postal survey

Parent carers' level of satisfaction regarding each therapy was recorded relating to three general aspects rather than scoring different teams or providers. It is noticeable the relatively high proportion of respondents who recorded partially or strongly dissatisfied with services. Responses relating to physiotherapy were more different from the other therapies, possibly because the more physical nature of treatment enables outcomes to be visible to all. For example, the child's progress in walking practice that facilitates independent walking can be seen by parent, child and physiotherapist alike. There was a general feeling that physiotherapy needed to be assessed and practiced within the home rather than always in the therapy department alone. There seems to have been particular problems with staff continuity since the opening of Seaside View (Integrated Disability Service). Similarly fewer children and young people were able to access psychology services which parents felt disadvantaged their child.

These general aspects were the assessment process, the amount of therapy and the quality of provision and findings are shown in Appendix Two.

Key findings from short survey were:-

- **Ratio of 'dissatisfied' and strongly 'dissatisfied' ratings** about the amount and quality of all therapies were relatively high. Once the child saw a therapist they were more likely to be satisfied with the quality of service suggesting a weakness with the system rather than therapists' practice. In general parents praised individual therapists their child saw.
- **There was reported difficulty both accessing and sustaining ongoing** therapy – parents were unhappy with age cut offs or cessation of therapy if the child changed school or provider because the child's needs for therapy had not changed.
- **Long waiting lists** were considered problematic/unacceptable because of the missed window of therapeutic opportunity for the child, and frustration for the family who had to cope unaided in the meantime. Problem could become more severe and hard to solve during the waiting period.
- **There was confusion about the role of therapies**, and some parents felt their child could have benefited from input but the services were not offered. Impartial information and clearer route to assessment needed.
- **Families wanted more therapy to be based within the home**, and within a co-ordinated multidisciplinary plan. Impression that therapies actually functioning in parallel rather than together.
- **Need for better communication and feedback**, and inclusion of the parents' expertise.

Recommendations

- Focussed six month review team, including parent carers, to develop and implement strategic plan for therapies across different providers in the community. The plan must provide consistency and quality across diagnostic groups, age bands and range of providers and co-ordinate with children's hospital services. Joined health service and CYPT attention to long term issues and unmet need.
- Development of local training delivery plan that addresses skill deficits, and deployment of highly trained therapists in integrated teams working in the community. To include resourced training for parent carers to support therapies and maximise potential of child.
- In the new governance arrangements for the CYPT Board, to include representation directly from the Parent Carers' Council so that discussion and decision can proactively include local families' experience and views, also Acute Commissioning group and the Continuing Care panel.
- Meaningful, secure funding for the Parent Carer Council so that it can build its evidence base, representational capacity and independence. Currently the CYPT provide inadequate funding of only £5,000 p.a. on a discretionary basis from (short term Aiming High Funding). Inequality with level of funding, management and profile invested to the mainstream Parents Forum (c50Kp.a.) and Youth Council (c150Kp.a.).

Actions by Parent Carer Council and partners

Immediate

- a) Promote examples of good practice from the families' perspective by publicising nominations of individuals' and teams'. Articles in City and CYPT publications.
- b) Build active membership of the PaCC to strengthen its representational capacity.

Next four months

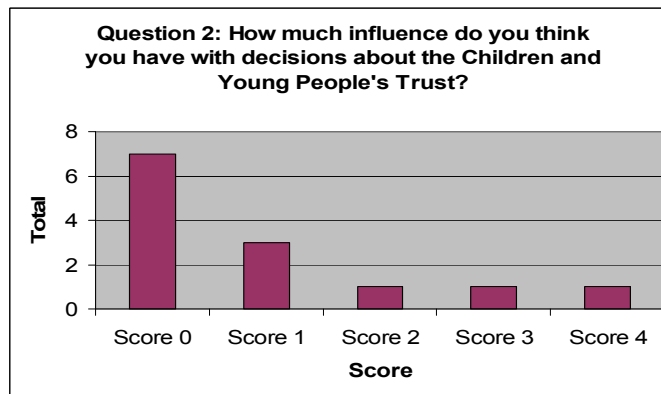
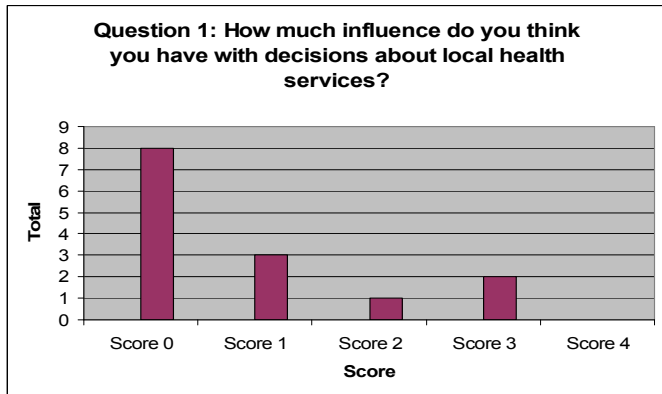
- a) Wide dissemination and discussion of Parent Carers' Council reports with key groups about local families' experiences and need for more therapies in the community.
- b) PaCC meetings with 'listeners' who attended event and therapy managers and commissioners to address issues raised and record of outcomes.
- c) Investment in website for local parent carers to raise profile of parent carers and capture local experience, ideas and solutions.
- d) Plan launch event in early summer term.

Ongoing

- a) Improve effective funding to enable fulltime development worker for PaCC, build capacity, independence and partnership links with Parents Forum and others.
- b) Formalise clear routes for families' experiences to feed in to decision-making processes with audit trail of where this makes a difference to outcome.

Appendix One: Baseline survey 11/07/08

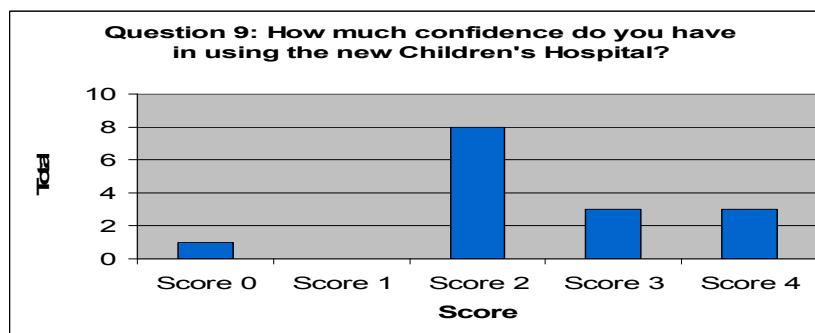
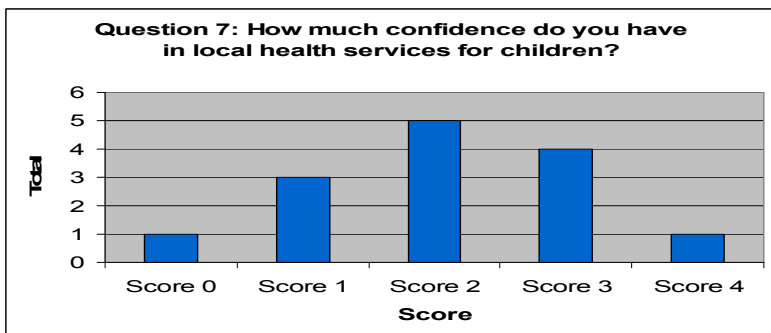
Score 0 to 4 (where 0 means none and 4 means a huge amount)



**Question 4:
How much influence do you think you have about decisions in your child's school?**

- Woodingdean School
- Patcham High School
- Downs View
- St John's School
- Hillside
- Downs Junior
- Cedar School
- St Luke's School
- Downs Park
- Angmering/uni
- unnamed school

Score	Score	Score	Score	Score	Score
0	1	2	2.5	3	4
				1	
	2	1		2	
					1
	1				
	1				
					1
			1		
		1		1	
		1			
		1			



Appendix Two : Short Survey Findings

Levels of satisfaction regarding assessment, amount and quality of therapy (all ages included)

