

APPENDIX 2
Children and Young People's Overview and Scrutiny Committee
Brighton & Hove
The experience of local families of children with additional needs
Update Report: January 2009

Dr Carrie Britton:
Health Co-optee to CYPOSC
Children's Services Engagement Advisor (Brighton and Hove City Teaching PCT)
Lead Advisor Parent Carer Issues, Amaze Research and Training

Purpose of this briefing update

1. To provide an update to the original briefing paper, especially with regard to the focus group work of the local Parent Carers' Council (PaCC).
2. To build the evidence base and understanding about the experience of local families of children with disabilities or complex needs.
3. To raise awareness of key issues and assist committee members in their overview and scrutiny role.

This report is to be read in conjunction with the PaCC report "More therapies in the community" because it provides an explanation about the recent experiences of local parent carers. Parent carers feel they have little influence in local services, despite national policy, huge effort and local rhetoric. The PaCC report, albeit from an unrepresentative sample of 47 families reveals relatively high ratio of dissatisfaction with current therapy services organisation, but warm appreciation of individual practitioners. This pattern and level of dissatisfaction is consistent to that reported nationally in the Aiming High for Disabled Children (AHDC) Cross Party report 2007¹. However there is a wider range of unmet needs historically for families of children with complex health issues.

National context

There have been many reviews of services for children with additional needs during the past fifteen years and local parent carers have taken a full part in them. Parent carers' views were addressed within the comprehensive guidelines of the 2004 National Service Framework, and later the Every Child Matters (EDC) Agenda for Change. Yet during the 2006 AHDC Cross Party hearings, the Children's Commissioner for England, Prof. Sir Al Aynsley-Green, stated that the evidence was known, policies were in place but delivery was lacking.

The review directly lead to £340 million being released nationally and from March 2008, three instalments totalling £2.4 million was allocated to Brighton & Hove as a Pathfinder for improvement of short break services for families of disabled children, ending in March 2011. Two conditions for AHDC funding was the meaningful involvement of parent carers in decision making processes and a commitment by Brighton & Hove to deliver by 2011 the Local Authority and PCT Charters (Appendix 2).

Defining the population of children

The 2004 government survey² estimated 14% of children have special educational needs, including between 5 and 7% of children who are disabled: yet the proportion of funding afforded to disabled children has changed little since the pre 2004 level of 3%. In contrast to parents of fit and well children, parent carers of children with additional needs, especially where those needs are moderate, severe or complex is considered a 'seldom heard group' because their daily lives involve multiple deprivation, and daily effort to accommodate appointment, treatment, and/or therapy.

¹ Parliamentary hearings on services for disabled children, October 2006.

² The Family Resources Survey 2002-3, Department of Work and pensions 2004, available from www.dwp.gov.uk/asd/frs

Local history

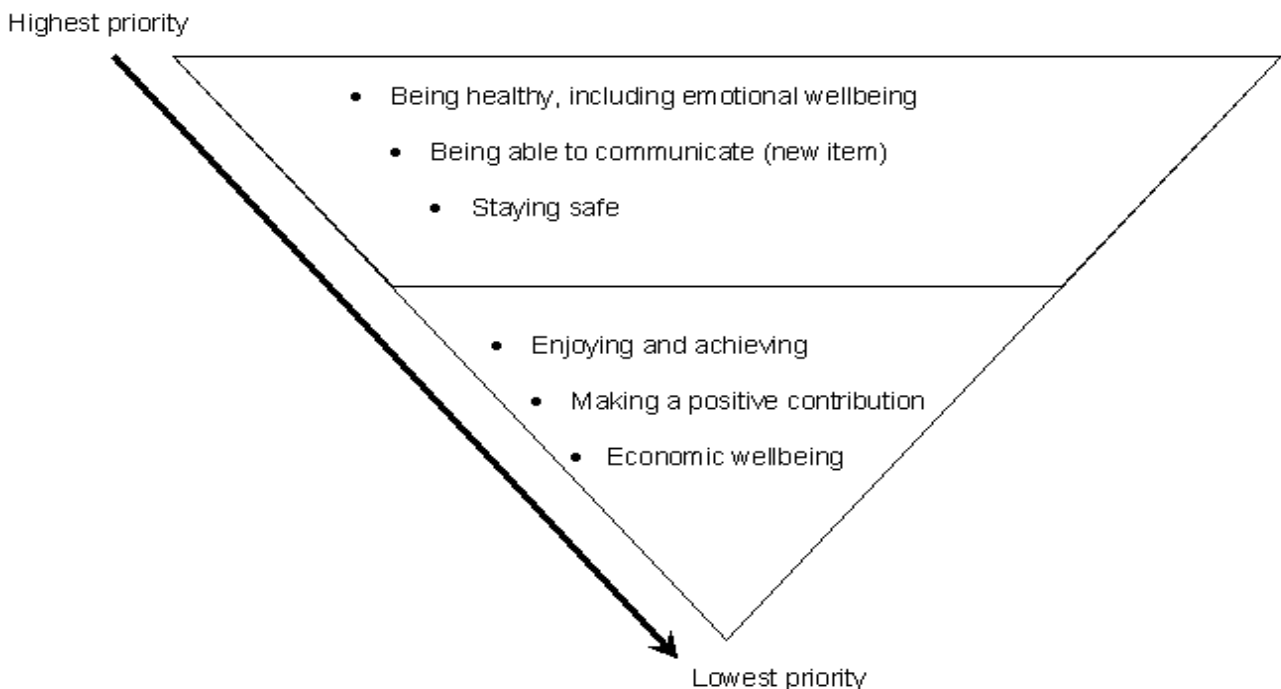
The new Disabled Children Strategic Partnership Board, which includes parent representatives, has begun to co-ordinate the use of AHDC funding, and to rebuild the damaged relationship with the parent carer community that emerged during the problematic local review³ and reported threat of closure of the children's community nursing service. Two years later changes in provision and upgrade of facilities have happened and a parenting support strategy has been published, yet parent carers report that little has improved in terms of what is available for their disabled child. They report deep concern about commissioning decisions (like the closure of Charily Heritage nursery for the most disabled children) and still seek transparent and accountable decision-making that involves them in a timely and meaningful way.

Hierarchy of Every Child Matters outcomes for disabled children

The five ECD outcomes, that is Being healthy, Staying safe, Enjoying and achieving, Making a positive contribution and Economic wellbeing, are usually considered of equal significance to children and young people, and therefore to service providers, commissioners and assessors. However, recent national research⁴ recommended important adaptations to these outcomes in relation to services for disabled children. These are:-

- Overall, the five outcomes are relevant for disabled children but crucially they omit communication, a fundamental capacity, so this needs to be added as a sixth outcome. Far greater attention to communication is fully endorsed by findings from the recent Bercow Inquiry into speech and language provision, and echoed consistently by local parent carers' views.
- The outcomes mean something very different to disabled children and their parents compared to fit and well children and their families.
- The outcomes need to be used in order of their relevance to disabled children and their parents. The research team recommend a hierarchy as illustrated below:-

Every Child Matters: Outcomes framework adapted for children with complex health needs and disabilities



³ In Brighton & Hove the community of parent carers put considerable effort into the review of services that lead to the formation of the CYPT, for example 268 completed questionnaires were received from parent carers. A sound and detailed plan for service development was agreed in 2006 that responded to families' feedback. However, with the change of leadership of the review group, workforce development of the new CYPT became the priority in preference to implementing the agreed plan. I refer to it here because it has seriously damaged the parent carers' /CYPT relationship and still contributes, like the events around the community nursing issue, to their feeling of not being heard, valued or meaningfully involved with the work or decisions of the CYPT and relevant health service organisations.

⁴ Priorities and perceptions of disabled children and young people and their parents regarding outcomes from support services: by Bryony Beresford, Parvenneh Rabiee and Patricia Sloper: Social Policy Research Unit, University of York, 2007

The researchers also noted the significance of maintaining quality of life, sometimes in the context of deterioration of abilities. These research findings concur with studies with older service users, and reinforce the importance not just of outcomes but also the WAY in which the service is delivered – ‘users have long argued that the impacts of the way in which services are delivered can be as important as the outcomes of the service, and the way in which something is done can undermine or contribute to quality of life outcomes’⁵.

Why are these research findings important? Because they endorse the local finding of widespread dissatisfaction from parent carers and the need for more therapies in the community to assist their disabled children maximise their abilities (especially during finite developmental windows) and maintain their quality of life. The research findings also evidence the importance of understanding the way local services are delivered and decisions made from the service users’ perspective rather than just accepting managers’ reports, providers’ policies or commissioners’ intentions. This is also a key learning point from the recent Baby P Inquiry.

Understanding the parent carers’ journey

There is a body of evidence from international research with parent carers over the past twenty years that explores important aspects of the parent carers’ experience, and the parent carer/practitioner relationship. One aspect of this relationship is the tension between managers who prefer to affirm positive news of their service and parent carers’ delivery of the unwelcome message that far more needs to change. Meanwhile, parent carers continue to combine the hard physical work of delivering 24 hour care with chronic stress, clinical fatigue, raised ongoing anxiety and uncertainty, cycles of grieving (Chronic Sorrow), social isolation and reduced income. A brief summary of the parent carers’ journey may assist Councillors and managers to contextualise issues raised in reports and by their constituents.

Early stage:

- Anxiety and effort to secure diagnosis – route to diagnosis impacts how they relate to professionals later, for example speedy route to diagnosis and treatment leads to greater trust, but if diagnosis delayed, missed or incorrect, families less likely to trust professionals later.
- Shock and feelings of helplessness and powerlessness about child’s diagnosis and treatment – completely unfamiliar territory for parent
- Eagerness to put child in hands of experts who have solutions
- Isolation – do not know other people who live with this situation, dislocation with family and friends
- Actively seeking information and people who can help
- Feeling of crisis and that life will now always be different

Middle stage:

- Clearer understanding about child’s individual experience of condition and individual needs
- Coping with conflicting advice – having to choose who to believe
- Realising things cannot always be fixed
- Trying to do everything that is advised –unsustainable emotional and physical effort –finding resource limits
- Learning about the future and impact on each family member
- Emergence of chronic sorrow (cycles of grieving) and clinical chronic stress which can become permanent
- Learning to ‘fit into community’ – inclusion issues arise
- Navigating different education, health, social care and benefit systems

Later stage and ongoing:

- Search for ‘normality’ – each families’ unique sustainable pattern for daily life
- Developing confidence about own expertise and family’s limitations
- Finding individual family solutions to challenges
- Finding others who live similar lives
- Learning to advocate effectively and fight to have child’s needs met
- Willingness to campaign so that other families do not experience such a difficult journey

⁵ Qureshi H and Henwood M (2000) Older People’s Definitions of Quality of Services, York publishing Services, York.

Parent carer/practitioner relationships

Practitioners' training usually concentrates upon the child or young person, rather than gathering evidence based expertise dealing with parent carers. Also practitioners who only see children at a particular stage or age are less likely to be aware of the longer term impact of their intervention, and the impact of their style of practice. For example practitioners who mainly work with preschool children will be more used to overtly directing and advising parents in the early stage because parents may not yet have developed confidence in their own expertise as either parents or carers. In contrast, a practitioner working with older children will be more used to incorporating the child's wishes and negotiating with more confident parents.

The carer/practitioner relationship evolves and a policy devised for one stage will not necessarily fit another stage, but a consistent feature is respecting the parent carers' role and input because we know that the parent carer has the greatest impact upon outcomes for the child. Feedback from parent carers' prioritises the need for much further training and specialism, together with a respect and understanding of the parent carers' contributions. This is especially true where children have complex or enduring health needs and practitioners deploy a medical model approach that can view parents as passive receivers of professionals expertise rather than key partners.

In the context of disabled children, decisions are made about equipment, toys and room layout within the family home, about who visits the home, about which nursery or school the child can attend, which care package and many other decisions are all taken by strangers, often service managers. Dealing with this level of daily intrusion into normal family autonomy is again part of the experience of being a parent carer and explains why the relationship with statutory providers is often tense and different from that of parents who are not also carers. Parent carers also comment that it seems that the more senior the decision-maker (and therefore making the decisions that have the biggest impact on the family), the less they understand the individual child (PaCC report).

Key facts to understand the multiple vulnerability of families of children with complex needs or disabilities.

- On average, it costs three times the amount to raise a disabled child compared to raising a child with no disabilities⁶
- Family breakdown - in the general population of Brighton and Hove, 27% of households with children are single parent households (2001 Census), while single parent households form 36% of families on the Compass database. Single parent household nearly all headed by mums, looking after boys.
- Greater likelihood of disabled children experiencing neglect and abuse.
- Lower income
 - a) in the population of households with children in Brighton & Hove, 61% of mums and 86% of dads are in paid work, compared to the Compass families where 16% of mums and 63% of dads are in paid work.
 - b) 50% not claiming or unsuccessfully claiming Disability Living Allowance⁷.
 - c) 55% of disabled children live in or on the margin of poverty

Brighton & Hove figures from Compass Database (2006)

Just over 1,000 children with additional needs on database representing about 2% of all Brighton and Hove children (aged 0 to 19 years). Therefore if 5 -7% is the expected proportion of disabled children, the 2006 data represents less a third of those with additional needs. Limits to resources invested into database mean that very limited recruitment of some groups of children, like children with enduring health needs. Of those children we do have information about:-

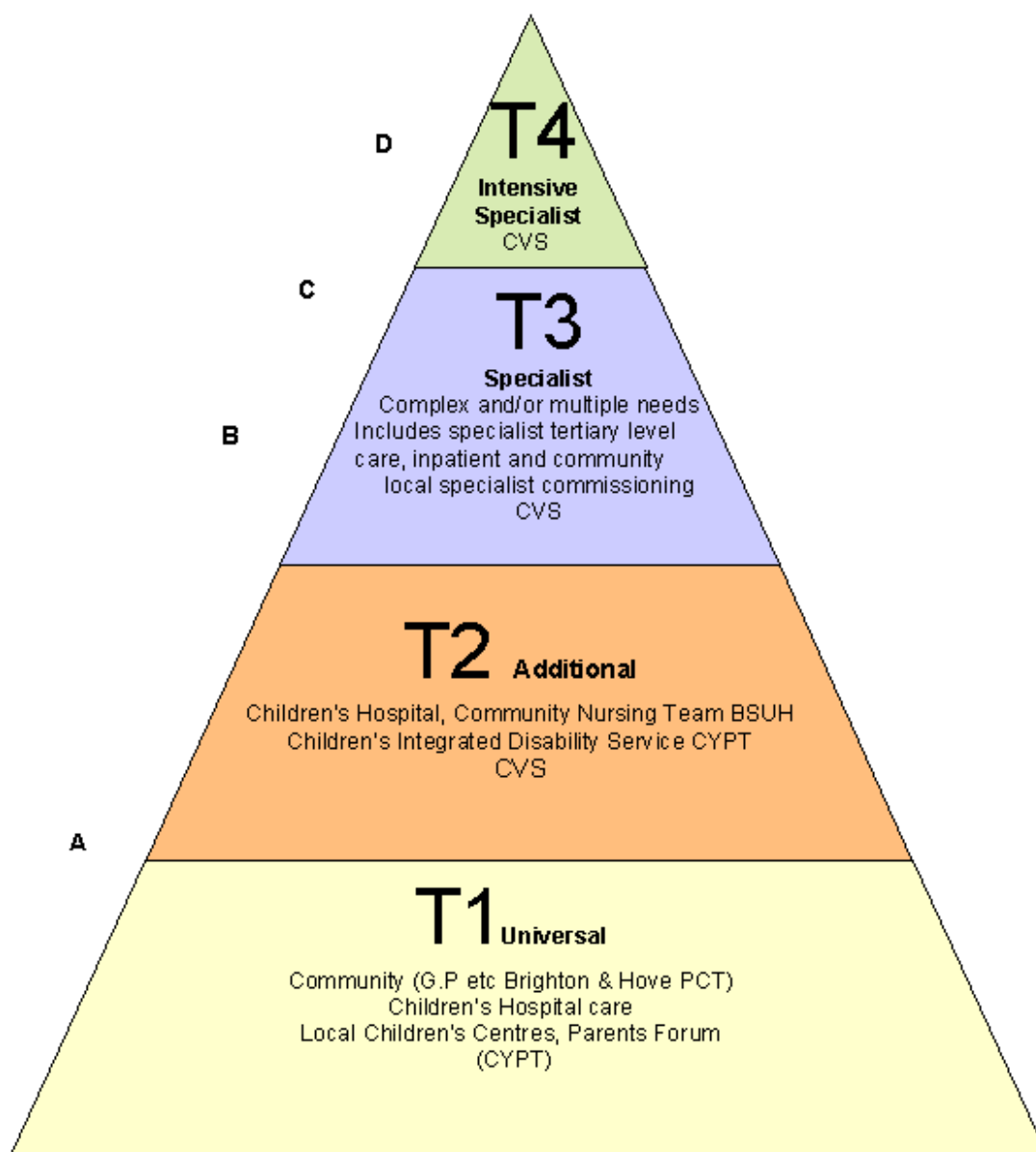
- 72% of the children were male
- 10% of families have more than one child with special needs
- 50% of families where the main or sole carer does not usually get a night's sleep, rising to 60% where more than one child with SEN

⁶ Disabled Children & Child Poverty: briefing paper from Every Disabled Child Matters, 2007

⁷ as above

- Disabled children more likely to be living in most deprived neighbourhoods (see Compass report)
- 24% of parents think their housing is not adequate to meet the needs of their disabled children
- 50% receive no support from extended family, for example from grandparents
- In about a fifth of families with non-disabled siblings, these children share in care of the disabled child – but Young Carers services focussed upon young carers of adults.
- Only 4% get support from social services (compared to 15% of all families in Brighton and Hove who have any social services support)
- 55% of children on the Compass have been bullied, and 27% have been involved in bullying. Both these figures rise when related to the children who are excluded from schools.
- A child with special needs is 7 times more likely to be temporarily excluded from school, and 13 times more likely to be permanently excluded.

A to D Four sub groups for ongoing scrutiny



- A Low achievers at school** - who have high risk of disengagement, exclusion, bullying, membership of NEET and involvement in criminal activities. Early identification and intervention in Year 6 to assist parents and family gain strategies to boost skills, performance and self esteem.
- B Children needing therapy** - (speech and language, occupational therapy, physiotherapy and psychology). Across ages, diagnostic groups and service providers, response needed to parent carers issues raised in report "More therapies in the community". Training issues and greater specialism needed.
- C Children with chronic illness or complex health needs** – historic unmet need for community support that is available for adults with same condition. Greater strategic vision across both statutory and third sector providers and meaningful partnership with parent carers and disabled children.
- D Severely disabled children** - need for greater specialist support services, including intensive specialist services to child and family. Absence of transparent decisions, resourced specialist support in local community and coherent continuing care strategy that is responsive to families' needs.

Recommendations for CYPOSC

1. **Annually review delivery** of the Local Authority/PCT Charter which the CYPT has already signed up to and progress of Disabled Children's Strategic partnership Board. Check what is promised is actually delivered and how it is experienced by service users.
2. **Encourage better joint intelligence** about the numbers and needs of children and families currently attending hospital and community services and better sharing and use of this evidence base. This does not mean another mapping exercise but rather refocus of effort to collect relevant data, and not just data related to targets (also recommendation from Brighton & Hove City PCT's Annual Report Brightening Up 2008).
3. **Widen evidence heard at CYPOSC** - seek reports from other providers and service user groups. Following Baby P inquiry recommendations, seek wider views about service delivery and effectiveness and encourage dialogue with of 'critical friends'. For example from the Parent Carers' Council and the Children's network of Community and Voluntary Sector Forum.
4. **Work with partners to reform and reconfigure of services across hospital/community boundary for children with ongoing and complex health needs**, and consistent values across diagnostic categories or ages. This includes therapy services across all age groups but also community nursing, phlebotomy, podiatry etc.
5. **Seek and support representation from the Parent Carers' Council** within the new governance arrangements for the CYPT Board so that discussion and decision can proactively include local families' experience and views.
6. **Smarter use of consultation information from service users groups.** Deploy new engagement strategy but recognise specialist nature of engagement. Maximise learning from engagement and consultation processes, avoid duplication, unrealistic timeframes but most of all show consultees how their input made a difference.
7. **Promote secure funding for the Parent Carer Council** at effective level 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 other similar work for example the mainstream Parents Forum (estimated 40Kp.a.) and Youth Council (estimated 150Kp.a.).