

# “Talk Health...”

Parent Carers' Views on Health Services  
in Brighton & Hove 2012



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“This year, my child has seen two community paediatricians, a gastroenterologist, a neurologist, an occupational therapist, a physiotherapist, a speech and language therapist, a dietician, a ketogenic diet team, a geneticist, a surgeon, a school nurse, a community nursing team, several different teams of doctors and nurses at the children’s hospital, ten different paramedics and her GP. She has attended medical appointments or hospital visits over 40 times.”

## 1. Executive Summary

Every parent's first wish is for their child(ren) to lead as healthy a life as possible. When you become a parent you may expect to have some involvement with health services. You would expect to visit the GP and have, maybe, the odd visit to A&E. You might expect the occasional broken bone and high temperature.

Yet nothing prepares you for the journey you begin when you have a child with a disability. Due to their complex health, mental health and wellbeing needs this group of children use a wide array of health services.

### a. Who are we?

The Parent Carers Council (PaCC) is a group of 190 parent carers of children with disabilities, complex needs or long term conditions from across the city. The group was set up in 2007 as a work stream of Amaze, a long established parent led organisation supporting parents of children with any special need in Brighton and Hove. Amaze supports approximately 1,600 families of disabled children in this area. PaCC is mostly funded by NHS Brighton & Hove with some funding from the Integrated Disability Services in Brighton & Hove and the DFE (Department for Education).

### b. Why listen to us?

Disabled children's interaction with a wide range of health services can be intensive, extensive and expensive: they are high cost, high incident users of health services. A range of different health services are required including universal services (such as GPs), specialist services (such as specialist neurology services) and condition specific services (such as a service for children with visual impairment). Many of our local children travel up to London to see specialists in a specific field. However, this report is concerned with the services that are provided locally, in Brighton & Hove.

Health professionals from across acute, primary care, specialist services, palliative care and community-based services must actively seek the views of these young patients, and those of their parent carers, if they are to ensure that their experience of health services are as positive as possible. We have sought the views of parent carers who use health services extensively in order to create this report which we hope will help to improve the efficiency and quality of the health services from the perspective of children with disabilities and special needs. For instance, children with disabilities and complex health needs and their families may have used A&E services at all times of the day or night and can provide expert views on what could be improved more than the occasional users. We hope that by addressing the concerns of parent carers, the following outcomes could be achieved:

- More efficient use and targeting of scarce health resources
- Improved quality and 'fit' of service
- Greater user satisfaction with services and fewer complaints

### c. Key Recommendations

See the report below for our full lists of recommendations but the top three key areas that we urge further attention and investment in order to improve the lives of disabled children and young people and to assist them to fulfil their potential are:

- Further improving Parent Participation

The parent carer voice needs to be represented at the highest level in order to ensure that services are as good as they can be for disabled children and their families. The Care Quality Commission's (CQC's) review of services for disabled children [see below] showed that there were few care plans across Sussex with little information about waiting time for therapies but that Brighton and Hove was the only area with "adequate involvement of children and families in assessments, inductions and training". This is very positive and can be built upon. The voice of parent carers needs representation on the new Health and Wellbeing Board, Children's

Committee and Clinical Commissioning Group's Children's Review Board. The PaCC needs increased financial support to ensure that it continues to carry out its vital participation work and reach new, further marginalised groups of parents in the city. We believe that Public Health should match the investment in PaCC that the PCT/CCG makes in order to continue this very valuable work, and that the new CCG should continue this funding at a higher level, if possible, to reach families who face multiple disadvantage and face health inequalities. There needs to be better evaluation of health services. Parent Carer feedback could be standardised across all health service using a standard form. Health services should invite parent carers in to 'evaluate' their services using the Partnership Charter [see appendix 1]. CAMHS has already asked to do this and this should form part of a wider 'parent review' of CAMHS.

- Increased resource for services

The need for increased community support is a strong theme throughout health services. A specialist paediatric epilepsy nurse would be cost effective in the long run, reducing stays in hospital and greatly reducing stress levels in family members looking after children with very complex epilepsy. The community nursing team is under resourced, and there are only two specialist health visitors, who provide vital 'early' support. Also, the disability liaison nurses in adult services are making a huge difference to the experience of adults with learning difficulties in hospital. The same post for paediatrics would greatly improve the experience of young people and their families in hospital. This would reduce complaints and even reduce hospital stays as this valuable professional can give advice over the phone too. Many parents play a 'keyworker' role in their child's health care and this should be recognised and supported with increased access to resilience training (Insiders' Guide offered by Amaze). For those families who do not feel able to play this role, a keyworker is needed and this will become even more vital with the implementation of the new single Education, Health and Care Plan.

- Improved communication and transparency

It is frustrating to see that after 5 years of review, access to therapies is still a huge problem for many children and waiting times are still unacceptably long. There needs to be a citywide code of practice for GPs and young people in transition. Parent journey training (taken up by some professionals) should be made mandatory for all professionals, including consultants. This would greatly improve communication between health professionals and families and reduce complaints. Communication needs to be improved between the multitude of health professionals involved in children and young people's lives. Parent carers should be routinely copied in to any correspondence about their young person and should be routinely given details of eligibility criteria and waiting times.

## 2. Focus on Health: Why Now?

### a. Increasing levels of disability and complex health needs

Nationally, we have seen a marked increase in the number of children with disabilities and complex health needs, due to the increased survival of pre-term babies, children making a better recovery from severe trauma and illness and an increase in children on the autistic spectrum and with mental health issues. This trend is reflected locally.

### b. Child Poverty & Health Inequalities

There is a well-documented link between disability and poverty. It costs 3 times more to bring up a disabled child than a non-disabled one and over half of all families with disabled children are living in (or on the edge of) poverty. [Appendix 2 shows the membership of the City's Disability Register, The Compass, by ward].

In Education, there is a City-wide, strategic drive to 'narrow the gap in attainment' between children in schools with Special Educational Needs (SEN) and we believe there should be a focus on reducing health inequalities (as far as possible) in this population. It is known that inequalities exist for adults with learning disabilities, as underlined by Mencap's report Death By Indifference (which highlighted cases of undiagnosed illness and even avoidable death). A new Children and Families Bill will set in place provisions to allow families with a single Education, Health and Care Plan access to a personal budget by March 2014. If successful, we believe the single planning aspect will provide an opportunity to see a more joined up approach.

PaCC representatives have been significantly involved to date in the SE7 Pathfinder looking into some of these new ways of working. It is still unclear how planning for health outcomes will be incorporated and whether any elements of health budgets will be passed to the family to direct. What is clear is that it is parent carers are provided with sufficient support in any new system to ensure the family get the desired benefits in terms of increased feelings of choice and decision making/buying power.

### c. New Health Bill

The PaCC aims to represent the views of local parent carer in the areas that really matter to them and their children. During 2010-11 we reported on parent carer views on education at a time when SEN (special educational needs) was going through huge change and reform (and this work is ongoing). The same is now happening within health, with the biggest changes in the system for 60 years.

We want to ensure that disabled children's very unique needs are prioritised within this, not only at a national level, but also locally in Brighton & Hove. Amaze and the PaCC have fed into the Children's and Young People's Health Outcomes Forum, co-ordinated by the Council for Disabled Children.

Our focus on health has also been timed to coincide with the establishment of the City's Clinical Commissioning Group (CCG) and the movement of Public Health back into the local authority and we hope to present our findings to these Commissioners and feed into the City's Joint Strategic Needs Assessment (JSNA) and new Health and Well-Being Board

### d. The evolution of parent participation

Parent Partnership working is evolving in a really exciting way in the City, in some areas resulting in true co-production and this must certainly be the way forward. When parents and professionals work together, from the earliest stages of service design, outcomes improve for disabled children. We need to ensure that the voice of parents of disabled children is heard at every level and this is starting to happen in Brighton & Hove because key people operating at a strategic level are working closely with parent carers.

Parent carers are represented on the city's key decision-making boards including the Disabled Children's Strategic Partnership Board, the CAMHS Partnership Board, the SEN Partnership Board and the Learning Disability Partnership Board. They are involved from the outset on the development of information for families about local services for children with disabilities. Parent carers are also now being included on interview panels for key health professionals such as occupational therapists, speech and language therapists and nurse consultants.

In fact, Brighton & Hove is by national standards, well advanced in parent partnership work. Last year saw the launch of the Partnership Charter, a ground-breaking piece of work based on the principals of Aiming High for Disabled Children where teams of trained parent carers 'assess' local services. [see Partnership Charter in Appendix 1].

Although locally, parent partnership has come a long way as with many things, some services and individual professionals are doing this better than others. We hope this report will set out some of the good practice that is occurring in health and highlight where this can improve.

### 3. Methodology and Report Structure

This report has been written to capture a snapshot of parent carers' views of local health services. Given the number of different health services families with disabled children make use of, the PaCC Steering Group decided to prioritise discussion about just four. These are:

- The Royal Alexandra Children's Hospital (RACH)
- Seaside View Child Development Centre (Seaside View)
- Child And Adolescent Mental Health Services (CAMHS)
- General Practitioners (GPs)

At the event we did ask parent carers their views on community health services. However many of the comments that parents made were about community services provided by RACH and Seaside View and therefore we have decided to incorporate these views in to the relevant sections.

We asked parent carers to feed into this report in a number of ways:

- The PaCC held a 'Talk Health' event [in March 2012] providing parent carers with the opportunity to discuss the four areas above, with a senior professional from each service area in attendance to listen to their feedback. [Appendix 3 lists the professionals who attended.]
- The Amaze Health Information Fair took place in November 2011 as a launch event to our focus on health and providing parents and practitioners to come together and share information. A focus group was facilitated to allow parents to discuss 'communication with healthcare providers'.
- The Amaze Parent Carer Survey circulated via the Amaze newsletter to 1200 families. 114 responses returned.
- In addition, we carried out telephone interviews with a further 30 parent carers and asked for feedback on the PaCC Facebook group, which has a current membership of 50 parents.

As such, this report is the result of PaCC talking face to face to over 50 local parent carers about their experiences of local health services as well as email, Facebook and survey results from 164 parents. Our hope is this report will clearly present a picture of the common experiences which families with disabled children face when using healthcare services in Brighton and Hove.

We aim to table this report at the newly established Health & Well-Being Board and the new Health & Wellbeing Overview and Scrutiny Committee, among other key strategic meetings in the City. Our purpose is to facilitate discussion and raise the agenda of improving health services and ultimately the health outcomes for this disadvantaged group of children and their parent carers.

## 4. Parent Carer Findings

This is a snapshot of parent carer experiences in Brighton & Hove. It aims to represent the wider local experiences of health services that families encounter on a daily basis.

### a) The Royal Alex Children's Hospital (RACH)

#### Positive findings

- The hospital

Parent carers acknowledged that the new RACH was a fantastic resource to have on your doorstep, without having to travel out of area. The new children's A&E department was really well received by parent carers and many recalled the 'horror stories' of taking their child to the adult A&E. The triage system worked well and mainly the feedback about communication and understanding of disabled children's needs was good.

- Community services linked to the hospital

Parent carers told us that community support was good, but would like to see the service expanded. Parent carers were very positive about the community nursing team which provided excellent support to parent carers in their homes teaching them to care for nasal gastric tubes or gastrostomies. Parent Carers described them as "well briefed" with a "good understanding" of their child's condition.

- Departments providing an exceptional service

Phlebotomy services came out as particularly strong in the way they interact with disabled children. This was reported by several parents who also noted that the service had "really improved" over recent years. There is also regular paediatric first aid training offered for parents free of charge and this has been offered on a 'bespoke' basis for one family who have a child at risk of choking and having breathing difficulties. This is really exemplary.

#### Areas for improvement

- Parents were left unsupported prior to diagnosis

Often children with disabilities need to be monitored for long periods of time before they get any firm 'diagnosis' or plan of action. Parent carers understand this need to 'wait and observe' approach but felt that some sort of early support while they are waiting would have been ideal.

- Communication between different professionals was often poor

Disabled children have many assessments carried out by a myriad of different professionals. Communication between them could sometimes be improved.

Communication also needed to be strengthened between RACH and Seaside View and parent carers reported a 'disconnect' between specialists at Seaside View and, particularly, reports of A&E visits or unplanned admissions at RACH. Many of the children were treated in specialist units in London and communication could break down between these specialist London hospitals and RACH. One parent reported that having been transferred from Kings College Hospital in London to the RACH, they were approached by a member of staff who asked them "why they were there". The parent became quite agitated before a plan of action was drawn up.

- Parent Carers had to repeat their 'story; over and over (and over) again

Parent carers told us that this can be really irksome. Some noted that taking their child's 'most recent letter' helps but even this didn't totally prevent the repetitive process. The Disabled Children's Acute & Community Liaison Group is looking in to improving this experience by producing an All About Me document that would be carried with the disabled child and their family. This gives basic information about diagnosis, medication and communication methods etc. Hopefully this will help to improve the in-hospital experience of families of disabled children. This is not a 'local' problem but a national one and has been noted in the Kennedy Report.

"My son is on the autistic spectrum and is very anxious. They had really thought through the whole experience. They had an extra member of staff to help and had his favourite DVD poised to play as they took the blood."

"My little girl had a very traumatic birth but despite the fact that her EEG showed abnormalities we were left to 'watch and wait'. We went up to the main hospital and she was 'observed' by junior doctors but nothing seemed to be moving. We found it very difficult to get in to the process, despite the fact that I, as her mother, knew something was wrong."



"I feel that the liaison between consultants at the hospital and professionals at Seaside View is not strong enough. My son has severe seizures and cerebral palsy and when we arrived at hospital, they said that did not know him and could not advise. We had to tell our story again from the beginning. It was if the consultant we were talking to knew nothing about children who attended Seaside View."

"They just don't have time to talk, or to listen"

"The consultant presumed that my son has no understanding of language, because he is wheelchair bound and has a progressive disorder. He started to talk about 'end of life' options in front of him! I was absolutely horrified."

"We were given the first appointment, only for the consultant to be late. He sauntered in 30 minutes late, as my child finished dismantling the over-stimulating waiting room."

"My son hated being on a mixed age ward. No adjustment was made for different ages - in terms of waking times etc... It wasn't an appropriate environment for a teenager."

- Nursing could be inconsistent.

Parent carers reported examples of outstanding practice. They reported that some nurses had extensive experience of working with children with disabilities and special needs. For instance, one child was looked after by a nurse who had worked at a local children's hospice.

However, there were also examples of inconsistent practice. Parent carers told us about nurses who appeared to lack basic disability awareness training, had little understanding of parent carer experiences in hospital and the demands this placed on them. This meant that even to make a simple trip to the toilets had to be planned to ensure that their child was not left unattended, even for a minute. Staff were not always proactive at offering this help and only did so when they were asked. Some staff gave confusing and conflicting advice about specialist equipment and had a 'rushed' approach to parents.

Parents overwhelmingly felt that they were the 'experts' on their child's care and that without them, many nurses would not know how to effectively care for their disabled child. Several parents reported that the lack of a paediatric neurologist on site was difficult when a child with complex epilepsy presented in A&E in 'status epileptics'.

- Consultants can lack sensitivity and make judgements about children with disabilities.

Parent carers reported that some consultants could be patronising or distant. Often there were several students in the room "who were not introduced to me or my child". Some interactions with consultants had lasting and devastating effects. One new mother was told to put her newborn baby down in the cot while she was told 'what was wrong with her'. One family were treated with a lack of empathy and told that "their daughter had half a brain" with no appropriate explanation or a caring delivery of such devastating news.

- Waiting times.

Consultants did not automatically put children, with special needs, first on the list so children who found it difficult to wait had to wait for long periods of time. This was improving, but consultants needed to be mindful that they needed to start their clinics on time, where possible.

- Parking facilities are unacceptably poor

There is one disabled bay at the Children's Hospital. All the parent carers were dismayed by the parking facilities. There were bays in the car park but most of the time, there was such a long queue (often a waiting time of half an hour or more). This was very stressful for families who had a child with special needs. The on road parking nearby was on a hill and parent carers reported "struggling" up and down hills with a wheelchair or a child who was unwilling to walk. One parent carer reported that the experience was so stressful for her child, who is on the autistic spectrum, that her son started to "head bang and hit us" before they had even made it to A&E.

- Mixed Wards and Transition anxiety

Teenagers with a learning disability were placed on a 'mixed age' ward and while difficult for any teenager, this was particularly difficult for a teenager with a disability or special need.

Parents reported a general anxiety about the transfer to adult services, particularly if they had not had a brilliant experience at the children's hospital.

### Parent Carers' Recommendations about RACH

- Parking

Priority should be given in the car park to those with a disabled badge allowing them to queue jump as the bays are there but parents can't get to them and more bays that are currently for 'drop off' freed up for 'disabled badge' holders only. The parking situation frequently puts a visit to hospital off to a really bad start. This could easily be solved.

“I cannot think how my son [now 14] could manage being in a mainstream adult ward in hospital! We need to know he will be catered for and supported in adult services by making available specialist 1:1/2:1 staff to be with him on the wards, appropriate medication/equipment with a single room, giant cot/portable safespace, sedation etc.”

- Parent carer involvement in regular groups

Since the PaCC health event, a PaCC representative is now on the Disabled Children's Acute & Community Liaison Group (a group that aims to improve the experience of disabled children and their families at RACH and also the links with community health services) but parent carers want a wider consultation group and opportunity for senior managers to listen to their concerns.

- Parent journey training for all

Parent journey training should be part of the standard induction for RACH staff and should include consultants, doctors and nurses working at RACH. Amaze offers training workshops, delivered by parent carers, which cover the parent carer journey. We could also develop a protocol on how to treat parent carers differently when they arrive at RACH, in partnership with staff there.

- 'All About Me' Documents

Since holding the health event, it has emerged that this is an area that is being looked at. Although this is a great idea in principal, professionals need to think carefully about who holds this document and how several copies need to be kept updated (in settings such as school, respite home, GP and family). There needs to be a really clear explanation of the difference between these and the 'passports', traditionally used by the main hospital. Many parents will need help filling these in. There needs to be thought about how these documents will change/be modified during transition.

- Disabled children given priority

Disabled children should routinely be put first on the list and where possible consultants should ensure that they arrive on time for clinics especially when the first appointment is for a child with special needs. There needs to be some liaison to ensure that as many appointments as possible are on the same day so that parent carers aren't having to repeat the trauma of a hospital visit unnecessarily.

- Specialist disability liaison nurses

This would be the ideal. There isn't a paediatric 'disability' specialist available and it is 'hit and miss' whether you get a nurse with any real experience. A specialist nurse could train up nurse teams on ethos and approach and ensure consistency. For instance, Kings College Hospital employ a Nurse Patient Liaison Officer that parents can contact at any time. She is able to give direct advice over the phone or contact another professional for advice if required. This has meant that unnecessary trips to London have been avoided because parents can be reassured over the phone.

## **b) CAMHS**

### **Positive findings**

- New Parent Group

The service is listening to parent carer concerns and is keen to develop its partnership working with parents to improve the service.

- Specialist Nurses offer home visits

Several parent carers reported a really positive experience with the specialist CAMHS nurses. One said that she felt "supported and understood" and that really useful, practical help was given with daily challenges, such as going on a simple shopping trip.

### **Areas For Improvement**

Out of all our local health services, parent carers report that CAMHS is the hardest to access and the most difficult to negotiate.

- The waiting time for an assessment is too long (and no support is given in the meantime).

Parent carers reported being "stuck in the system" and "left to it". Guidance for parents as to how to deal with

“CAMHS has really taken on board everything that has been said by parents and their stories all correlate with each other. So hopefully we will see some improvements.”

“We had to wait nearly a year to be seen and they also said they would review my son [once seen for the first time] and this hasn't happened. You can only be seen by a specialist in ASC if you have a statement.”

This story, from a mother who has a son with mental health problems, is typical.

“I have a child with mental health problems. CAMHS? Where can I begin? It takes far too long from point of referral to actually seeing someone, even if your child is really quite poorly. They take stance of it being a family problem as opposed to a medical one or with the child. I have found psychiatrists quite arrogant and often not up to date with the latest developments. I had to make formal complaint and see a third psychiatrist from another county before got anywhere. This psychiatrist said that that my son should have had a proper care plan from the outset. It is the most stressful and exhausting experience I have ever encountered.”

their children at home whilst waiting to be seen by the consultant was not forthcoming and parents felt that time was wasted.

- Parents were not empowered or treated as equals in their child's care and reported that they felt their confidence had been eroded

Many parents reported a feeling of 'disempowerment' when engaging with CAMHS. Several parents described feeling as if professionals felt they were to 'blame' for their child's autistic spectrum disorder. Parents were universal in their criticism. Several parents reported turning to voluntary organisations, such as Amaze and Ayme (Action for Young People with ME) as they were not getting a quality service from CAMHS.

- Transparency was poor

Parent carers reported that there was little transparency on how to access the CAMHS system, and how it works once you are in. Also, this feeling of a lack of transparency was exacerbated by the use of 'psychiatrist's' language and lingo that parent carers did not understand.

### Parent Carer's Recommendations about CAMHS

- Better information (about what CAMHS does and who is and isn't eligible for input and the different sections of CAMHS). Parent carers need to be involved in the creation of this information from the outset.

- User satisfaction survey to be sent out (as agreed by the Children's Overview and Scrutiny Committee last Autumn) and results analysed and presented back to the Disabled Children's Partnership Board and Health and Well-Being Board.

- Transparency about pathways of care and waiting times.

- Training for psychiatrists in the parent journey. There needs to be an ethos change so that parents are seen as the experts in their child's care. This was a very powerfully voiced recommendation from parent carers who said that psychiatrists (some of whom were very newly qualified) made them feel "patronised".

- Autism specialist needed.

- Behaviour network for children with severe behavioural difficulties set up. This would provide much needed support for families who are struggling with behavioural issues, allowing them to support each other as well as get professional input.

#### c) Seaside View Child Development Centre (Seaside View)

The relatively new integrated child development service has been well received by parents and this is a huge strength in Brighton & Hove, compared to other areas which do not have integrated services. Parents reported a feeling of 'joined up' care and really good liaison between different professionals.

### Positive findings

- The coordination and communication between professionals at Seaside View was very good. This was universally reported by parent carers. One talked of the new 'invitation to join', which meant a key Seaside View professional was able to refer you to a new service, without having to get the parent to revisit their story from the beginning again. Seaside View was also working really well with outside agencies (one parent carer reported that the therapists worked really well together at her child's mainstream school). Parent carers also reported the excellent service by the receptionists who always passed messages on efficiently. They were also very welcoming to families and included the children and young people when they visited the unit.

- Personable and approachable staff

One parent carer reported that her child on the autistic spectrum was very anxious about her visit to the

“When giving the diagnosis (of a rare chromosome disorder) we felt they could tell us very little but surely they could have referred us to Unique or even used it themselves to download information?”

occupational therapist but viewed it as a very positive experience. She was very understanding and had a real grasp of her child's difficulties.

- Excellent team of paediatricians

All the parent carers gave positive feedback about paediatricians who they described as 'knowledgeable' and 'empathic'. Many parents described their paediatricians as 'going the extra mile'. Almost all parent carers reported that they were "treated as equals" in their child's care.

- Keyworkers and Specialist Health Visitors

The new team of keyworkers was well received by parent carers. However they were a very small team (of two) so many families (who have multiple professionals involved with their child) were left without a keyworker. This will become even more resonant, with all the changes proposed by the SEN green paper and there will need to be very careful consideration as to how families are supported. Parent carers were universally positive about the small team of specialist health visitors at Seaside View but as it is only a team of two, it is limited.

### Areas For Improvement

- Waiting time transparency

One parent reported their child had been referred two years ago and was still waiting for an appointment. Another parent carer reported that her child was referred every two to three years and was still waiting for an OT appointment. Her child was now due to start secondary school in September. Eligibility for Seaside View services and how children are prioritised needs to be clearer.

- Better signposting

Parent carers reported that, on the whole, professionals at Seaside View were very good at pointing them in the direction of Amaze of further help/advice. However it was felt that this could be improved. Parent carers felt it would be helpful if Seaside View staff could have signposted them to national support services as well and would have preferred a professional steer rather than "scaring myself on the internet."

- Equipment

This was a widespread problem. Parent carers reported huge delays in equipment (a 6 month wait for a sling/slide, for example). They also reported a lack of highly specialised equipment. The waiting time could be so long, that by the time the specialist equipment arrived the child had outgrown it. This is a particular problem at transition, too. There is confusion over who has responsibility to provide/replace/monitor equipment once a young person reaches 19.

- Therapies

Significant problems still existed with the provision of therapies. The PaCC and Amaze produced a report, "More Therapies", four years ago see [http://www.amazebrighton.org.uk/editorial.asp?page\\_id=253](http://www.amazebrighton.org.uk/editorial.asp?page_id=253) and whilst there had been some improvements with improved information about the services provided many of the problems identified in that report had still not been resolved. There was a perceived lack of parity about who was eligible for therapy and how much input they got as well as serious concerns about waiting list times for referrals as well as appointments.

Waiting times from referral to treatment were above the national average in 2011 for occupational therapy and physiotherapy see Care Quality Commission's review of Support for Families of Disabled Children see: [http://www.cqc.org.uk/sites/default/files/media/reports/20092010\\_Support\\_for\\_families\\_with\\_disabled\\_children\\_BrightonandHoveCityPCT.pdf](http://www.cqc.org.uk/sites/default/files/media/reports/20092010_Support_for_families_with_disabled_children_BrightonandHoveCityPCT.pdf)

In particular, parents reported some children were receiving speech and language therapy (SALT) once or twice a year and others got SALT in intensive blocks of weekly provision for a set number of weeks. Parent carers reported finding it very difficult to get sufficient physiotherapy and OT input, even if it was on their child's statement as services were 'overstretched'. One parent reported that it was not clear how occupational

therapy was broken down. One family was told they could not get any 'sensory integration' input for their child and it was only when they complained that this was provided. Some parents reported a high staff turnover within the physiotherapy team had led to inconsistency of provision. Some parent carers were buying in private services to supplement what they get. Parents also report that therapy input appears to be reducing in schools and there is confusion as to whose responsibility this is. Also, there needs to be better planning for therapy provision once young people reach transition. Parent carers report that often families have "no idea" what is going to happen next or who is responsible for next steps. There are problems within Speech and Language therapy services as adult services use a different set of symbols to the Makaton symbols young people are used to and need to embrace the continuing use of VOCAS (Voice Output Communication Aids).

We have been provided with the current (July'12) waiting times for therapy services and some of these still seem unacceptably long:

Speech and Language Therapy	referral to first assessment 6 weeks	referral to first treatment 8 weeks	
Physio	urgent/semi-urgent 4-8 weeks	non-urgent 52 weeks	
Health OT	pre school children with complex needs as part of a multi-disciplinary assessment 10-12 weeks	School age children as part of a multi-disciplinary assessment 22-26 weeks	
	pre school children with complex needs 12-18 weeks	School age children 52 weeks	
Social Care OT	urgent needs 5-10 days	High priority 10-20 days	Chronological order of referral 9-12 months

### Parent Carers' Recommendations about Seaside View

- Therapy Assistants

Following the More Therapies report several years ago, the local authority carried out a review by an external consultant. One of her recommendations was to introduce therapy assistants. Whilst parents would rather have fully qualified therapists working with their children, there is acceptance that this is unlikely to happen given the current lack of additional funding. In this climate, we would welcome a renewed discussion on how therapy assistants could supplement the work of fully trained therapists – providing guidance to TAs and parents about how they can help their children in between appointments.

- Transparency about waiting times and eligibility

There needs to be a coherent system (across therapy services) telling parent carers who is eligible for what and why and what estimated waiting times are. Parent carers need useful advice in the form of advice sheets/parent groups (such as the Hanen Programme which was run at the child development centre in the past) to help them feel 'skilled up' to help their child in the interim period.

- Information at Seaside View is good but could be better.

Professionals need to ensure that they have the very latest information on different conditions and that they can always signpost parents to other areas of support. Whether this is locally (Amaze or local parent groups such as Pebbles or Sweet Peas) or nationally (websites, support groups such as Unique, for children with a rare condition or Swan, for children with an undiagnosed condition). We understand the Council and Amaze are undertaking a joint project to improve web based information for parents which might help to resolve some this

“OT is particularly hard to get. My child has cerebral palsy and severe epilepsy and we still struggle to get any advice about what do at home. The only service we get is that they advise school on a termly basis. We have sourced and paid for all our equipment apart from his commode. We would benefit from advice on exercises that would help with my son's self help skills but this service has been overstretched and understaffed for as long as I can remember. There seems to be a real inequality in this service”

situation but it needs to be recognised that not everyone has access to the internet. Information needs to also be produced in hard format.

#### **d) GPs**

Research carried out by Contact a Family shows that 75 per cent of families with disabled children do not visit their GP about their condition. The relationship between families with a disabled child and their GP is particularly vital on many fronts particularly as children's care is transferred to their GP at 18. GPs knowledge base is understandably wide and their in depth knowledge about specific medical conditions can be limited. For children who have learning difficulties and/or other medical needs but are not eligible for a paediatrician, the GP is absolutely the key medical figure in that child's life.

#### **Positive findings**

- Innovative local solutions

Parent carers reported that some GPs offered services that were making a real difference to families. Such services included an Online booking appointment system for GPs, a drop in clinic for children, a separate room organised for child with challenging behaviour, 'telephone' appointments and home visits.

- GPs see the family as a whole

Parent carers reported that their GP was very holistic, seeing the family as a whole and gave 'carers' support. Families reported being regularly asked how 'their' health was as the main parent carer. GPs also got involved in much needed referrals for respite. Parent carers reported GPs asking if they got enough respite and if they could write letters to support their access to more help.

- Some GPs are taking annual health checks seriously

All adults and young people in transition will have to have annual health check and some GPs are ahead of the game on this. One parent carer reported that her daughter had already had a health check at 14. It is hoped that health checks will pick up health problems that may have gone unnoticed or undiagnosed.

#### **Areas for Improvement**

- GPs sometimes lacked knowledge about specialist services

Parent carers reported having to 'fight' to be referred to specialists or that GPs knew nothing about the variety of specialist services which might be available. Parent carers may find visiting their GP so stressful and demoralising that they avoided taking their young person to their GP. This sometimes resulted in a child becoming very ill before their parent accessed medical health. Some parent carers reported going to A&E as an alternative.

- Prescription errors

Parent carers reported incidences where the GP had written a prescription for their child which was inaccurate. Medication and dosages had been changed by specialist consultants who had not communicated this change to the GP. There seemed to be an understanding that parent carers would update the GP which was felt inappropriate. One parent carer reported that her GP was brilliant at double checking medication but that the labels on the bottles of medicine were often out of date and inaccurate.

- Inconsistency across the city

Whilst some parent carers reported that they had a very good relationship with their GP, others find it problematic. One parent reported that her son, who was on the autistic spectrum, did not have a community paediatrician and that she only took him to the GP if he was 'really ill' as he had little understanding of her son's complex needs. Also, out of hours doctors didn't always know the family history and needed to ensure that they respect the views of parent carers. When visiting the surgery, parents reported differing experiences of their initial contact with reception staff. There was a lack of understanding and, as one parent put it a "can't do" attitude.

"My son has a very complex health problem. Our GP knows him really well. But the problem is when you see a locum GP out of hours. Our son needs antibiotics at the first sign of a chest infection as, otherwise, it can turn into a life threatening problem and he ends up in hospital for weeks needing suction. A locum GP told us that he was not 'ill' enough for antibiotics."

“My GP is very helpful but there is little recognition of the emotional and mental problems that go with a disability, both for the young person and the parent. Also, appointment times are too short when your child has such complex difficulties. GPs need improve how they signpost to other agencies”

“I am hugely worried about transferring care to the GP. My son is unable to wait in a waiting room, there is no disabled parking at my GP and he has not specialist knowledge of learning disability. One parent I know had an awful experience when her child had to stay in the car, as they were restrained, in order to be seen by their GP.”

- Some GPs do not 'take care' of the whole family

Many GPs do not realise that they have a statutory responsibility for the health of parent carers.

When young people reach 18 the main professional becomes the GP. In the lead up to this, if families and young people have not built up a relationship with their GP this transition is problematic because the GP does not always have enough understanding and knowledge about their complex medical condition. This did not give families confidence in the GP's ability to look after their young person. Challenges were also faced by parents whose children were 16 and had learning difficulties. They were not able to take responsibility for their own health needs and parents found that professionals who lacked knowledge in this area were asking them to do things they were not allowed to do.

### Parent Carer Recommendations about GPs

- A route map of services that will give GPs information and points of referral to specialist services when a parent goes to them for a consultation. This information also needs to be given to the parent so that they have a clear idea of possible wider medical concerns. Information could be provided by Amaze.

- Disabled children need to be prioritised

Waiting times should be reduced. Disabled parking bays need to be provided routinely outside GP surgeries. If access is not possible, then provision needs to be made for disabled patients to park in the private GP car park.

- Home visits given routinely to children with disabilities and SEN who find it difficult to successfully visit the surgery. More thought must be given to out of hours GP services to allow families that have difficulty accessing the services during the day time to go to the GP when the surgery is also less busy.

- Training for GPs and families on power of attorney/mental capacity act so that families are clear about their responsibilities and GPs do not put families in a difficult position by asking them to make decisions for their young person that they have no power to act on in the eyes of the law. GPs also need to be given the parent journey training alongside other professional so that they can empathise with families who have a caring role.

- A holistic approach needed by all GPs.

They have a duty to look after parent carers too and should routinely look at their health/coping capacity. GPs should produce a protocol to ensure that the needs of the wider family are taken in to consideration when a young person visits the GP.

- Transparency and communication

Eligibility for referrals needs to be clearly explained to parents. All communication from specialist consultants should be routinely copied to parents and the child's GP. There needs to be really careful monitoring of medication and communication between the parent, GP and the pharmacist. This is particularly pertinent when new medications are introduced or doses are changed. GPs, pharmacists and specialist consultants need to routinely review the medication and ensure all labels are up to date and accurate. Many children receive respite care in other settings and inaccurate labelling could lead to medication errors resulting in serious harm. Information stored in the All About Me document needs to be transferred so that it includes the out of hours service provided by the GP.

- Health reforms- need a parent voice

The new CCG is currently consulting on how to engage patient populations and are keen to develop Patient Participation Groups (PPGs) at GP practice level. Amaze has fed into this consultation that it is very unlikely PPGs will be accessible to parent carers so there needs to be other attempts made to hear their voices. We suggest Amaze and the PaCC can represent parent carer views on a city-wide basis and we should be invited onto key strategic decision making groups where possible to present these views and be influential at service design.

• Extend examples of good practice that are making a real difference to all GP surgeries.  
Code of practice for disabled children and their families to be disseminated throughout.

• GPs who are responsible for a child with a learning difficulty or other special need that do not have a specialist paediatrician, need extra support and training.

They are the key person and need to be supported to fulfil this role. This group should be earmarked and liaise with each other and access specialist training (e.g.: training on the autistic spectrum, how children with communication difficulties express pain and so on...). This could be done through the Nurse Consultant at RACH.



## 5. Conclusions and Parent Carer's Key Recommendations

So what are the priorities for parents? Often, it is not blue sky stuff, such as a magical cure or revolutionary new treatment, but the less measurable, subtler nuances of care. Parents, who are at the coal face after all, experience the care, rather than live it. It is an emotional journey that is their daily life.

### a) Parent Participation

i. A seat for parent carer (PaCC) representatives on the new Health And Wellbeing Board, Children's Committee, and Clinical Commissioning Group's Children's Review Board. The parent carer voice needs to be represented at the highest level in order to work in partnership to drive improvement in health services for the most vulnerable children in our local community. This is a vital starting point.

ii. Recognise the value of parent participation and partnership working and invest in it  
As mentioned earlier in the report, the PaCC (receives some funding for its engagement activity via the PCT (now emerging CCG) but this contract will expire at the end of March'13. It is vital that the CCG can replace and if possible increase this funding so that this group of disadvantaged children can be well represented by their parent carers.

Indeed we are keen to reach more families who are not currently engaged with the work of PaCC and Amaze to improve our ability to represent the full diversity of needs across the City, but additional funding is required to do so. We believe Public Health should match the investment in the PaCC that the PCT/CCG makes in order for us to help them in their target to reduce health inequalities for this group further.

iii. Recognise and value the parent carers' role as child's keyworker in health care provision  
Our comments come from our proven expertise of being the 'key worker' and deliverers of health care, therapies, education and emotional care to our children 24/7, 365 days a year, for their childhood, through their adolescence and often for many decades of their adult lives.

Navigating the health care system is not a skill that parents of disabled children are born with. It is one that they have to learn 'on the job' (a job they did not apply for...). They find that, not only do they need to adjust to new parenthood but they need to adjust to their role as a 'parent carer'. Parents describe themselves as having to be multi-skilled and have almost super human powers of resilience.

iv. CAMHS Parent Carer review  
Parent carers need to work in partnership with CAMHS to review transparency and communication across the service at all tiers.

v. Service evaluations and user satisfaction surveys  
It is good practice for 'customers' to be asked what they thought about a particular service and all health services should be asking for feedback as a matter of course. A standardised form could be developed and then rolled out across all services, including health. These would need to be allowed to be completed anonymously and sent into a centralised research team and results presented to the new Health and Well-Being board.

In addition, all the health services discussed here should be encouraged to invite pairs of parent carers to independently assess their service using the Partnership Charter. CAMHS has already asked and is due to be evaluated in the autumn of 2012. The (0-3) star ratings should also be made public and presented to the Health and Well-Being Board, Children's Committee and other key groups and communicated to families via the Amaze newsletter and most importantly by the service itself.

“I am my daughter’s nurse, her psychologist, her OT, her speech and language therapist, her gastroenterologist, her epilepsy specialist, her teacher, her advocate, her pharmacist, her PA... I am everything in my daughter’s world and it takes enormous amounts of energy and resilience to keep everything together. Sometimes, I just want to be her mummy.”

## **b) Increased resource for services**

### **i. Bolster Community Support**

Support in the community is very powerful, supports the principles of early intervention and is cost effective. For example, a specialist epilepsy nurse (which Brighton & Hove does not have in paediatrics) would give much needed support in the community. This would cut down visits to A&E, 999 calls, the input needed by community paediatricians and greatly reduce stress levels within families who have children with very complex epilepsy. The community nursing team gives invaluable support to children and keeps them out of hospital but they are under resourced and sometimes can't make it to families when needed. Specialist Health visitors are a key professional at the very early stages and offer vital 'early support' but there are only two of them and many children cannot access their help. We need more specialist nurses and specialist health visitors (with greater focus on disabled children) working in the community to support our most vulnerable families optimise their health chances.

### **ii. Paediatric Disability Liaison Post at the RACH**

Parents need somebody to liaise with over their child's stay in hospital. At the moment, the hospital experience is not consistent. Such a post would greatly improve the experience of children with disabilities and young people and their families. This would reduce complaints and reduce stress levels in already over stretched services.

### **iii. Where necessary parents should be allocated a key worker**

However, parents feel they are often expected to bring everything together, in a 'key worker' type role, and this is not always possible e.g. many parent carers might also have a disability or health concern of their own, there are other siblings to care for etc. Indeed, the ability of a parent carer to navigate all the health services their child needs, might be more or less do-able depending on where they are on their carer journey'.

As such, some parent carers are unable to take on this keyworker role and in some instances this is not appropriate. This will be even more necessary with the implementation of the new Single Plan.

### **iv. The need to invest in parent carers' resilience**

We also need to be very mindful of the health of the whole family. Families who have a child or young person with a disability or special need experience immense levels of stress. Research by Contact a Family reveals that 49 per cent of the parents surveyed had been to their GP about feelings of depression and isolation and received either medication or counselling. In Brighton & Hove, 52 per cent of all carers have been treated for stress related illness.

Many parent carers in the PaCC have attended the Amaze 'Looking After You' and 'Insiders' Guide – Building Resilience' 6 weeks courses which have been highly evaluated as invaluable by parent carers as they tackle feelings of isolation and provide techniques and strategies for dealing with everyday situations, asking for help and building their family's resilience. The PaCC would like to see these courses being built into the Amaze core funding so they can be offered to families each year, and delivered in 'harder to reach' neighbourhoods where families may be more at risk of crisis.

## **c) Improved Communication and Transparency**

### **i. Improved Communication about services, eligibility and waiting lists**

Parents would like to see improved communication between GPs, consultants, hospital departments and families. Parent carers would like to be routinely copied in to any correspondence written by these professionals. They would also like to be kept informed of the eligibility criteria for services provision and the length of waiting lists so that expectations of service delivery times can be realistic. Parent carers are still 'in the dark' across many services about who is and who isn't eligible and how long they will have to wait to receive a service. This needs to be urgently tackled so that there is absolute transparency for families from the outset. Greater transparency of the services provided will ultimately lead to increased confidence in the system and fewer complaints.

“As a Parent Carer, years are spent in an adrenalin-fuelled, ‘flight or fight’ mode. Life is truly a rollercoaster of emotion. I have seen many families break down under the stress of it all and most of my friends, who are parent carers, are on (or have been on) antidepressants and have regular counselling to cope with the immense pressures they face parenting their child.”

ii. Therapy waiting times

This is still a problem despite therapy services being the subject of the first PaCC report in 2009 and subsequent internal and external reviews following this. We need to reduce waiting times urgently and be transparent with families about why the waiting times are so long.

iii. Training opportunities extended to all staff in the health care profession

The PaCC would like to see the ‘Parent’s Journey’ adapted into mandatory training for all health care professionals working with children with disabilities and complex health needs. This will give professional a much better understanding of the context that being a parent carer has e.g. practical difficulties as well as emotional and physical demands. This would result in fewer complaints and much improved communication between the medical profession and families.

iv. GPs and transition

There needs to be a city wide code of good practice for GPs on disabled children’s transition. Too many GPs lack an understanding of their young people who have a disability or special need and this can be calamitous when they take over their ‘care’ at 18.

**Content provided by parent carers, compiled by:**

Amanda Mortensen – Chair of PaCC  
Debbie Collins – Amaze Parent Participation Officer  
Rachel Travers – Amaze CEO

July 2012



## Appendices

### Appendix 1

#### Partnership Charter Outline

The Parent Carer Partnership Charter comprises 4 staged elements, each the result from extensive consultation and each supported by full documentation. They are:-

- Partnership Standards short checklist
- Parent carer star assessments
- Partnership Standards full checklist
- Disabled Children Integrated Services action planning strategy

Under each of the core offer standards the Parent Carer Partnership Charter sets out delivery milestones in three categories; 'at basic stage', 'in development', and 'advanced' – to give clarity to local areas about what they need to do in order to meet the core offer standards. The milestones:

- 'at basic stage' will have been met by local areas just beginning to think about and plan services that deliver on the core offer.
- 'in development' will relate to local areas that have progressed further and have many of the necessary elements in place.
- 'advanced' will have been met by local areas who are fully delivering on the core offer standards, with families firmly at the heart of their service planning and delivery.

This document will continue to be updated as practice develops.

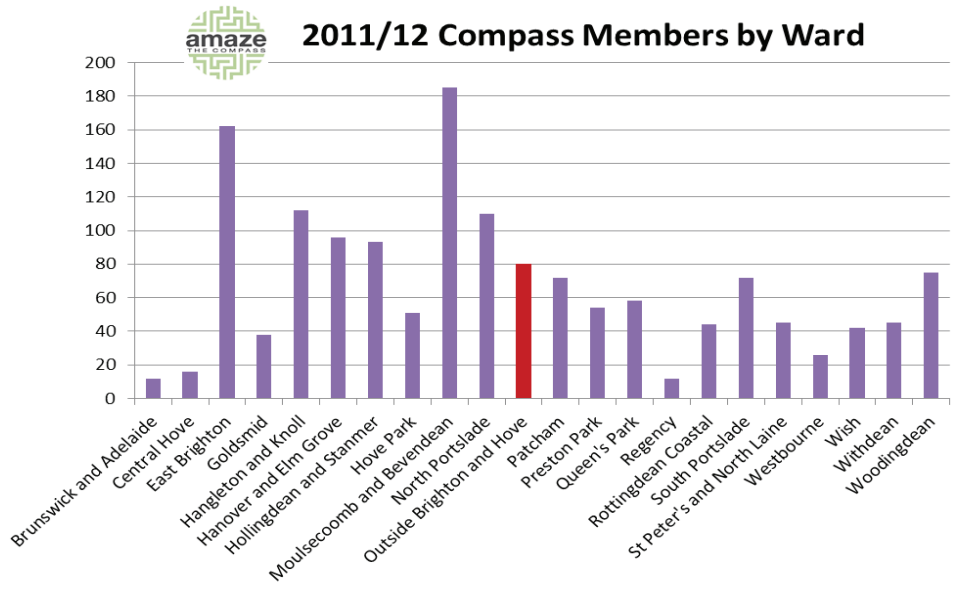
The aim is to provide a constructive vehicle for on-going improvement in quality of partnership working between families of disabled children and service providers across all sectors. The function of the Partnership Standards is to provide an agreed baseline of good practice in partnership working and offer a constructive framework for on-going service improvement.

#### Key Features and Characteristics

The key elements which we believe are integral to the Parent Carer Partnership Charter and which we believe define it as a product are:

- a. Defining and agreeing the standards and process in partnership with parents right from the start of the project
- b. Training up of parent ambassadors to carry out the assessments, with this role being paid for in line with the Amaze Parent Engagement Policy, recognising parents as equal professionals. The Parent Ambassadors are suitably supported, supervised and accountable.
- c. Positive assessment approach focussing on identified strengths as well as areas for development and allowing for the development of a relationship and dialogue between professionals and parents
- d. The assessment findings are published in a transparent way including an agreed plan of actions with commitment where improvements are needed

## Appendix 2



## Appendix 3

Key senior officers/professionals attending the 'Talk Health' event were:

### For RACH:

Janet Lee  
Linda Gilmour

### For CAMHS:

Tim Ojo  
Peter Joyce

### For Seaside View:

Jenny Brickell  
Sian Bennett  
Tracey Young

### For GPs:

Dr Xavier Nalletamby

