



Amaze provides information, advice and support for parents of children with special needs and disabilities in Brighton & Hove.

The Parent Carers' Council is the local forum and voice representing the views of parent carers on services their disabled children receive. It is supported by Amaze.

information . advice . support . Parent participation

about Amaze and the PaCC

- Parent-led independent charity since 1997
- Mission - empowerment of parents and building their capacity and resilience
- Provide information, support and advice services to parents of disabled children e.g. 4,000 calls per annum to helpline (86% increase in 5 years)
- Manage city's disability register – The Compass – has in depth details of 1,800 children
- Support the PaCC – the local forum for parent carer, now 190 parent members and 7 partner organisations
- Parent representatives are supported to sit on 12+ strategic, partnership, decision making, boards and subgroups across the city
- Reports published:
 - More Therapies 2009
 - Education and Special Educational Needs 2010
 - Talk Health 2012



“To be a good supporter of your child, you need great support yourself”.



Focus on health

- High cost, high incident users of health services
- A range of different health services are required including universal services, specialist services and condition specifics
- Services *must* actively seek the views of these young patients, and their parent carers, to ensure that their experience of health services are as positive as possible and achieve:
 - More efficient use and targeting of scarce health resources
 - Improved quality and ‘fit’ of service
 - Greater user satisfaction with services and fewer complaints
- Should be a focus on reducing health inequalities (as far as possible) in this population
- Feed into the City’s Joint Strategic Needs Assessment (JSNA) and new Health and Well-Being Board



“I wouldn’t swap you for the world... except for when you wake up at midnight... 2.15am... 3.30am... 4am”



A Personal Story



Talk Health – key findings

1) RACH +ve

+ve: RACH was a fantastic resource to have on doorstep, without having to travel out of area. New children's A&E department very well received.

+ve: Very positive about the community nursing team

+ve: Departments providing an exceptional service



"I was at crisis point when I found Amaze, support from this organisation has literally changed our lives, we owe them so much!"



Talk Health – key findings

1) RACH -ve

- ve: Monitored for long periods of time before any firm 'diagnosis'
- ve: Mixed wards and transition anxiety
- ve: Communication between different professionals was often poor
- ve: Have to repeat their 'story; over and over again
- ve: Some nurses lacked basic disability awareness or understanding of parent carer experiences in hospital
- ve: Some consultants could be patronising or distant



"I was at crisis point when I found Amaze, support from this organisation has literally changed our lives, we owe them so much!"



Talk Health – key findings

1) RACH - suggestions

- ? Parking priority should be given to those with a disabled badge allowing them to queue jump
- ? Parent carer involvement in regular groups
- ? Parent journey training for all
- ? ‘All About Me’ Documents
- ? Disabled children given priority
- ? Specialist disability liaison nurses



“I was at crisis point when I found Amaze, support from this organisation has literally changed our lives, we owe them so much!”



Talk Health – key findings

2) CAMHS +ve and -ve

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

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

-ve: Parents were not empowered or treated as equals in their child's care

-ve: Transparency was poor



“We spend a lot of time feeling as if we are in a parallel universe and that we’re on the outside of life looking in.”



Talk Health – key findings

2) CAMHS - suggestions

- ? Better information
- ? Extend the CYPOSC user satisfaction survey
- ? Transparency about pathways of care and waiting times.
- ? Training for psychiatrists in the parent journey
- ? Autism specialist needed
- ? Behaviour network for children with severe behavioural difficulties



“We spend a lot of time feeling as if we are in a parallel universe and that we’re on the outside of life looking in.”



Talk Health – key findings

3) Seaside View +ve

+ve: The coordination and communication between professionals at Seaside View was very good

+ve: Personable and approachable staff

+ve: Excellent team of paediatricians

+ve: Keyworkers and Specialist Health Visitors



“Being a parent to my child is an honour and a pleasure – although my child has turned my life upside down we wouldn’t have had it any other way.”



Talk Health – key findings

3) Seaside View -ve

-ve: Lack of transparency about waiting times

-ve: Could improve signposting

-ve: Huge delays in equipment

-ve: Significant problems still exist with the provision of therapies (communication, transparency, waiting times)



“Being a parent to my child is an honour and a pleasure – although my child has turned my life upside down we wouldn’t have had it any other way.”



Talk Health – key findings

3) Seaside View - suggestions

? Trial innovative approaches to reduce waiting times e.g. Therapy Assistants

? Transparency about waiting times and eligibility and provision of exercises/advice whilst waiting

? Information at Seaside View is good but could be better



“Being a parent to my child is an honour and a pleasure – although my child has turned my life upside down we wouldn’t have had it any other way.”

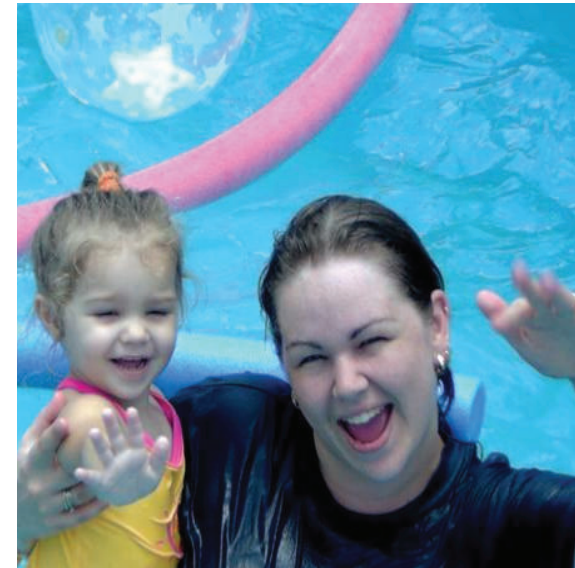


Talk Health – key findings

4) GPs +ve and -ve

- +ve:** Innovative local solutions
- +ve:** GPs see the family as a whole
- +ve:** Some GPs are taking annual health checks seriously

- ve:** GPs sometimes lacked knowledge about specialist services
- ve:** Prescription errors
- ve;** Inconsistency across the city
- ve;** Some GPs do not ‘take care’ of the whole family



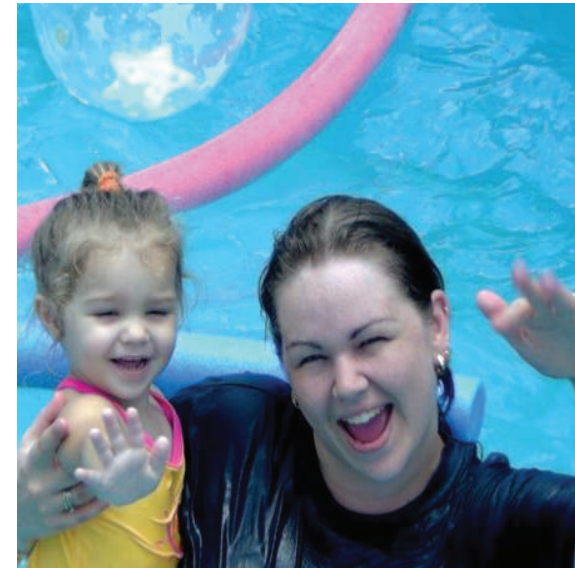
“A look, a cry, a reach, the stamping of feet... you become a communication detective when you have a child with speech difficulties.”



Talk Health – key findings

4) GPs – suggestions

- ? Consistency of how families are treated – Partnership Charter for GPs
- ? A route map of services available
- ? Home visits given routinely to children with disabilities
- ? Training for GPs and families on power of attorney/mental capacity act
- ? A holistic approach needed by all GPs
- ? Eligibility for referrals needs to be clearly explained and all communication routinely copied to parents
- ? Amaze and the PaCC can represent parent carer views on a city-wide basis (unlikely to participate in PPGs)



“A look, a cry, a reach, the stamping of feet... you become a communication detective when you have a child with speech difficulties.”



C&YP Health Outcomes Forum

HOF and Kennedy report very similar things as PaCC:

Challenges

- Health outcomes for C&YP are poor esp C&YP with disability
- C&YP and families struggle to get voice heard
- Training in paediatrics is poor esp. for GPs
- Care is not joined up and focuses on the system rather than individual
- C&YP low priority for GPs
- Wide variations in care



“Sometimes we want to do things that other families take for granted. Other families have to accept that we are a little bit different.”



C&YP Health Outcomes Forum

Recommendations:

- Put C&YP and families at heart
- Services need to demo how they listen to C&YP and families
- More paediatric training for all health services
- Better integration between hospital and community nurses (esp complex needs so can treat at home)
- Tightening drug procedures incl. drug errors
- More integration betw. Health, Education, Social Care
- Local Healthwatch to reflect C&YP issues
- Services to identify CYP with LT conditions, disabilities, SEN etc



“Sometimes we want to do things that other families take for granted. Other families have to accept that we are a little bit different.”



To sum up...

Further improve (and fund) Parent Carer Participation:

- Representation at H&WB board, CCG, RACH.
- Gateway funding
- Ask for service user and parent feedback

Increased resource for services

- Paediatric and parent carer training for medical staff
- Paediatric Disability Liaison post
- Sussex-wide Epilepsy Nurse
- Access to therapy services

Improved communication & transparency

- Between services and to parents

HWOSC

- To champion our recommendations?
- To refer to H&WB next meeting?



“Sometimes we want to do things that other families take for granted. Other families have to accept that we are a little bit different.”



