



Mental Health and Wellbeing - views from parent carers of disabled children - April 2014

1. Introduction

Brighton and Hove City Council (B&HCC) and Clinical Commissioning Group (CCG) are developing a Mental Health and Wellbeing (MHWB) strategy which has been identified as one of the key priorities for the city. The strategy pivots around the Department of Health report 'No Health Without Mental Health' which highlighted the connections between an individual's physical health and his/her mental wellbeing. The idea is to invest more on the preventive aspects and resilience, in order to avoid people from getting ill in the first place, combined with high quality responsive services to support people when they are unwell.

For Brighton and Hove the need of an all-inclusive MHWB strategy is even more urgent. In fact people living in the city have higher levels of mental ill-health than the average for England, across a range of indicators. A third more people have a diagnosis of severe mental illness and nearly 10% more (aged 18 and over) have a diagnosis of depression, recorded by their GP. In addition, twice as many people are admitted to hospital following self-harm and approximately a third more die by suicide. People living in Brighton and Hove report lower self-reported wellbeing and experience high levels of anxiety, also fewer people report high score for life satisfaction and happiness. The economic recession and its effect on people's lives have to be taken into account too.

The local CCG funds Amaze to gather information and suggestions on health care from parent carers about services they or their disabled children access. Since 1997 Amaze is the city's 'one stop shop' for parent carers of children with disabilities or special needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Amaze believes that parent carers are the experts, they know what they and their children need, they need to be engaged at all level of services provision for the child, for themselves and for the whole family. Amaze is one of the engagement gateways which work closely with CCG.

Amaze hosts the Parent Carers Council (PaCC) a city-wide engagement group for parent carers who have children and young people with disabilities, complex health problems or other special needs. The PaCC enables parent carers to work collaboratively with statutory partners to help improve services and support. PaCC Parent Reps sit on various strategic boards within the city.

Amaze manages the city's Disability Register on behalf of the Council and is in regular contact with families of about 1,600 children with special needs with active/up to date records on the Compass.

As at April'13 children on the Compass were classified (by their parents) as having:

- Anxiety and depression	163
- Attachment disorder	61
- Emotional/behavioural	348
- OCD, ODD, PDA, Tourettes	84
- Other mental health problem	60

We know nationally that children's mental health is getting worse. In February 2014 SEN Magazine reported of a recent poll by YoungMinds found that a third of children and young people are not

aware what support there is when they feel depressed or anxious. The same pool revealed that half of children and young people have experienced bullying. The biggest issues to young people were sexual pressure, bullying, school stress, access to counselling and employment (<http://tinyurl.com/pp8kydw>).

In addition, we know caring for a disabled child puts incredible strain on the mental health of their parent carers. Amaze aims to carry out its own **Parent Carer Survey** every two years and we have included some results from November 2011 (114 parent responses) and in particular September 2013 (341 parent responses) as there was a focus on the impact of caring for child with a disability or special need on the mental health of his/her parent carer in this latter ones.

As such, this report aims to set out what parent carers think about what is important for the MHWB of their child(ren) with special needs or themselves as a parent carer.

2. Methodology

This particular consultation was carried out by an on-online survey (see appendix 1 for survey results) which was sent in February'14 to all families with a disabled child on the Compass Register and by a PaCC focus group (see appendix 2 for template used to gather data) which took place in March 2014 during a wider PaCConnect forum on Mental Health.

We received **73 completed on-line surveys** which responses were combined with ideas / comments / suggestions from **15 parent carers** who attended **the focus group**.

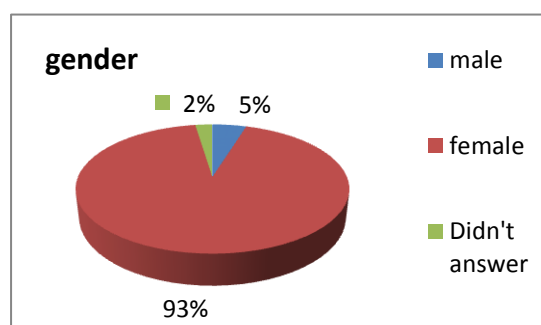
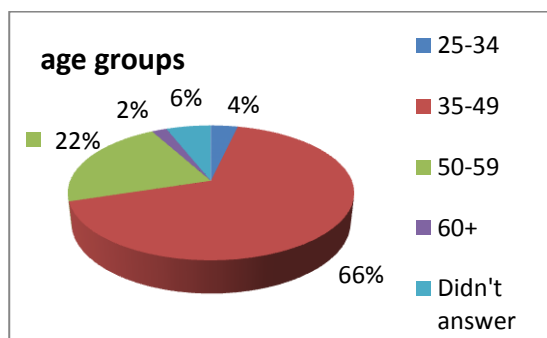
We attempted to incorporate questions about the National mental wellbeing strategy's Five Ways to Wellbeing:

- To connect with people around you
- To be physically active
- To take notice of the world around you
- To keep learning, to try something new
- To give, do something nice to someone, to volunteer

We incorporated questions and suggestions from CCG and B&HCC in to our consultation by adapting them to parent carers' needs and priorities.

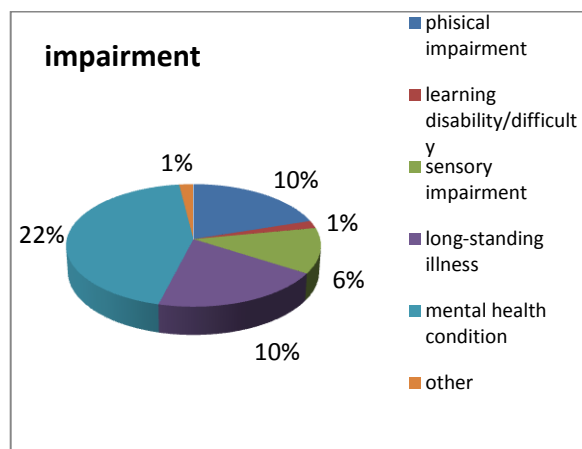
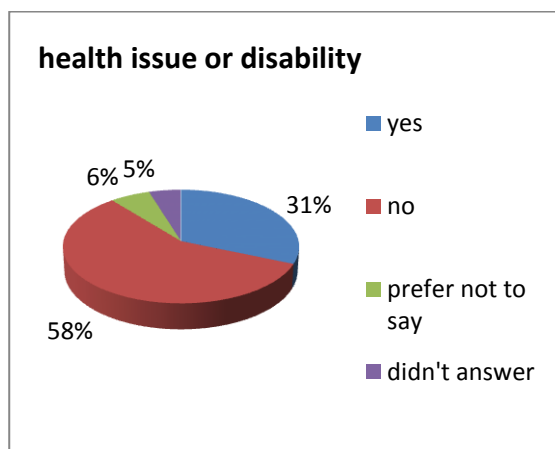
3. Demographic

A total of **88 parent carers engaged with our recent MHWB consultation**. Below here the demographic breakdown of on-line survey and focus group participants (note these do not include the demographics from the other Amaze surveys mentioned above).

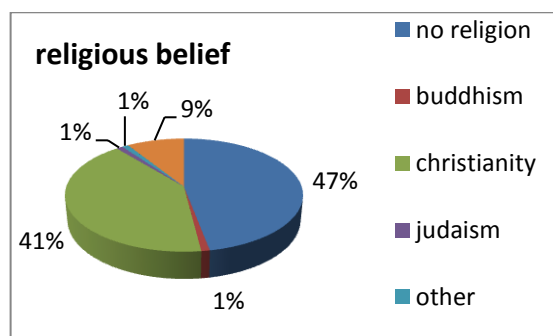
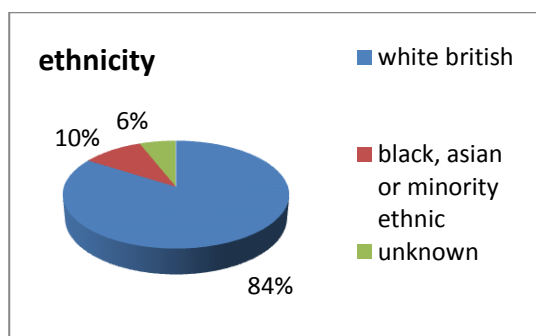


We attracted a slightly older age of respondent – with fewer 25-34s completing the survey than we have proportionately on the Compass register.

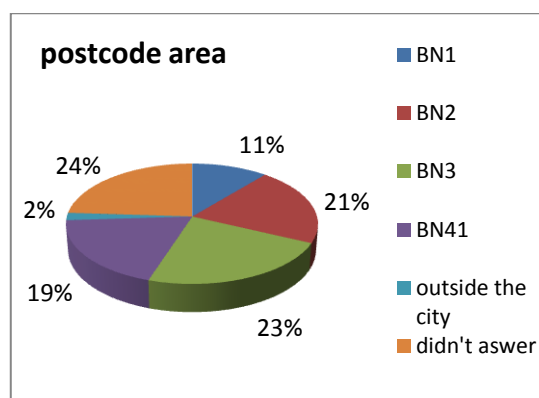
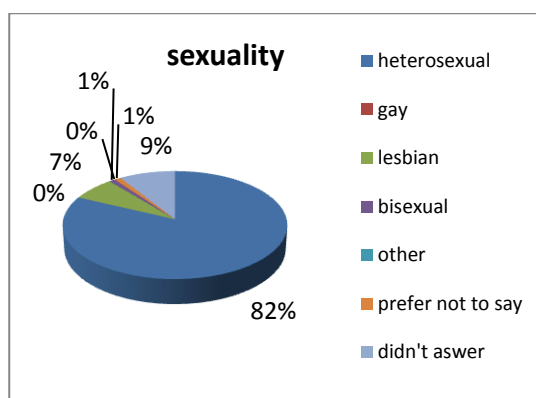
Amaze finds all its services are accessed far more heavily by mums than dads as they take on more of the caring role – hence the weight of female replies.



Significantly 31% of those engaged felt they had their own health issue/disability. Of those who felt they had their own health issue/disability 22% with a mental condition and 10% with a physical impairment.



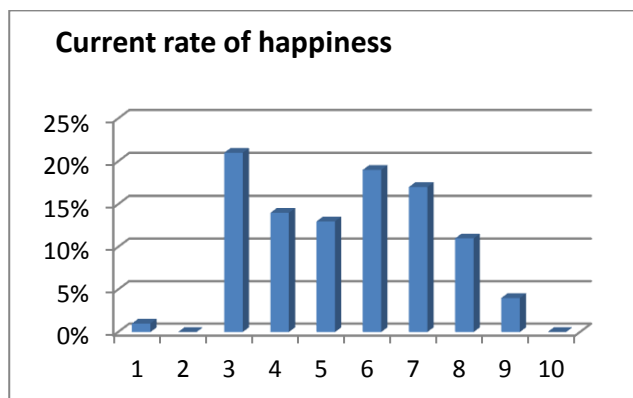
The majority of people who engaged with the consultation, 84% were white British. In terms of religious belief 47% had no religion and 41% were Christians.



While 9% of respondents didn't provide an answer in terms of sexuality and 7% classified themselves as lesbian, the majority 82% were heterosexuals. We were able to engage with parent carers from across the city, to notice the much larger population from Portslade, 19%, than would be expected as only 12% of Compass live in the area.

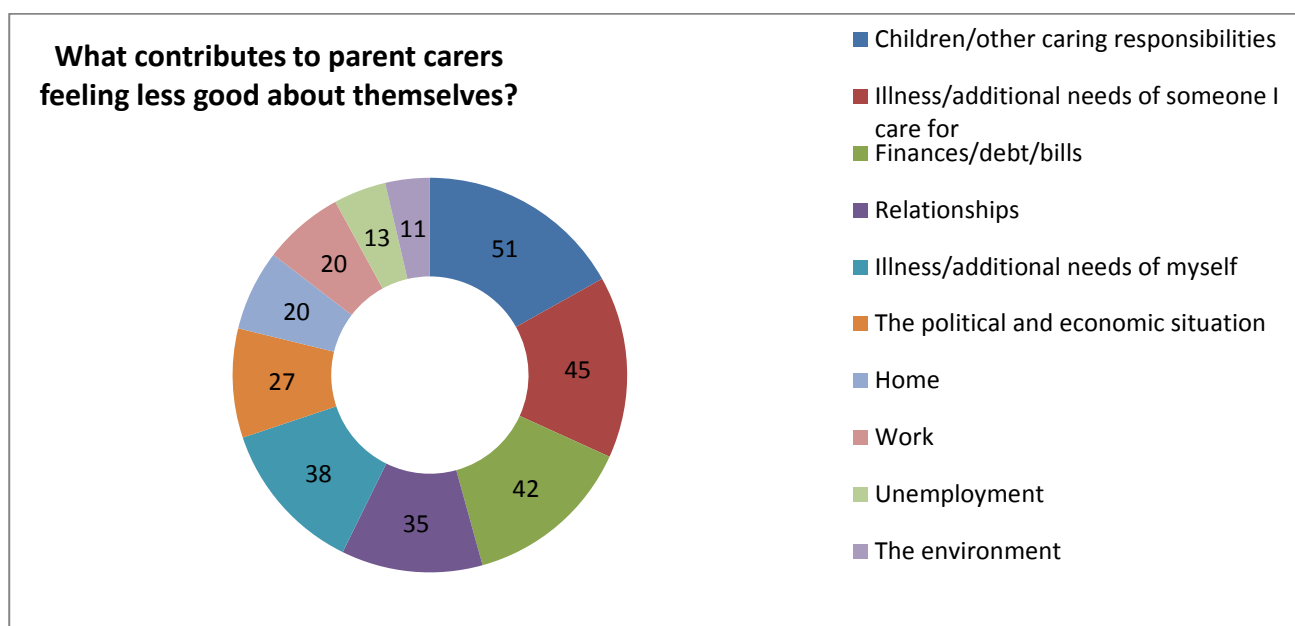
4. Results

a) How would parent carers rate their current state of happiness?



The survey revealed that the majority of parent carers considered themselves fairly happy, in fact 51% rated this 6 or above out of 10 (1 being the lowest and 10 the highest) while over a third of parent carers rated at 4 or less out of 10. No one rated as 10/10 and only 1 rated as 1/10.

b) What contributes to parent carers feeling less good about themselves?



Uncertainties about their children's future, mentioned by 51 participants, and **health and other caring responsibilities**, mentioned by 45 participants, were the main reason why parent carers felt unhappy about themselves. Also 38 participants are worried about their **health**.

The impact of this situation was also felt on the family as a whole with 35 people mentioning **polarisation of family roles and relationships breakdown**.

... CAMHS refusing to support because he does not have a mental health condition or learning disability; paediatricians are also unable to offer support; bearing in mind he is an adopted child with very complex start to his life but it seems that is not enough to have some kind of regular monitoring. I am angry and upset that he is being let down like this. We are completely alone

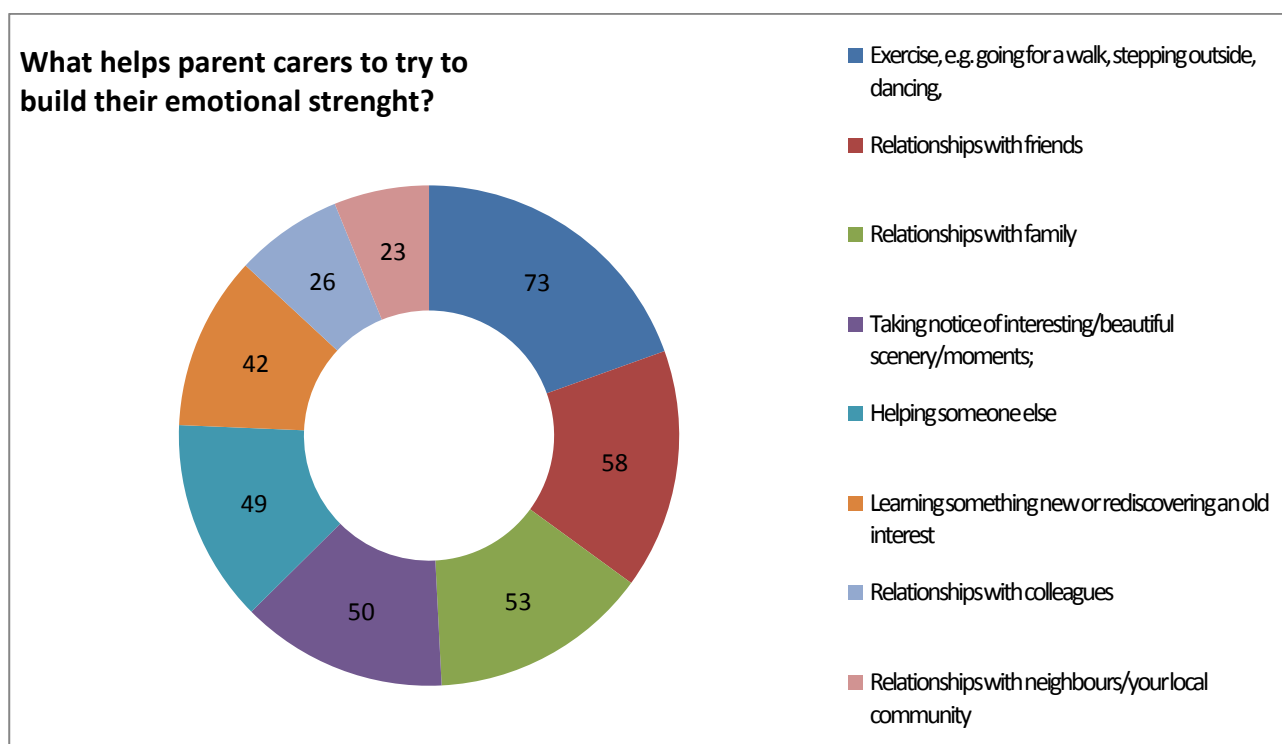
should anything happen to me he will disappear into an uncaring system. I live with these thoughts/worries daily ...

The **financial situation, debts and paying bills** are one of the main worries. Some parent carers highlighted situation where only one parent can work or in the case of single parents no income from employment coming in. Not be able to hold a job, loss of status and loss of income created additional stress which in turn results in **illness and additional needs for the parent carer**.

The economic downturn and its impact on services provision worried some respondents. For example the loss of befriending from Children's Society, closure of Portage and CAMHS funding cuts.

(See appendix 3 for a detailed breakdown of data and extra comments from parents)

c) What helps parent carers to try to build their emotional strength?



Connecting with friends and family is reported as one of the best ways for people to feel better about themselves.

'Talking to mums at school whose kids don't have issues can make thing feel 'normal' for the moment. Having positive relationships is very important'

A smaller percentage of respondents mentioned relationships with work colleagues, with neighbours and local community or their faith.

Respondents **would like more support in form of activities, advice and free or low cost counselling for parent carers** who are unwell and disabled themselves.

Provision of respite and appropriate proactive strategies put in place by the professionals involved in the care team are seen as huge benefit.

Schools could provide parent meetings for children with similar conditions and also more feedback on how children are at school besides 'reports', for example let the parent know about the child's emotional progress and wellbeing.

Few people also mentioned flexibility in the work place and more empathy from employers.

Be active and exercise – going for a walk, dancing, stepping outside, playing a game or swimming - activities that are very popular choice for people to build their emotional strength.

‘Running – it is free and you can do it anytime!’

Some respondents would like more activities to be provided and be advertised for parent carers on a website, for example more hydrotherapy treatments and alternative therapies.

There was also a call to keep facilities like public pools open.

Take notice of nature or something artistic and be aware of the world around you helped half of the respondents.

‘Going for a walk, being in the sunshine, we all feel better when the sun shines’ ‘ To enjoy when things are going well, it gives strength for not such good days’

People would like coffee meet up’s in the park for an hour or so, it would fit with busy life situations but also beach and promenade walks.

It was suggested also to promote and support community events to enable groups to form and support network develop.

Keep learning new skills, either through fixing like broken toys and furniture or volunteering help people to feel better.

‘Working as a volunteer at Amaze gave me confidence, friends and colleagues and improved life quality and wellbeing’

Respondents would like more days out at locations in the city for gardening, tai-chi, also cookery classes or sailing at Hove lagoon. If there were weekends away been organised then the whole family could attend.

People also suggested short half day courses and activities to fit in with hectic lifestyle and family life.

To give and help someone was reported as contributing to their wellbeing by over half of the people who participated in our consultation. Again volunteering is seen as a good way to improve personal mental health and wellbeing. However sometimes the person’s health acted as a barrier to get more involved:

‘Would like to volunteer for something but my health is not too good’

People would like more online forums, as for example Ehlers–Danlos syndrome (EDS) sufferers’ forum and also email newsletters. Some people suggested finding courses for charities to train volunteers in order to have more volunteering opportunities available for parent carers.

(See appendix 4 for a detailed breakdown of data and extra comments from parents)

d) Services for adults or children with mental health issues

i. Good and positive findings about services

Nearly **90% of respondents** or their family have accessed services for adults or children with mental health which is higher than we were expecting.

The majority of people receive mental health support through their **GPs and counselling**, both services received satisfaction scores of 6 out of 10 (1 to be the lowest and 10 to be the highest).

An equal number accessed also **CAMHS** but their average satisfaction was a lower at 4 out of 10, however, there was a real range of feeling towards CAMHS with some finding them very good and others very bad (see comments in survey for further details).

Surprisingly other organisations accessed by fewer people scored very low as for example Mind, Mind Out, Samaritans and Grassroots, which surprises us but we are not clear why this is and it might be worth following up.

Respondents appreciated practices that **de-stigmatise and reduce isolation and include whole family/siblings**. People liked those services that **provide continuity of staff** and staff that are dedicated and well-meaning; one respondent praised in particular the specialist nurse.

Quite few people benefitted enormously from **counselling**:

'I was not sure if I wanted counselling but it really helped pull me out of a prolonged period of feeling depressed. I had some really negative feelings about looking after my disabled son, and I needed to stop thinking so negatively. Abbie from Seaside View Development Centre was amazing, and it really helped us as a family.'

Another parent carer commented:

'Seaside view counselling, they dealt with my issues, rather than my parenting skills. Tansy Walker, developmental psychologist at Seaside View, she personalised work with my autistic son.'

'The Brighton Buddhist Centre and Patched have been great and both gave me back my self-worth and confidence to get on with my life.'

Provision of counselling at Rock Clinic was also praised.

Some respondents benefitted from **group therapy** which they received from MIND and **CBT**.

GPs provide good support when they know the family and its history.

'My Doctor has been very approachable, understanding and helpful and put me in contact with people to help over the years. The group therapy at MIND in New England Street and cognitive therapy at Brighton General made me more aware of some of my issues and ways to try to help deal them. They are not 'cures', but sometimes it is easier to deal with.'

People valued GPs who understand mental health issue and who don't patronise. A respondent felt that by having a GP who explained depression and stress as a chemical imbalance made the patient feel less stigmatised. On our consultation **many parent carers highlighted the need for GPs to be more aware of different conditions as for example autism**.

'Cleft psychologist from South Thames Cleft Service, they are based in London but cover Brighton and Hove. Someone supportive, with a good knowledge base as an expert, and willingness to build relationship and care and understand. Also they were part of a wider service our family uses, so not working in isolation.'

Good services are those which are **very patient centred** and those which **treat patients as a partner**, not someone to be told what to do.

People would like a **more joined-up support**, where mental health is properly connected to ASC assessment in order for people not to be stranded between them with no help from either.

Support groups are a source of information and help, and when they work in partnership with other groups their impact is enhanced, as for example being part of mACSot and connecting through Amaze and PaCC. Amaze is mentioned for its whole approach to support, from mental health to courses, information and advocacy. Organisations that support young people are much valued, e.g. MIND, RuOK, Extratime. TAPAS provides early psychosis intervention, the service does home visits or even meet in a cafe, it is much more person centred.

(See appendix 5 for a detailed breakdown of data and extra comments from parents)

ii. Amaze services which contribute to MHWB

Parent carers reflected that many Amaze services have supported their mental health and well-being, indeed Amaze's mission is to help build parent carer resilience so in turn they feel more able to support their disabled child.

In particular (% in brackets) parents found the Compass Card (84%), DLA Project (63%), Handbook/newsletters (54%) and Helpline (41%) all contributed to improvements in their MHWB.

Whilst comments were generally very positive about our services, parents made many suggestions on how Amaze services could be improved further. In particular, parents would like us to invest more in our telephone helpline so more calls can be answered when parents ring rather than them having to leave a message (as it's so busy!).

(See appendix 6 for a detailed breakdown of data and extra comments from parents)

iii. Negative findings about services

Participants to our consultation commented on the unsatisfactory support from **Social Services** when not 'joined up' and sometimes don't offer what it is needed. It seems that unless seen as 'not coping' the person won't get any help, even when requesting support. It was also pointed out that the **post adoption team and 16+ team** don't share information, even when that information is crucial.

In relation to GPs, some people feel that they don't recognise how much care and support a parent carer provides to a child or young person with special needs.

'My GP wasn't helpful when I've been at the end of tether, just told 'keep going', 'doing really well' and 'get on with it'.

Other people commented on some GPs limited knowledge of mental health pathways and how to make good referrals.

Specialised Mental Health Services are seen fragmented and some staff don't seem to have the management, training and support they need to offer a decent service. The **waiting time for an assessment** from Mental Health Services for adults **too long**:

'I've waited for at least a year now'.

Quite few parent carers feel that **CAMHS** doesn't really listen to them, doesn't value their experience and knowledge of young person. Sometimes the parent gets labelled as over protective, over anxious and attention seeking. A parent commented on the medical model of mental health not to have 'a wellbeing' approach when refers to a child as a 'patient'.

Parent carers would like **more 'joined-up' working** in the community, including **early intervention**, e.g. from school, and home visits to see how a child functions. Services should look at better ways of working as other services do provide good quality support.

People would like to see services that deal with the 'whole' not just point of crisis 'triggers' as well as **more information shared** with parent carer.

More emphasis on activities rather than treatment e.g. subsidised sport activity, nutritional therapy, mindfulness and other relaxation therapies like yoga.

A more personalised help for children on the autistic spectrum, **focusing on the child** rather than the parent. Sometimes parents feel under intense scrutiny which lead to greater insecurity and stress for parents. The focus should instead start with **supporting parents to improve their mental health and resilience**, and working with the child themselves, instead of this being a last resort after parenting strategies don't work. The two should happen in parallel.

(See appendix 7 for a detailed breakdown of data and extra comments from parents)

e) Additional results from Amaze parent carer surveys

From November'11 (114 respondents):

- 76% respondents experienced mental ill-health and 65% suffered physical ill-health or injury
- Only 29% get a good night's sleep
- 50% said their child with disability/special need had experienced bullying at some point
- 63% said they were very worried about their child (with special need's) future

From September 2013 (341 respondents):

- 71% parent carers feel they don't look after themselves well enough or are in fact neglecting themselves (rising to 85% if parent carer stated they have a disability/special need themselves).
- 58% respondents reported feeling stressed, anxious and depressed some of the time, 18% said they felt this way all of the time (this figure rises to 42% if the parent carer stated they have a disability/special need themselves).
- 17% of parent carers are currently on medication prescribed by their doctor
- 15% of parent carers say that they need but don't receive counselling
- 86% of parent carers spend none, or not enough, of their time doing things they value and enjoy while 53% of parent carers said they don't get enough social contact
- Only 19% said they attended a parent support group
- Many parents asked for us to increase the capacity of the Amaze helpline
- 99% said they would like more leisure activities or outings for their children and for the whole family

5. Summary of Recommendations

a) Improving current services:

- Increase medical professional's knowledge and understanding of children with disabilities (especially with ASC and learning disabilities). Especially CAMHS and GPs – **roll out parent carer journey training**.
- Amaze and PaCC to **follow up more detailed issues about CAMHS** as part of the Talk Health and Partnership Charter review
- Clarify what help CAMHS can offer to children with **ASC**. If families are turned away – need to be signposted to other means of support
- The **ASCSS** to provide more pro-active mindful, CBT, relaxation strategies and workshops for parent carers.
- CAMHS to be **more child-centred** and flexible when working with young people e.g. arrange to meet young person where they are not in clinical settings

- Involve **parents and young people in designing service user feedback** and evaluating services
- **GPs** to have more awareness/training of different conditions as for example autism especially in children.
- Services to be more patient-centred and treat patients as a partner, not someone to be told what to do. Services to **recognise parent carer expertise**. Consider how to further develop and roll out the parent carer Partnership Charter.
- Clarify how **'transition' into adult mental health services** works and communicate this better with families. Families report a 'drop off' in provision.
- Better **post-adoptive** support.
- Schools to provide space for parents of children with special needs to meet socially at the school
- Services to work **more jointly/holistically** together and communicate better

b) Investing in more mental health interventions

- **Protect investment in services for disabled children** e.g. respite/short breaks
- **Increase investment in provision of counselling and MCBT for parent carers**. Provide crèche facilities or pay for childcare costs so parents can attend counselling. Promote opportunities for counselling in Amaze newsletter
- **Longer periods of counselling available** (longer than 12 weeks)
- **Set up more support groups for young people with special needs** e.g. a 'Teens with Aspergers' group
- **Ensure families with disabled children are accessing all the right benefits** – Nationally about half of those eligible don't claim DLA. Could the CCG consider providing some financial support to Amaze's very successful DLA project which supports families to make successful DLA claims (return on investment of £40:£1) and which the University of Brighton evaluated as a very successful mental health intervention.
- **Funding to develop Carers' Card activities** - similar to Compass Card Activities but for all carers with a card – offering a financial discount and socialising opportunities to Carers Card holders, training, marketing and promotional support for activity coaches. Activities could include carers running, cycling, yoga, gardening, cookery, walking, singing, knitting etc and be followed by group coffee session at the end. Development of a Parent Carers' Allotment
- **Funding for resilience-building courses for parent carers** like the Insiders' Guide course (evaluated to provide social return on investment ratio of £28-34:£1) and the Looking After You course – both 6 weeks courses provided by Amaze but neither with identified funding post April.
- **Funding to increase capacity on the Amaze helpline**
- Amaze to research and promote various on-line/social media forums for different groups of parent carers

6. Appendices List:

Appendix 1: Amaze online survey results

Appendix 2: Template for analysis of responses from focus group

Appendix 3: What contributes to parent carers feeling less good about themselves?

Appendix 4: What helps parent carers to try to build their emotional strength?

Appendix 5: Good and positive findings about services

Appendix 6: Amaze services contributing to improving parent carers mental health/wellbeing

Appendix 7: More parent carer's suggestions about services

Appendix 8: Amaze parent carers survey September 2013

