



***'Sometimes I'd just like to 'check in' with someone at my surgery to take a whole view of the family that doesn't necessarily need signposting somewhere else...'***

## **Transforming primary care for parent carers July 2015**

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### **1. Introduction**

#### **1.1 Amaze, PaCC and CCG**

Since 1997 Amaze is Brighton and Hove 'one stop shop' for parent carers of children with disabilities and additional needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Amaze engages parent carers at all level of services provision for their child or young person, for themselves and for the whole family. The aim is to increase parent carers' resilience and confidence which in turn have a direct effect on the lives of their children and the children themselves. As from last financial year (2014/2015) In line with the new Children and Families Act, Amaze is supporting families, and children and young people with SEND themselves, up to the age of 25.

Amaze also hosts the Parent Carers Council (PaCC) a city-wide engagement group with 260 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs. PaCC also has 7 partners, some of them service providers, others community groups formed by parent carers. The PaCC gives a voice to parent carers using different engagement methods as for example focus groups to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve health, social care and education services for disabled children.

The local CCG, through its Engagement Gateway Contract, funds Amaze and the PaCC to gather information and present concerns and suggestions on health care services which they access as carers or for their disabled children (*See Annex 1: How Amaze and PaCC engage with parent carers*). As a result the local CCG is provided with clear intelligence about how children and young people with a variety of disabilities and their parent carers experience local NHS services. In addition the local CCG's understanding of the needs of disabled children and their parent carers is improved, and health services are correspondingly made more responsive and are targeted to actual need. And finally parent carers feel that their views are valued and that they can influence decision making regarding local NHS services, and help effect change

#### **1.2 Transforming primary care in Brighton & Hove**

Over the next few years the local CCG is working to transform the way primary care is organised and delivered so that people living in Brighton and Hove can live longer, healthier and happier lives. The aim of these changes is to tackle the fact that many people in the city are dying earlier from preventable causes and have worse mental health than other areas in the south of England.

We know that parent carers living in Brighton and Hove tend to neglect their own health as result of their caring role and tend to suffer more from isolation and complex mental health (*See Annex 2: Analysis of the Amaze Parent Carer Questionnaire July 2013 - page 5*). We also know that 35% of respondents to one of our previous consultation on health checks had a disability or long term health problem and that 61% of respondents haven't had their blood pressure checked recently (*See Annex 3: Parent Carers and Health Checks*). Those worrying results indicated that parent carers could possibly suffer from preventable health complications and their participation on this consultation is paramount.

The local CCG wants people to access the care needed, clinical and non-clinical, more quickly. GPs will do the initial assessment and delegate non-clinical work to pharmacists, nursing practitioners and other partners and organisations including local mental health services, social care, community nurses and voluntary sector services that are close to where people live.

The local CCG also wants people living in Brighton and Hove to be able to have a choice of where to access face to face consultations whether in their home, or in the pharmacy or at their GP, and at times more suitable to them. Patients will be part of putting together a care plan and be supported to use a patient held record called 'patient knows best'. That is clearly a move towards a more person-centred primary health care provided at time and places that are more suitable to everyone, including parent carers.

To make the above changes possible GPs will be encouraged to work more closely with other GPs through creation of 'clusters' where people can access and receive support (*See Annex 4: Brighton & Hove GP Practice Map*). GPs participating in this new primary care structure will be offered a new contract. The local CCG and Brighton & Hove City Council (B&HCC) are putting together a 'guide' to be included in this new contract, a sort of 'how to do it' which contains what and how the local people would like to be offered in terms of primary health care. PaCC and Amaze run this consultation so that parent carers and their children and young people's ideas, suggestions and recommendations can be included in the guide.

### 1.3 Parent carers and Primary Care

In January this year PaCC and Amaze consulted parent carers living in Brighton and Hove on how they experienced access to their GPs and explored again issues like: waiting time, understanding of disabilities and parent carers' needs by receptionists, provision of disabled parking and so on to find out if primary health care services had improved from previous consultations (*See Annex 5: Parent Carers and GP surgeries in Brighton & Hove*).

Some of the recommendations pointed to the need for better communication and relationships between parent carers and their GPs. Some parent carers felt that their GPs should improve their information systems whereby special and additional needs of their patients are better identified so that when a parent carer calls or arrives to the surgery this is flagged easily.

If primary care is going to be transformed then parent carers' voices can contribute to the way it is planned and provided. With this report we want to tap into parent carers' experience and knowledge of accessing GPs with the aim to provide specific recommendations around what sort of support should be provided, by whom, where and when.

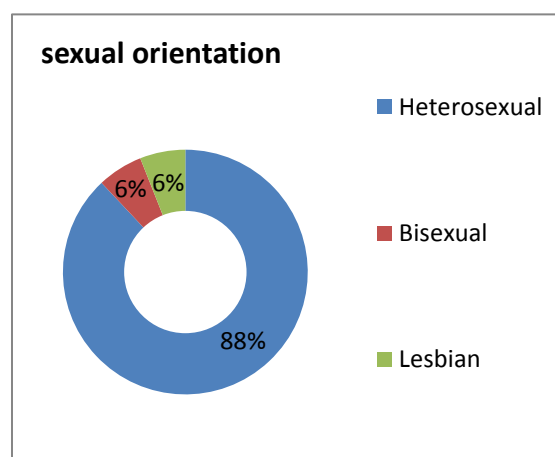
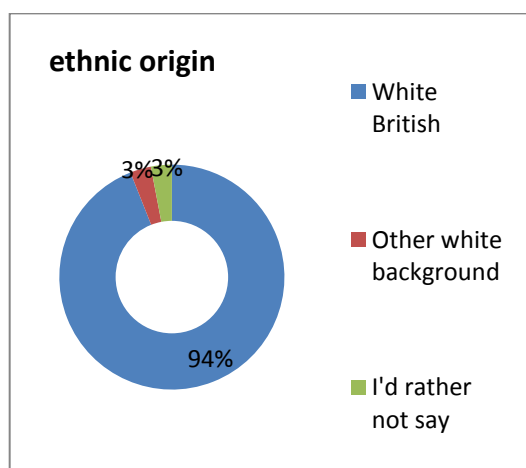
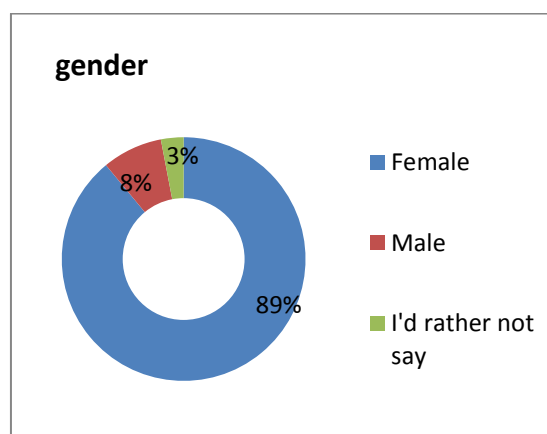
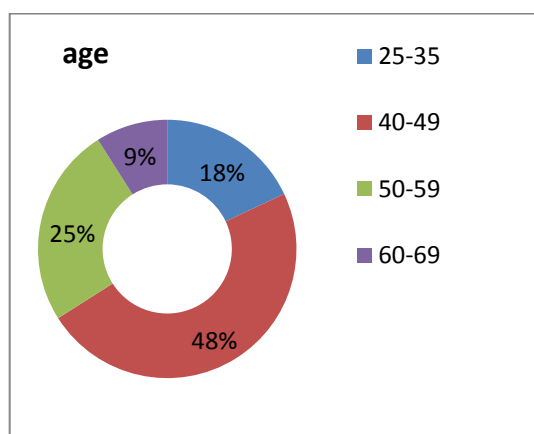
## 2. Methodology

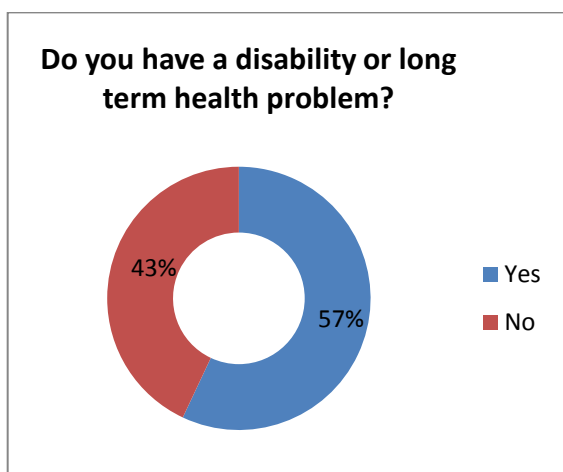
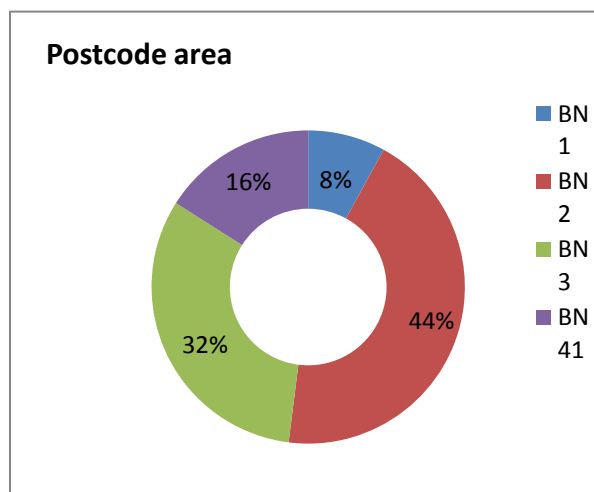
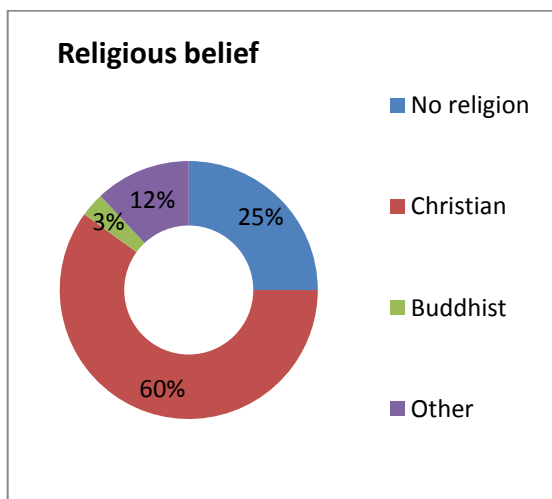
To better capture the variety of issues posed by this consultation we used two focus groups and an online questionnaire adapted from the engagement questions from Suzanne Novak's, Interim Head of Commissioning, Primary Care, Brighton and Hove CCG, handout (*See Annex 6: Engagement Presentation April 2015*).

The first focus group was held in Moulsecoomb with some parent carers from the Sunflower Support Group part of the Community Outreach Project run in partnership by Amaze and TDC. The group discussion helped us shape the online questionnaire which was then sent to parent carers who have a child(ren) or young person registered on the Compass database and also to PaCC members (*See Annex 7: How can Primary Care best support you?*). We also organised a second focus group together with Jane Burt, Carers Engagement Worker with the Carers Centre in Brighton.

A total of 37 parent carers took part in our consultation. The online questionnaire provided mainly quantitative data whilst the two focus groups generated lots of discussion and qualitative information. Data from questionnaires (*See Annex 8: Primary Care Survey Result – 14 July 2015*) and from the two focus groups (*See Annex 9: Transforming Primary care notes from focus groups*) were collated into this report.

## 3. Demographics





The high percentage of respondents who have a disability or long term health problem clearly indicates the impact of caring for a child(ren) on some parent carers' health. It also reflects previous findings and highlights the urgency of looking in to parent carers' needs.

## 4. Findings

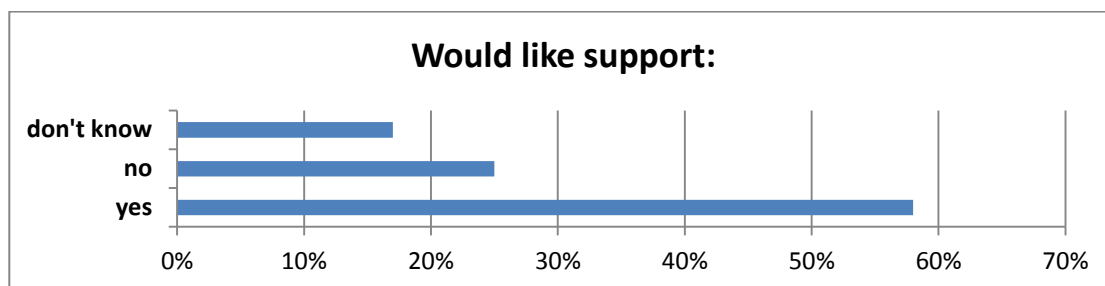
### 4.1 Healthy life and parent carers

When asked about what is important for them in order to have a healthy life, respondents to our online survey prioritised **being more physically active and to stay well through self-management, mentioned respectively by 73% and 70%. A healthy diet was chosen by 61%**, a further 38% suggested getting out more and meet people whilst an equal percentage of respondents, 11%, highlighted the importance of quitting smoking and drinking less alcohol.

A parent carer added to the online questionnaire '*By being able to prescribe swimming, by having more counselling and alternative therapies, by prescribing vitamins and a vitamin therapy programme, by prescribing fruit and veg vouchers*'.

A respondent commented, '*respite!*' which was echoed by another one " *... support for my two children with special needs to give me a break and to have adequate health care support*'

#### 4.2 Would you like to receive support to help you achieve a better life?



The **overwhelming majority of our respondents would like to receive support** in order to have a better quality of life.

#### And if so, what kind of support?

The majority of respondents, **58%**, **liked the idea of receiving support by attending a workshop or through being part of a group which also can help to combat isolation.**

Specifically a parent carer suggested '*... having a wider menu of specialist group work/specialist workshops for parents with children with mental health issues*'.

Nearly half of parent carers, **47%**, who participated in our online survey, **highlighted the importance of more time to talk to their GP.**

If GPs will do the initial assessment and delegate non-clinical work then the appointments needs to be more than the current few minutes. A parent carer commented '*Our particular GP is caring and nice, but even she is clearly under time pressure and at times the stress is visible and our discussions are cut short. As an autistic person, I am sensitive to peoples' moods and this adds to the stress of the appointment and makes me feel even more pressured because I have processing delays.*

*I already had to swap over to this GP, from another one in the practice who was singularly arrogant and dismissive and even wrote a clinically untrue comment in a referral letter, despite the correct evidence being on my medical notes and which led to a failure in health care resulting in me having to raise a complaint with the hospital'*

Another parent commented that '*To talk about my mental health I need more time, the issues are quite complex. If the GP makes referral then he needs longer appointments to be able to do that*'.

A further **42% would prefer to receive support through counselling.** One parent carer commented '*Make sure that carers understand what counselling support is available and check in with them periodically.*'

An equal number of parent carers, **26%**, **chose training and individual support by email and 21% mentioned individual face to face support.**

Communication by email, for IT literate people could be good '*It would be good to have email consultations, were I have questions but don't want to bother a professional about them*'

One parent carer specified: '*autism-specific support for two autistic children; a GP who was more autism aware; a GP who can make referrals without constraints or confusion as per requirements of patient; local support for my healthcare needs*'

Ongoing support from GPs is very welcome, as one parent carer who took part in a focus group told us *'Both my children have annual reviews, my son has a 'learning disability' and my daughter for asthma. I do think it would be more helpful if the doctors did this instead of the nurse, so medication can also be reviewed, changed and prescribe, which the nurse cannot do.*

*I don't think we have annual carer reviews and not sure how I feel about – they may get to hear more that they want if they ask me to come in and talk about my needs! I am not sure if we are marked as carers, which I think we should be, so our needs are seen in the context of needing to keep healthy to care for our children. I know my husband was rather cross with a sarcastic response from a GP, which made me wonder if they knew about our roles, which I think they should be aware of the stress we are under and need for swift recovery.'*

Parent carers who attended our focus group in Moulsecoomb talked about **parent carers experiencing poverty**, e.g. 6 weeks holiday during summer's break *'How can I provide for my child? Would it be possible to have free meals?'*

It was suggested that **economic support would be very beneficial** as for example a minor ailments scheme. A parent carer mentioned the difficulties with changing of benefits and how difficult and stressful is to keep up with the new system *'Could GPs provide support on that?'* The impact on carers is enormous and as a result their health including mental health deteriorate.

#### 4.3 Who is best placed to support you?

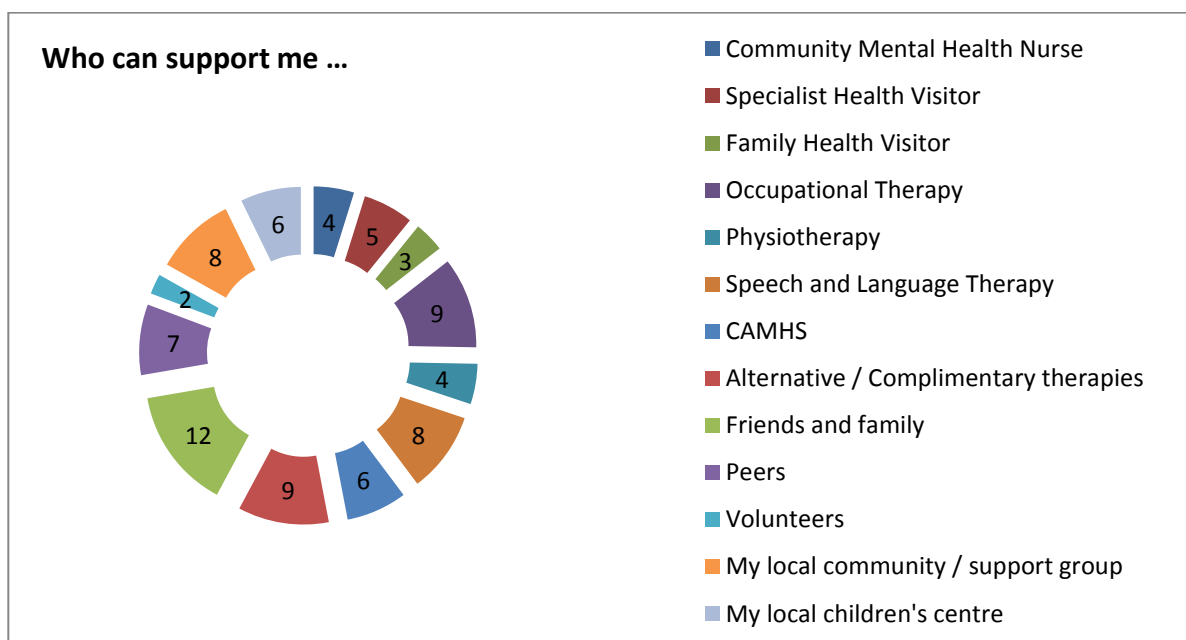
This question was formulated in a way that respondents were able to do a bit of 'blue-sky' thinking and use their knowledge and expertise in terms of organisations, groups, professionals or services which could support them.

The majority of respondents, **58% would like to receive support from their GPs or a hub of services**, that is lots of services together in one building. One focus group participant who lives in Whitehawk spoke highly about the Hub which also has parking spaces.

Half of parent carers who participated in our online survey, **50%, suggested that the community paediatrician, in this case based at Seaside View Child Development Centre at Brighton General Hospital**, could best provide that support. A further **35% suggested the practice nurse** as the best person to provide support, **27% chose the pharmacist**, 23% the hospital Paediatrician and 15% the Community Nurse.

A focus group participant suggested that the liaison nurse, who keeps families and patients informed of medical conditions and what the doctors are doing about the conditions, should be linked with the GP.

In addition to the above, parent carers would like to receive support from:



Other organisations or services mentioned were **Barnardos Link Plus (short break service)**, **children's charities** and **daughter's school**, which they already help the parent carer stay healthy and well and medical consultant.

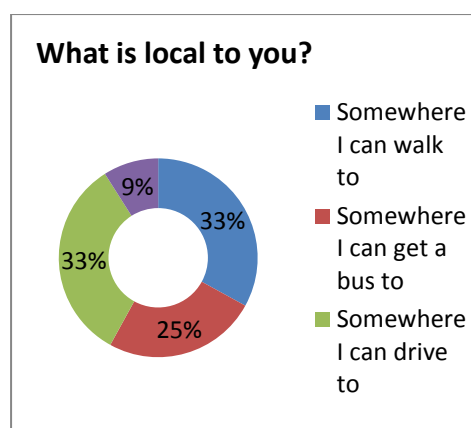
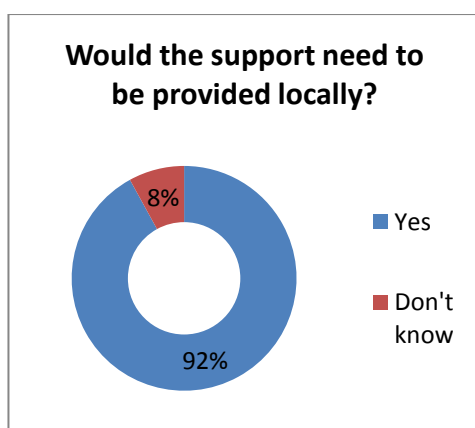
One parent carer from a focus group thought that it would be good to have **support at GPs from local organisations staff, perhaps once per month**.

One parent carer suggested: *'Specialist parent training during the day for conductive disorder'* while another commented *'I would have said CAMHS if they were competent but they aren't. Respite that doesn't involve going through social services; children befrienders to take them to activities; access to patient transport for out of town health appointments'*

A participant to the focus group proposed for the health visitor to be provided not just for children under 5, it should be until 16 and possibly a visit every six months.

#### 4.4 How 'local' is local for parent carers?

Support will be organised around clusters and GPs within each cluster will be required to work together. To help respondents with the online questionnaire we attached a link to the map of GP surgery clusters and we used the map during our focus groups. We asked our parent carers:



Under 'Other' one parent commented '*Somewhere I can drive to within 8 miles radius*' and another specified '*and parking for blue badge vehicles*'.

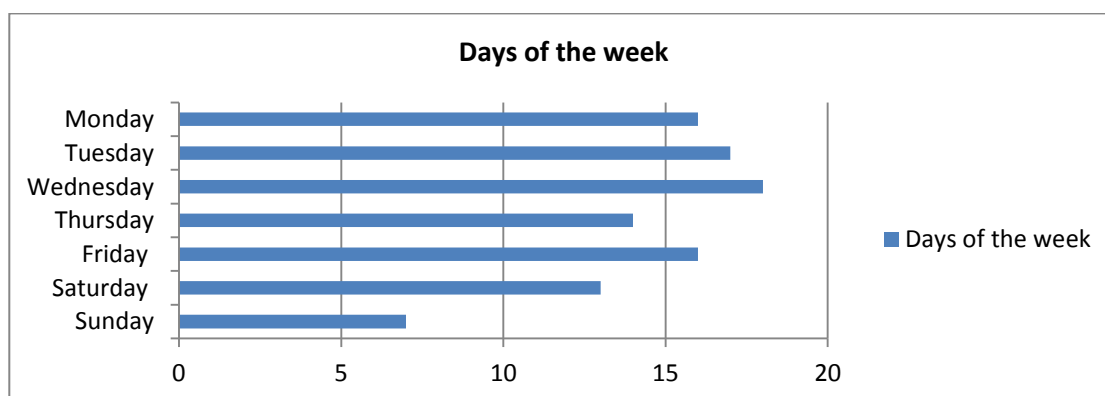
To the question what could help access support if provided within the parent carer's cluster, **44% of respondents said that they didn't mind as they would drive**. Among those people who don't or can't drive, **28% would like to be able to use affordable public transport** and a further **16% specified public transport that goes from their house to the place where support is provided**; a further 4% would like to use transport provided by GPs and from 'Other' one parent carer commented '*Our GP surgery is within short walking distance*'.

Some focus group participants would be happy to travel by bus if it was only one bus route and one commented '*Could GPs provide transport and pick up points?*' For people who are unemployed and/or live on low income use of public transport to access support could be difficult because of the cost involved.

It remains important for parent carers to be able to also receive support at home, one parent carer from a focus group said '*Morley St Dentist for disabled have come to the house, once every 6 months, to see my child with a dentist and a dental nurse and they are really nice. They handle my child very well. They check his teeth and give a prescription for special high fluoride toothpaste*'

#### 4.5 Day of the week and time of the day:

Parent carers would like to be able to **receive support throughout the week including Saturday and, to a small extent, Sunday**.



And while **morning is the preferred time, 88%** of respondents would like to receive support then, **52% chose afternoon and 48% evening**.

A respondent to our online questionnaire suggested '*Provide more accessible appointments for my disabled child, so that when I am concerned, I can get an appointment without having to be on the phone for ages at 8am, when I'm trying to also get my children ready for school. If we can look after our disabled children properly, it reduces our stress immensely.*'

And another commented '*I'm not keen on the ring back service used at my surgery. Calling at 8am for an appointment then waiting until 10am for a call back doesn't work for our working family with school age children.*'

A focus group participant suggested that during the weekend GPs could be open just for few hours, 2 or 3, and have evening appointments, perhaps two evenings per week.



A parent carer registered with Charter Medical Centre positively commented on the fact that she was able to book appointments and order repeat prescriptions on line. The reception staffs are also very helpful and pleasant and added *'All GPs were respectful of my concern and the reception staff ensured we saw the GP when we arrived and did not have to wait. I think they had just done some Amaze training, as this had not happened before – we previously had to wait and the GP apologised for this. I did not feel the doctors thought I was worrying unnecessarily, which I think can be a worry for parents'*.

#### 4.6 Other comments and suggestions:

Participants to our focus groups **liked the idea of a patient held record** something similar to the Health Passport. There was a general agreement that every GP practice should hold a 'carers register', carer's details to be recorded alongside the patient's details on the disability register.

If the referral system is going to work **communication between different professionals and services needs to improve**. One focus group participant told us *'Our issues seem to stem from the lack of communication between different health care professionals and making things that should be straightforward really stressful!*

*My child is under Dr Sarah James at CAMHS and at the last appointment she changed his medication. She gave a prescription for 30 days' worth of the new tablets, with instructions that the GP would continue to prescribe. I had to wait until I got the follow up clinic letter, which I copied, in case GP surgery hadn't received or filed their copy, and sent it with his repeat prescription notice, with a note pertaining to the change in medication.*

*Prescriptions should go straight through to the pharmacy, so I left the number of days plus several additional days until I went to collect his meds from the pharmacy. His other drugs were there but not the new one. Pharmacy confirmed they hadn't received that prescription, so I went back into the GP surgery. The receptionist said that for some reason the new prescription hadn't been printed off, she duly did this and got it signed by the duty GP for me. I took it back to the pharmacy who pointed out that the prescription was for 1 tablet only. I went back into the surgery and the receptionist assured me she would get it changed and sent through to the pharmacy. I waited 2 days as I knew the drug had to be ordered in, but when I went back to the pharmacy, they still hadn't received the prescription! Back into the surgery and was told it was handed to the GP but not sure what she had done with it! They printed off a new one and got it signed and thankfully it was fine, ordered and collected.*

*It was just a catalogue of errors, but just shows how stressful something simple like getting prescriptions can be in an already stressful life dealing with your disabled child'*

One parent described how her **GP has been supportive by being happy to be guided by psychiatrist in relation to medication for her child's anxiety**. But another commented that *'There is no communication between Hospital/Specialist and GP so medications didn't get to my daughter on time'*.

An **understanding GP makes all the difference**, as one focus group participant suggested *'My GP was not very knowledgeable at first but has shown patience and understanding, not hurrying appointment etc., and now my daughter will attend surgery without parent; comment 'small things like this make such a big difference as at 21 she can attend on her own...much better than me going in with her'*.

And finally a comment from a caring father *'GP always good with the mother but does not take into account the same stresses that affect the father, who often has work stress too. Too often the father has been dismissed as making a fuss when he has shouldered a massive amount plus a family unfriendly shift pattern.'*

## 5. Recommendations

- **Primary care to provide opportunities for physical activities and information and help with healthy diet – could the CCG provide some contribution funding to Amaze to develop ‘Carers Card Activities’ – similar to Compass Card Activities for their children with SEND? The City Council already provides funding for Carers Card offers (discounts etc)**
- **Primary care to provide support through workshops and/or support groups – Amaze has secured some funding to develop their highly evaluated Insiders’ Guide (6 week resilience building course for parent carers, currently focused for parents with children with disabilities) to develop a course for parents with children with mental health problems. Could the CCG provide some funding to commission this new course once developed so we can offer 3 courses per year to families?**
- **Primary care system to provide longer appointments with GP and time to talk about mental health and wellbeing**
- **Primary care to organise and provide more counselling for parent carers**
- **Primary care to provide support either by email or face-to-face**
- **Primary care to signpost to organisations helping with benefits – could the CCG make a contribution to Amaze’s highly evaluated DLA/PIP Project – to extend capacity to support families with young people with SEND up to the age of 25?**
- **Support to be provided by GPs or ideally hub of services**
- **GPs to be knowledgeable about what’s on offer in Brighton and Hove and signpost to relevant organisations and/or groups**
- **Parent carers organisation to provide support at GPs**
- **When support is provided within a cluster to identify those parent carers who cannot drive and offer alternative locations or travel arrangements**
- **GPs to open 7 days a week with limited hours during the weekend and some evenings**
- **To use the patient held record called ‘patient knows best’ and a register for parent carers to maximise communication and referrals**

## 6. Annexes

Annex 1: How Amaze and PaCC engage with parent carers

Annex 2: Analysis of the Amaze Parent Carer Questionnaire July 2013

Annex 3: Parent Carers and Health Checks

Annex 4: Brighton & Hove GP Practice Map

Annex 5: Parent Carers and GP surgeries in Brighton & Hove

Annex 6: Engagement Presentation April 2015

Annex 7: How can Primary Care best support you?

Annex 8: Primary Care Survey Result – 14 July 2015

Annex 9: Transforming Primary care notes from focus groups