



Parent Carers and GP surgeries in Brighton & Hove – January 2015

1. Introduction

Amaze and the Parent Carers' Council (PaCC) are one of Brighton & Hove voluntary and community sector groups contracted by the local Clinical Commissioning Group (CCG) to engage and involve traditionally excluded groups, in this case parent carers of disabled children and young people, around health care services. The local CCG 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.

Since 1997 Amaze is the city's 'one stop shop' for information, advice and support for families with children with disabilities or special needs (SEND), covering areas like 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 also manages the city's Disability Register on behalf of the Council and is in regular contact with families of about 1,600 children with SEND with active/up to date records on the Compass.

Amaze also hosts PaCC, a forum with over 240 parent carers signed up members who want to work collaboratively with statutory partners to help improve services and support. For example PaCC Parent Reps sit on various strategic boards within the city, it also organises focus groups and it gathers views/opinions and presents these to service managers to influence service delivery.

Why our focus on parent cares access to GP surgeries?

Families with children with SEND are often high incident and high cost users of health services. Amaze and PaCC are aware of this and apart from working with people who provide those services also run periodical consultations to find out what works and what needs to be improved in relation to health care.

In 2012 the PaCC's Talk Report http://paccbrighton.org.uk/wp-content/uploads/2013/06/Amaze_PCC_Health-Report_2012_V2.pdf (or see Annex 1, page 13 to 18) highlighted some areas which needed improvement: for instance parent carers felt that communication between GPs, consultants, hospital departments and families wasn't satisfactory. The report also pointed out that some professionals, including GPs, didn't seem to understand/appreciate the context of being a parent carer and concerns around GPs taking over responsibility for young people with SEND when they turn 18.

In our follow up to the report a year later (2013) <http://paccbrighton.org.uk/wp-content/uploads/2013/03/13-03-20-talk-health-feedback.pdf> (or see Annex 2, page 13 to 15) we reported on progress made and where actions had been agreed by service

managers like for example 'parent carer journey' training to be commissioned by the CCG for GPs.

In 2013 we also looked into Urgent Care Services <http://paccbrighton.org.uk/wp-content/uploads/2013/03/13-09-Amaze-and-PaCC-Engagement-Gateway-Report-into-Urgent-Care-Services.pdf> (or see Annex 3, page 5 to 7) that reiterated some of the issues highlighted by previous reports in relation to GPs' services, as for example the need of better system for booking non-urgent appointments, and parent carers difficulties to rely on the calling at 8.30am system which is no good for parents on school run.

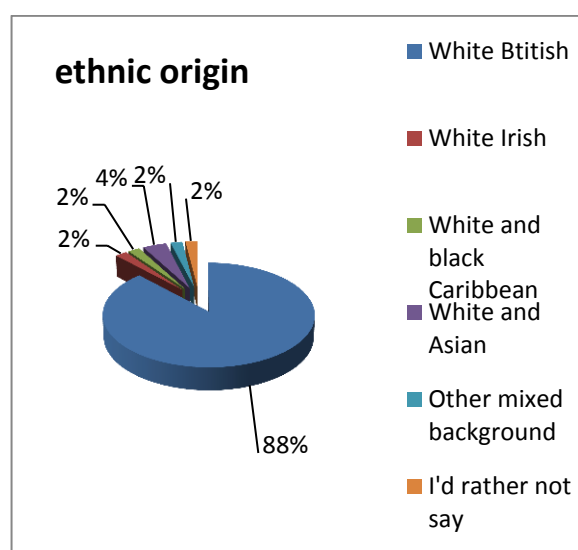
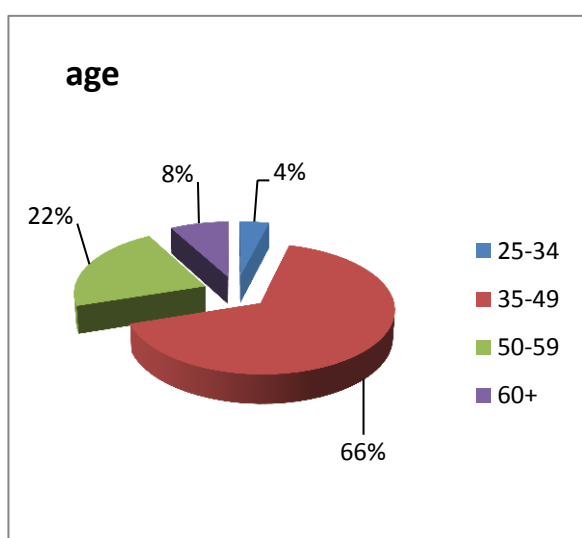
With this 2015 consultation we wanted to revisit some of those issues again, such as waiting time, understanding of receptionists, disabled parking, consistency of seeing the same GP at the practice, capacity to have a nominated GP, accessibility of premises and find out if provision of primary health care has improved and with that parent carers' satisfaction. Is there a case for measuring performance of GPs with respect to patients who are SEND and their families? And can the issues above function as measures?

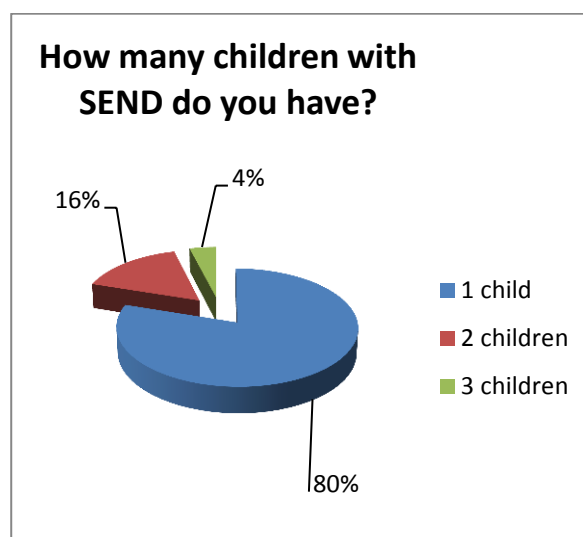
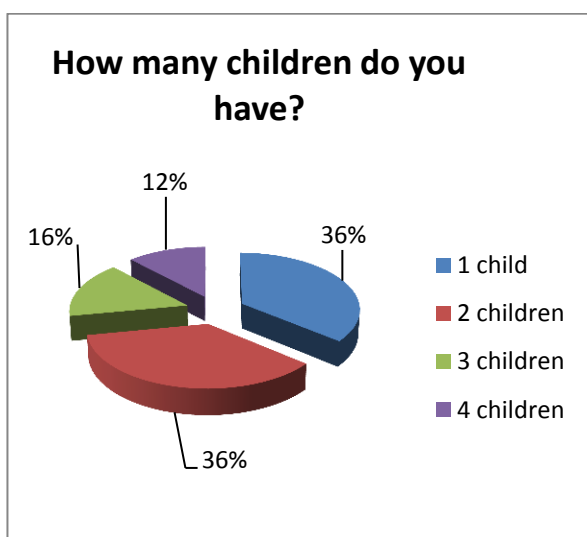
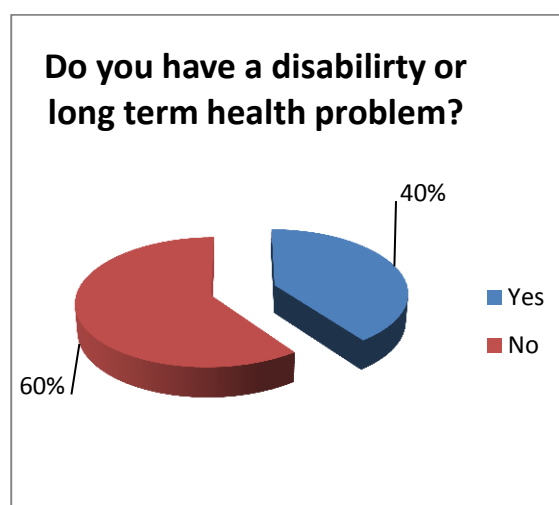
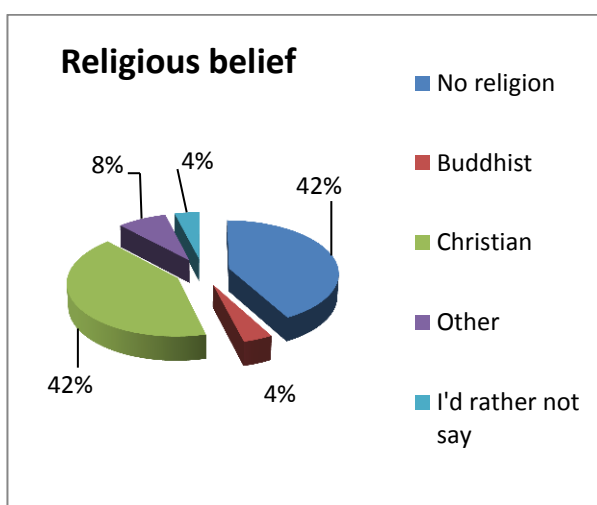
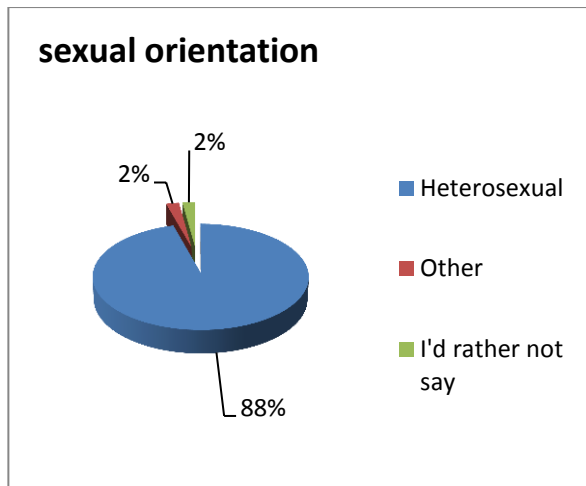
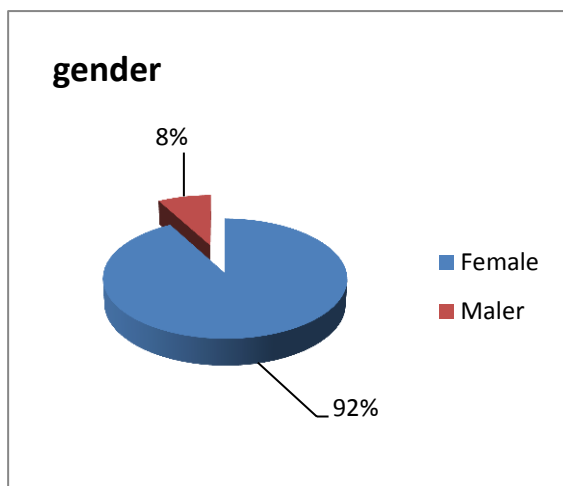
Finally we wanted to see if parent carers go to A&E when they not happy with their GPs as stated by a research carried out by Contact a Family (<http://www.cafamily.org.uk/>) which showed that 75 per cent of families with disabled children did not visit their GP about their condition.

2. Methodology

We designed an online questionnaire which was sent to parent carers who have a child(ren) registered on the Compass database and also to PaCC members. We also used social media to publicise our consultation. Most of the questions provided multiple choices: respondents could choose all that applied to them, we also left space for different and/or additional benefits and comments in the 'comment on any other services at your GP surgery' box (see Annex 4). Additional information from our line survey, e.g. impact of caring duties on carers' mental health and wellbeing and carer's finances, is not included on this report but attached as an annex (see Annex 5). We received 51 completed questionnaires.

3. Demographic

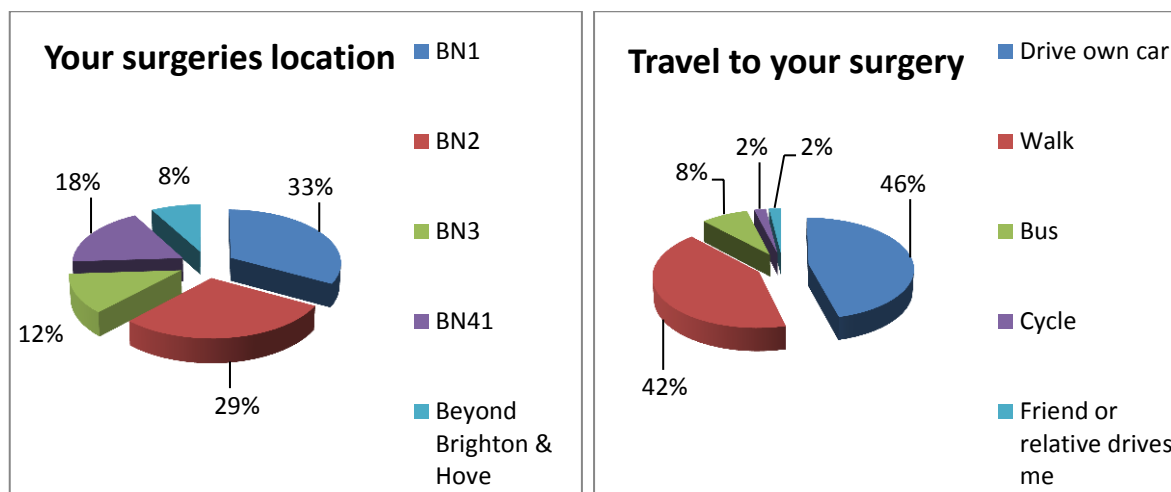




4. Information about GP surgery

All parent carers who responded to our online questionnaires are registered with a GP. Below details the location of surgeries where respondents are registered with and mode of travel to surgery.

We have anonymised comments made about some specific surgeries on this report. However we feel that certain situations should be followed up and we are happy to provide name of surgeries and list of issue on request, more information and the end of this report.



For each of the first four questions below respondents were asked to give a score between 0 (very poor) and 10 (excellent).

I. Booking the appointment at your surgery (average score 6 out of 10)

Respondents seem divided equally between those who find easy to get an appointment and those who find very difficult to get one. Some parents reported that they will eventually get **an appointment but sometimes up to 7 days/a week before they can actually see their GP.**

The time when people can start calling the surgery, **8am, it is a very difficult time of the day because many people get to the phone; it also coincides with preparing children to go to school.** Some respondents commented that it takes ages to get through and find a time that fits with school, work or weekend.

Parent carers would like to be offered the **choice to book appointments by phone or on-line**, a good and efficient service through which parents are always able to book an appointment.

Phone appointments, when GP calls back and does first assessment by the phone are seen unsatisfactory:

'Since the new system it's very hard to even see a GP, now it's all telephone consultations, which worry me when I have a screaming disabled boy screaming in pain waiting to see a GP. It now takes longer to even get through on the telephones'

Some parents make sure that their **child's record shows the learning need, e.g. SLD so to get an appointment quicker.** A parent commented: *'My surgery is aware of my son's autism and if my own GP has no appointment he will always call back'*

Some others find it stressful to have to explain complex problems/medical history again and again in order to get past the receptionist.

Some GP receptions are very busy, and parents find it difficult to wait on a queue sometimes for more than 30 minutes.

'Doctors are always changing, I always see different doctors each time and none of them I feel understand full history of our situation only by looking at notes so don't feel they fully understand but that's not their fault I guess'

One respondent commented on the difficulty of not being able to book appointments with GPs for anyone in his family, and as a result ended up **going to either A&E or the out of hours service**, also that he found the GPs complaints system didn't function at all.

II. Arriving at the your surgery (average score 8 out of 10)

Parking is a problem as nearly half of respondents drive to the surgery possibly as a result of their children's additional needs.

Some parents find difficult to park next to the surgery as parking spaces are often shared with other services, limited or inexistent.

'I have real difficulty getting a wheelchair in the building. Parking can be an issue and I have to push the chair up a hill. No disabled parking at all!'

Some choose to walk – possibly because they are aware of the parking problems or because the surgery is close to their home.

Quite few respondents are satisfied with parking spaces provided by the surgeries.

Most surgeries have a good access but others have only stairs to consulting rooms on the first floor. A respondent highlighted the fact that he/she has to request an appointment downstairs as there is not a lift available.

III. Checking in at your GP surgery Reception Desk (average score 8 out of 10)

Quite few parent carers use the **electronic checking system when available** which, while seen impersonal, is no doubt **useful as receptions are usually very busy**. Many parent carers like this system.

'You can do it either by computer on wall or with receptionist. Usually quick and easy, with nice staff to help'

Some respondents are very happy with receptionists who are seen as considerate, cheerful and polite, lovely and helpful. This could possibly due to positive impact of our 'Parent Carer Journey' training to GPs and non-clinical staff delivered by parent reps from Amaze and PaCC during spring 2014 following recommendations from the Talk Health report.

One parent commented on the GP waiting area: *'Waiting area is totally unsuitable for child with autism – open plan, large area – a private area or room would be great as my son gets distressed, or can be disruptive which upsets others'*

IV. Your appointment with GP (average score 6 out of 10)

Waiting time at the surgery is a big concern for parent carers, some respondents wait for a few minutes while others reported to have waited for more than half hour. Waiting with children is never easy but it can be more difficult with a child with additional needs. .

However one parent commented:

'The GP is not usually on time. I think he gives everyone, including us, the time that we need so he often runs late but that's fine because we appreciate he gives us as long as we need. We come prepared to wait (bring toys and not be in a hurry)'

Many parent carers are **happy with their GPs** and they appreciated it when their **GP knows about their children's additional needs. Where this is the case they sometimes** choose to keep the same surgery even when moving to a different part of the city. **Good communication and the GP's ability to put the child at ease** are also highlighted as good qualities.

'My own GP knows me well but I often don't see her. The GPs have supported my children well with their different complex physical and mental needs'

'GPs are polite, courteous and helpful, with no sense that we are being rushed'

'I feel the GP understands of our situation and my child's condition. All are willing to check my child over thoroughly, when he is ill, as he is unable to indicate where the problem is'

One parent carer points out that even if he/she has to see different **doctors they always refer to the notes.**

However, one respondent noted that information about her daughter's diagnosis is lost among the notes and suggested that better communication could save time and eventually a smoother transition to daughter eventually attending GP appointments alone.

Others would like to change GP but they can't because of the catchment area system:

'Since the retirement/leaving of three decent GP's only one unsympathetic/incompetent main one and some locums are left. I have not felt even taken seriously to be honest let alone properly dealt with. I will be changing soon. Tried to change to my partner and son's surgery as I am carer for both but was told I was outside catchment (we live separately) which makes life even more difficult'

Parent carers lament some **GPs unawareness about their children's needs or how to communicate to a child with learning disabilities** and prefer to see consultants at hospitals or get referrals through school instead of GPs. Some other parent carers feel that their GPs have no idea what parents deal with and so consequently no idea on how looking after a disabled child affects their health or mental health.

Repeated visits to GPs can be resolved with better communication, as a parent carer suggests:

'Repeat prescriptions are difficult and my observation is that the practice incurs a lot of cost simply because they are relying on practices which may not be fit for purpose but if they were to follow up on issues as they develop in practice operation then this could be overcome. For example the practice rarely calls a patient when a repeat prescription request is not approved and thus it is left to the patient to find out what is going on. More behaviour is needed where the practice puts itself in the mind of the patient rather than getting through the inevitable pile of tasks each day'

V. Other comments on other services at your GP surgery

Some respondents reported that they are **very happy with practice nurses when they take into consideration the needs and anxiety of children and parent carers**. Some respondents rated the extra services provided at their GPs excellent, with a **good support team and on site pharmacy**.

One parent commented: *'It is really useful to get other services at the GP surgery rather than having to go into town'* and another one: *'Using the practice nurses to do simple tasks that a doctor doesn't need to do is a really good idea as long as the doctor sees, reads and decides on resulting action'*.

Some respondents find it difficult to contact the practice nurse to arrange the tests requested by the hospital or just to arrange an appointment; **some nurses are very booked up**.

Longer opening hours would help many parent carers; some while happy with their GP use the 'drop in' surgery at Brighton station as it is open at weekends but has often long wait.

One parent carer, whilst understanding the pressure that services are experiencing, expressed concern about the **GP surgery which doesn't even acknowledge complaints about lack of duty of care to their respective patients and poor level of service in general**.

5. Summary of Recommendations

- *From our report it seems that there needs to be greater consistency in the quality of the GP service provided: some GP surgeries provide good or excellent service while others need to improve (we are happy to provide name of surgeries and list of issue on request).*
- **Need of a system for measuring performance of GPs with respect to patients who are SEND and their families**
- **Parent carers who do not have an established/knowledgeable relationship with their child's GP, or receive a poor service, choose to go to A&E instead of their GP**
- **GPs should offer a choice of phone and online appointment booking system**
- **GPs should have a patient information system where additional needs/SEND are easy to identify so that when a parent carer calls or arrives this is flagged easily**
- **GPs receptions which are very busy to provide an electronic checking-in system and appropriate waiting areas for children**
- **On-going 'parent carer journey' training to be made available as part of workforce development options and surgeries where families report difficulties to be encouraged to attend**

6. Annexes

- 1) 'Talk Health' report
- 2) 'Talk health' report follow up
- 3) 'Urgent Care Services' report
- 4) GP Surgery survey - questionnaire template
- 5) Additional information from our line survey
- 6) Amaze Parent Carer Survey Report 2013 (referred to on Annex 5 – Additional information from our online survey)

If you would like to get in touch with us about any of the issues touched by this report, including comments made about specific GP surgeries email Paolo@amazebrighton.org.uk