



“Any method that works”

Parent Carers, complaints, concerns and feedback – January 2017

Report Summary:

With this consultation Amaze and PaCC are exploring parent carers' views and experiences on putting in a complaint, raising a concern and giving feedback about healthcare services.

Parent carers can seem quite resourceful when it comes to putting in a complaint, raising a concern or giving feedback about healthcare services. They may know someone and/or organisations that can help and/or advise them with the process. Due to their children/young people having disabilities including complex needs, parent carers are normally best placed to provide feedback and raise concerns about a service on behalf of their child. At the same time, due to their caring duties, the systems are seen as too difficult to navigate and too slow/time consuming. Parent carers would like a complaints/feedback system that is clear and responsive to their suggestions and/or complaints.

Voluntary sector organisations and in particular Amaze Helpline staff, are hugely important on helping parent carers to find more about the different systems, how to navigate them and what the different journeys will entail. Ongoing financial support for voluntary sector organisations is therefore paramount.

Parent carers don't want to be seen as a burden or as a 'troublemaker' and they are scared of repercussions on their children's access to a service if they make a complaint or raise a concern. An effective, independent system that doesn't penalise future relationships between parent carers and professionals could benefit and enhance provision and delivery of a service.

1. Introduction

1.1 What Amaze does

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 also manages the Compass Database and the Compass Card, a free leisure incentive card for 0 to 25 year olds with significant disabilities or special needs who live or go to school in Brighton and Hove.

Since 1997 Amaze has been engaging parent carers at all level of services provision for their child or young person, for themselves and for the whole family. Their aim is to increase parent carers' resilience and confidence which in turn has a direct effect on the lives of their children. Since September 2014, in line with the new Children and Families Act, Amaze has been supporting families, and young people with SEND themselves, up to the age of 25.

1.2 What PaCC does

The Parent Carers Council (PaCC), hosted by Amaze, is a city-wide engagement group with over 300 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs.

PaCC also has 9 partners, some of them service providers, others community groups formed by parent carers. PaCC gives a voice to parent carers using different engagement methods as for example focus groups and forums 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 services for families.

1.3 Parent Carers' engagement through B&H CCG

Brighton & Hove Clinical Commissioning Group (B&H CCG), through its Engagement Gateway Contract, funds Amaze and 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. PaCC and Amaze provide regular feedback and updates on the engagement work to parent carers through their termly newsletter and through social media.

2. **Parent carers, complaints and feedback**

Parent carers, their children and young people, due to the complexity of their needs, access many services, including health care services. As a result parent carers and their families have extensive knowledge about how the services provided for them function. As part of improving commissioning and provision of those services, parent carers can also complain about a specific service they or their child receives. They can express dissatisfaction with the service available and/or with the conduct of a professional. Parent carers can also provide feedback in relation to some aspects of a service that identifies issues requiring a response.

The importance of complaints and feedbacks is highlighted by the Special Educational Needs and Disability Code of Practice

(https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SE

[ND Code of Practice January 2015.pdf](#)), a document that underpins the major SEN reforms programme which was started a couple of years ago. The Complaints Procedures chapter (p.266 - 271) of the Code of Practice sets '*the role of the Parliamentary and Health Service Ombudsman (PHSO) to investigate complaints that individuals have been treated unfairly or have received a poor service from government departments and other public organisations in the UK, and the NHS in England*'.

The document also describes the role of NHS England and local CCGs on how to deal with complaints, including those around the health services which a child or young person receives under an Education, Health and Care Plan (EHCP). If the parent carer is dissatisfied with the way in which the NHS has dealt with their complaint, they can contact the PHSO, though usually the NHS will need to have had a chance to resolve it locally.

Part of the work Amaze and PaCC do is to listen to parent carers' experiences of accessing services and also inform parent carers and their families about their entitlements and what they should expect from those services.

This report is an opportunity to find out more about how the complaint and feedback system could be improved. We aimed to explore both knowledge and navigation of the complaint and feedback systems and barriers that parent carers encounter when thinking of or actually making a complaint. Recommendations from this report will be passed on to B&H CCG.

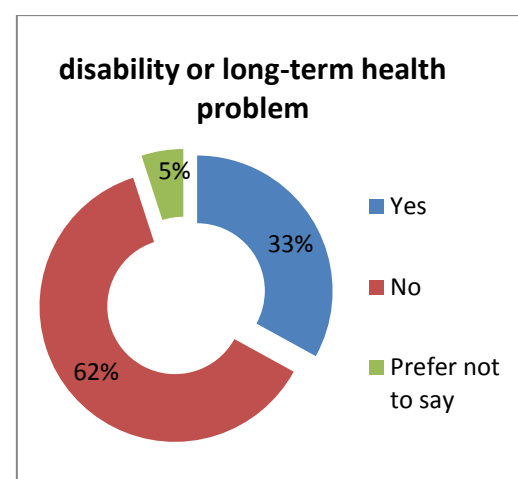
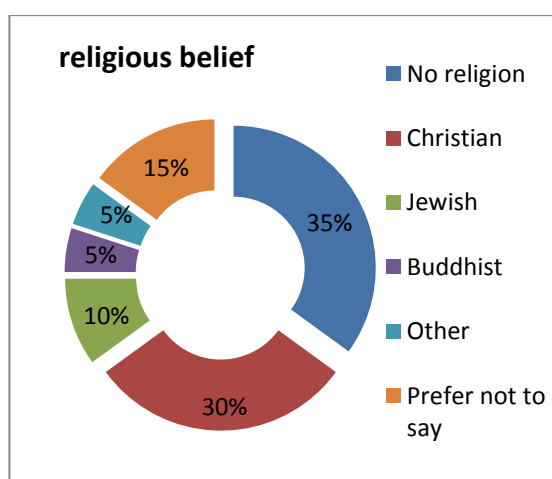
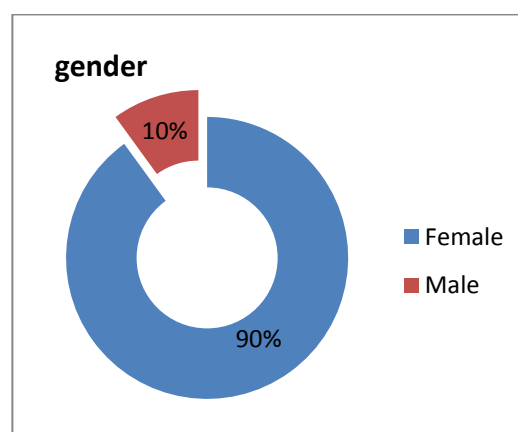
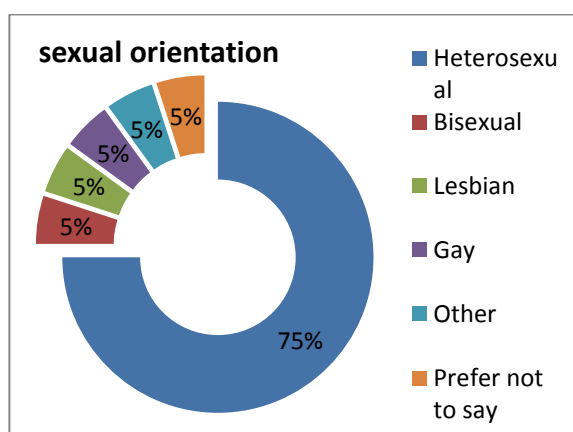
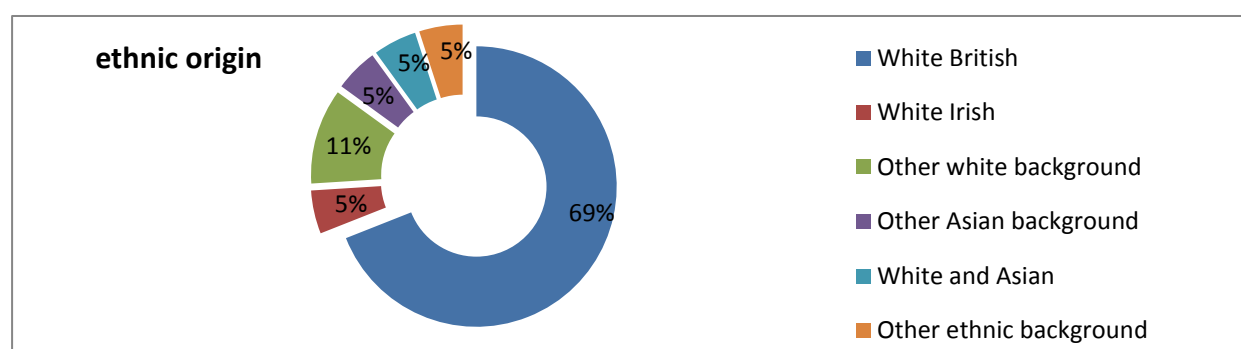
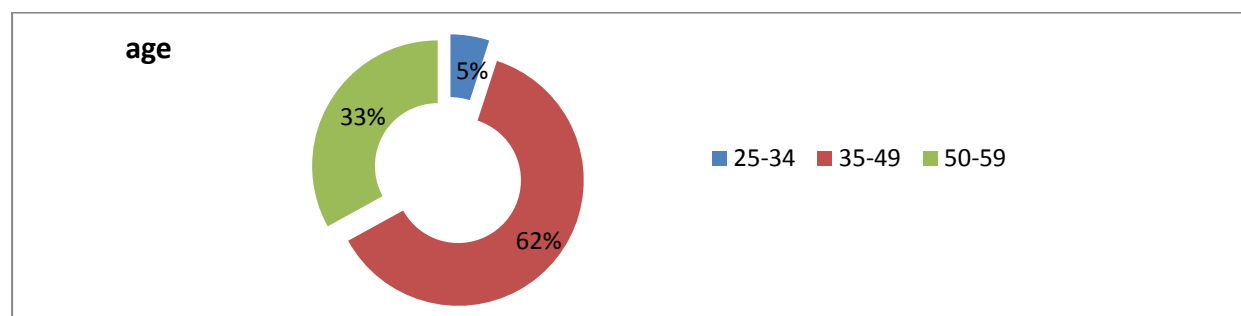
3. Methodology

Information and data for this consultation was gathered by an online questionnaire and by a face-to-face interview with one of Amaze's Helpline Advisors.

The online questionnaire was designed with help from the Carers Centre Brighton & Hove Engagement Worker and the Amaze Database Manager. The online questionnaire had a few questions with 'please select' and 'tick boxes' options and boxes to provide extra information and feedback (*See Annex 2: PaCC-Amaze Survey on Complaints, Concerns and Feedback about Health Services*). The questionnaire was sent to parent carers who are on the Compass Register. We received 24 completed questionnaires which were collated into two summaries (*Annex 3: PaCC_Amaze Survey on Complaints, Concerns and Feedback about Health Services* and *Annex 4: PaCC_Amaze Survey on Complaints, Concerns and Feedback about Health Services - 2*) and used to inform this report. Parent carers' contributions to this consultation are reported in verbatim so to better reflect their experiences and comments.

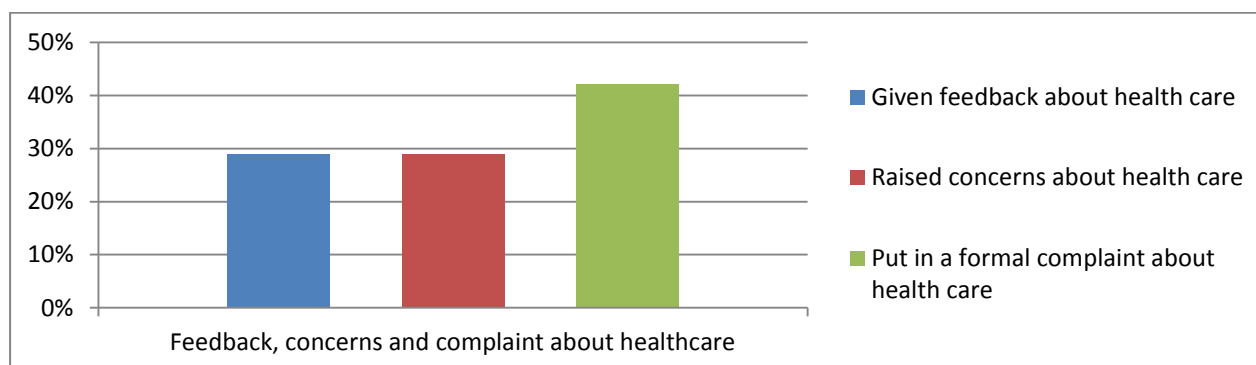
The interview with Amaze Helpline Adviser provided intelligence on how parent carers who call the helpline with a complaint are supported and advised. Amaze Helpline is open during term time Monday to Friday from 9.30am to 2pm and Wednesday to 4pm. It receives approx. 4,000 calls per year in relation to services, support and information round SEND services.

4. Demographics from online questionnaire



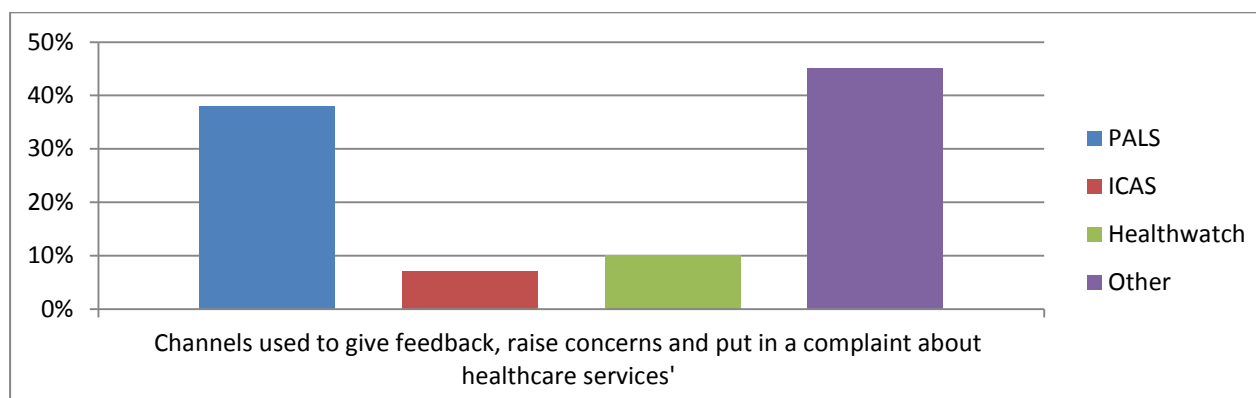
5. Findings from on-line questionnaire

5.1 Feedback, concerns and complaint about healthcare



The majority of responses to our online survey, 42%, reported to have put in a complaint about healthcare services and/or professionals. An equal percentage of 29% reported to have given feedback and to have raised concerns about healthcare services.

5.2 Channels used



To the question 'Could you tell us which channels you used to give feedback, raise concerns and put in a complaint about healthcare services' the majority of respondents, 45%, chose 'Other'. A slightly smaller percentage, 38%, used Patient Advice and Liaison Service (PALS), whilst 10% used Healthwatch and 7% used the Independent Complaints Advocacy Service (ICAS).

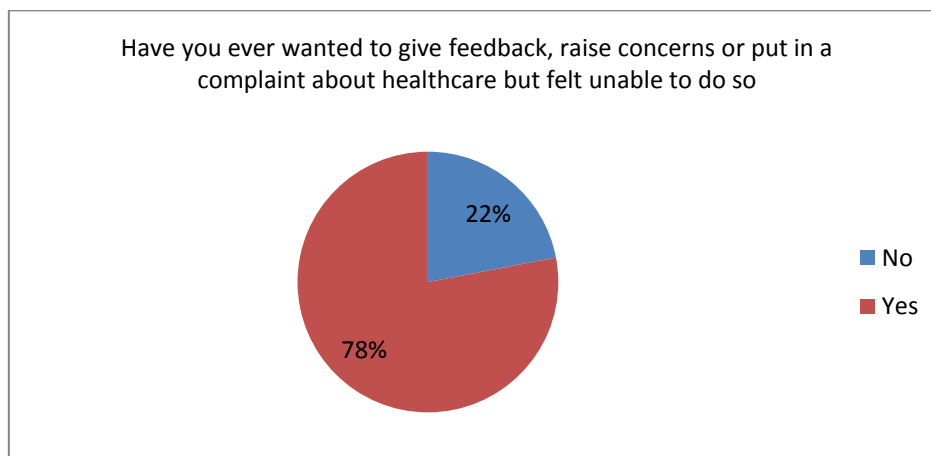
Overall the responses highlighted the fact that **parent carers know someone and/or an organisation that can help them through the feedback and complaint systems**. Apart from the more formal avenues, parent carers also contacted directly the professionals who delivered the healthcare service or supported them, for example the Adult Epilepsy Support Nurse, the GP practice manager and manager at Sea Side View and the Ward Manager. One respondent to our online survey stated '*Emails, phone calls and meetings, always trying to resolve everything amicably first and only going for formal complaints after being stonewalled by Seaside View Managers*'.

One parent reported '*I wrote directly to the manager of CAMHS regarding concerns over the poor service I received with regards to my son's ASC assessment, time taken and lack*

of communication and co-production from them'. And again in relation to CAMHS another parent commented *'Informed CAMHS, CAMHS family therapist, gave general information and emailed Pebbles group leader who was collecting information'* (Brighton Pebbles is a parent-run charity for families with disabled children aged 4-14 who live in Brighton and Hove).

Others parents contacted their local Councillor and MP or the Brighton and Hove Council Complaints.

5.3 Barriers to give feedback raise concerns and put in a complaint



To the question *'Have you ever wanted to give feedback, raise concerns or put in a complaint about healthcare but felt unable to do so?'* an astonishing 78% of our respondents said 'Yes' whilst only 22% replied 'No'.

We used two questions on our online questionnaire to further explore the different, and we imagine complex barriers that parent carers experienced.

Many respondents commented that they felt too tired, due to their caring role, to actually engage with the complaints and concerns system which were seen as *'too tiring and stressful'* and *'needs time and energy'*. A parent carer commented *'Lack of time and energy. We constantly 'fight' for not only health but education and social care too that we are mentally and physically exhausted. Often overlooking our own health'*. Another parent noted *'Knowing who to go to. Accessibility of the process. Having the energy to sit down and put it all in writing'*. Those points were echoed by Amaze Helpline Adviser who reported that **parent carers are always prioritising where to spend their energies due to their caring duties** *'Parent carers prioritise all the times, what they can do, what energy they have to do that, how long it takes them to get there'*.

A parent carer noted *'At the time I was feeling vulnerable due to the recent news about the life-shortening illness my son had just been diagnosed with and the physio managers and her superiors at seaside view were stonewalling me and many other parents so I waited until I was feeling stronger before I could muster the energy to fight back the planned reductions in physiotherapy for my son. I don't know how single mothers with more than one child and trying to hold down a job manage to fight back when the NHS tells them that their children will not receive X treatment or that their physio/OT will be reduced. I have a husband who's very supportive, I have a postgraduate degree, and I'm the mother of only*

one child and I still find the continuous struggle to get the right medical support for my child almost unbearable. There are barriers everywhere and many NHS managers make parent carers feel as if they are the 'selfish' or 'demanding' because we object to our children's provision being cut when it's still badly needed'.

Amaze Helpline is open every day of the week and, in this case it can be seen as a first step towards a complaint or sometimes mitigate a complaint. Helpline workers invite the parents to explain their concerns/questions and then discuss with them their options including following a formal complaints procedure, if the parent has said they want to make a formal complaint. The complaints process (and where to start) would be explained. The Helpline service is impartial, so parent carers are invited to openly talk through all the options and discuss any concerns they have about the process or impact of making a complaint. Helpline staff will support parents to decide on the next steps and can offer ongoing support which may be signposting to other services, support with writing an initial letter, or reviewing an initial letter written by the parent, ongoing support from a caseworker if appropriate. **For some parents, talking things through with a helpline advisor will be sufficiently empowering for them to start the process themselves or may help them have closure on an issue.**

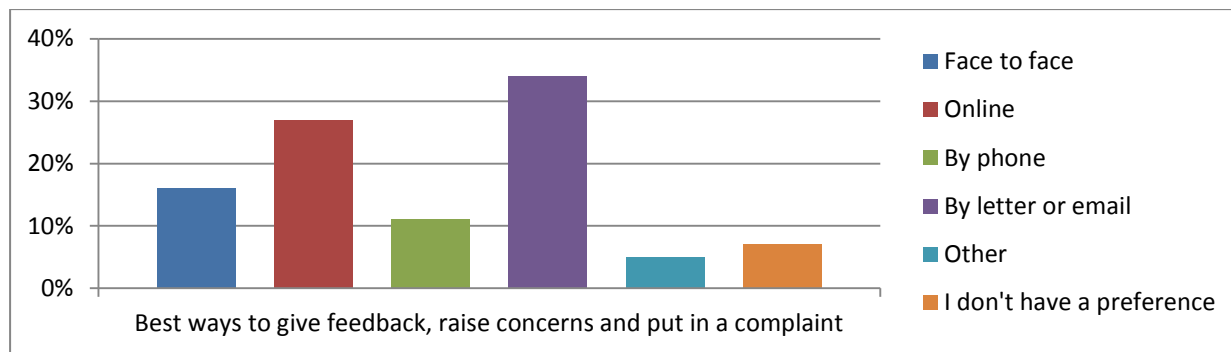
The complaints and concerns system is sometimes seen as difficult to navigate *'not sure who to complain too', too slow 'We put a complaint in in April 2016 and still waiting for a response' and 'the responses take so long'. And by some parents as unclear 'Lack of knowledge of complaints procedure, these are not clearly published within every organisation' and not very responsive to suggestions,* as for example in the case reported by a parent *'I raised a concern with former GP practice manager and they weren't open to any prospects for change. I was asked to change surgeries if I wasn't happy with GP on question. As a parent I have felt judged and feared this would reflect negatively on my child'.*

The main barrier, however, seems to be the effect that making a complaint or raising a concern can have on the way the parent/s is seen and the way the service will be provided to the child. Quite few parents commented that they didn't want to be 'blacklisted' or that professionals would dislike their child. A parent commented *'Scared that it will reflect on the care of my young person. It certainly did when I raised issues with education'.*

A respondent to our online questionnaire remarked *'If a parent complains about healthcare they risk being targeted by malicious professionals (yes, this really does happen) by being reported to social services. Social services believe everything a health professional tells them, precisely because they are a professional and because this supposedly means they are paragons of virtue and 'experts'. So even if a clinician has only seen a child in a clinical situation in which a child is not comfortable enough to be their true self (inhibited etc.) and the clinician does not know the child and may have poor understanding of their condition, their word will still be taken as accurate. Ask social services colleagues how many 'investigations' they are conducting on parents of children with health issues. Health staff have a huge impact on other services a child may need, such as EHCP, school support, DLA etc. and there is a cynical parent blame culture among many professionals. It is well known the complaints process in the NHS does not work; there is a culture of cover-up. This has to change'.*

The Amaze Helpline Adviser recognised that many parents fear negative reactions on the way services will be provided once they made a complaint or raise a concern *‘There is also a fine line between putting a formal complaint about a service that is not there for you enough and then have to access it. I think parent carers would think twice about doing that because repercussion on actually getting the service’.*

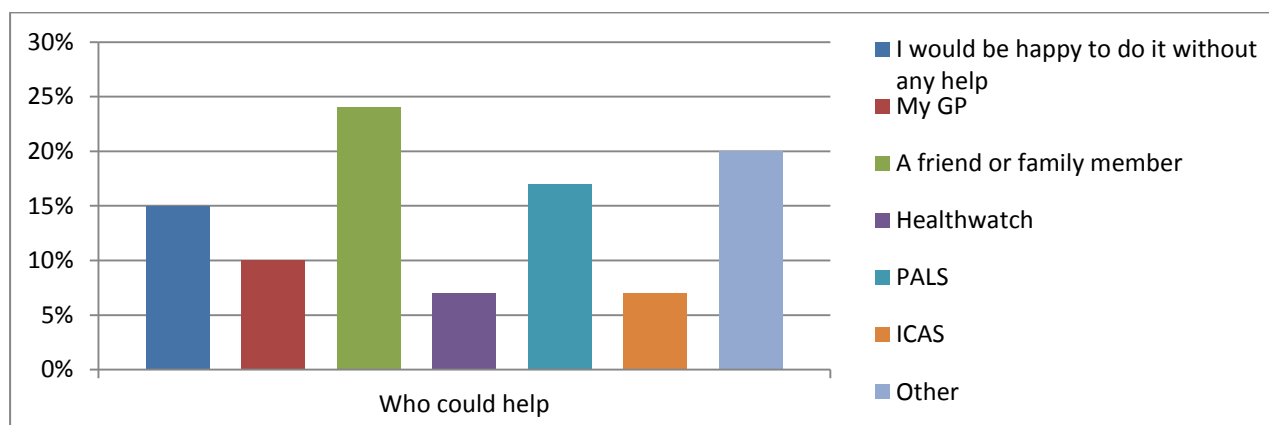
5.4 Best ways to give feedback, raise concerns and put in a complaint



Our next question explored the best way for people to provide feedback, raise a concern or make a complaint to which the majority, 34%, chose email or letter whilst 27% preferred online/websites, 16% face to face, 11% by phone, 5% other methods and 7% reported to not have a preference.

It seems that our respondents whilst preferring email and/or letter as a form of communication are quite happy with *‘Any method that works’*. A parent suggested *‘Any channel where there’s a written record of the complaint and where the results of the complaint can be easily accessed for solicitors, investigators, etc. There has to be accountability for those NHS managers (at SSV, for instance) that are constantly being mentioned as the culprits of mistreatment (stonewalling, bullying, not following the right NHS procedures) but that seem to continue in their jobs with no disciplinary action to the dismay of parent carers that are suffering at their hands’.*

5.5 Who could help to give feedback, raise concerns and put in a complaint



We finally looked in to who better is placed to help parent carers to access the different systems. **The majority of responses, 24%, indicated a friend or family member, whilst 20% chose ‘Other’ which included Amaze, PaCC, local MP, local councillor, a solicitor**

and the parent carer itself *'I would be happy to do it myself and I did but I was ignored and forced to return to the same professional'.*

A respondent to our online questionnaire felt very discouraged by the whole system *'SPFT are useless, Healthwatch can take no action and PALS just send it to the department you are complaining about! I have written evidence of SPFT PALS deceit and collusion!'*
(SPTF is the Sussex Partnership Foundation Trust)

8. Recommendations

- **Parent carers would like a system that is clear, easy to navigate and responsive to their suggestions, concerns and/or complaints.**
- **Ongoing financial support for voluntary sector organisations to enable them to help those parent carers who want to find out more about their options in relation to raise a concern or put in a complaint.**
- **An effective, independent system that doesn't penalise future relationship between parent carers and professionals and which could benefit and enhance provision and delivery of a service.**

9. Annexes

Annex 1: How Amaze and PaCC engage with parent carers

Annex 2: PaCC Amaze Survey on Complaints, Concerns and Feedback about Health Services - online questionnaire

Annex 3: PaCC Amaze Survey on Complaints, Concerns and Feedback about Health Services - summary

Annex 4: PaCC_Amaze Survey on Complaints, Concerns and Feedback about Health Services – summary 2

For more information on the services that can help you with any issues relating to healthcare services please follow the links below:

Raising Concerns Informally:

Healthwatch

If you are experiencing issues with your health care which you would like resolved, but are not making a complaint, you can contact Healthwatch Brighton and Hove. This is an independent organisation which helps local people by assisting them when they have concerns about health and social care services.

<http://www.healthwatch.co.uk/complaints> or <http://www.healthwatchbrightonandhove.co.uk/> or call the helpline 01273 234040

Patient Advice and Liaison Service (PALS)

PALS are not a complaints service, they help with issues. PALS services can be found in hospitals, community trusts, mental health trusts and ambulance trusts. Please check the website of the relevant hospital or trust for local PALS contact details.

Making a formal complaint about an NHS service:

NHS Independent Complaints and Advocacy Service (ICAS)

ICAS are a free and independent source of help and advice on making a complaint under NHS regulations. They can provide information and advice and support from trained advocates if needed. In Brighton and Hove the service is provided by Impetus. Please click on the following link for more information: <http://www.bh-impetus.org/projects/independent-complaints-advocacy-service-icas/>