



Parent Carers Annual Survey 2017/2018

Report Summary:

This 2017/2018 annual survey is one of the engagement activities delivered under the Brighton & Hove Communities and Third Sector Prospectus (TSIP). With this survey we wanted to tap into the idea of involvement and how PaCC members felt about it. More specifically we wanted to explore if parent carers felt that their voice is heard and that they have made a difference on the way services are reviewed and developed.

Parent carers who are supported by or get in touch with Amaze and who want to get more involved in shaping local services for families with children and young adults with additional needs and/or disabilities are invited to join PaCC. PaCC members are offered various opportunities to engage, e.g. online consultations, forums, focus groups as well as being part of PaCC social media.

Every year PaCC runs an online consultation for its members. In that way we make sure every member of PaCC has an opportunity to provide suggestions and ideas on what the forum should focus on during the coming year.

PaCC members told us that they would like:

- **PaCC to improve the way it informs and keeps in touch with its members**
- **PaCC to have a dedicated space on the PaCC ebulletin to promote its Partners**
- **PaCC should, after taking in to consideration capacity, increase the use of its social media**
- **PaCC to inform its members about the idea of co-production and the benefits of it. PaCC to publicise their co-production statement. PaCC to make sure the LA commits to coproduction by signing the statement**
- **For PaCC to reiterate importance of coproduction when attending board meetings and to make sure recommendations from consultations and forums are taken in to consideration and acted upon**
- **For PaCC and Amaze to carry on using various forms of engagement and to always look for innovative ways to reach out to parent carers who don't have much free time**
- **PaCC to use findings and priorities from the report to shape PaCC's strategy for next 12 months.**

1. Introduction

1.1 What Amaze does

Amaze is Brighton and Hove's '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 levels 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

PaCC, hosted by Amaze, is a city-wide engagement group with over 350 members who are parent carers of children and young people with disabilities, complex health problems or other additional needs.

PaCC also has 9 partners, some of them service providers and others community groups formed by parent carers.

PaCC gives a voice to parent carers using different engagement methods such as focus groups and forums to gather views/opinions which are then presented 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 Carers' engagement through B&HCC and local CCG

Brighton & Hove City Council (BHCC) and the local Clinical Commissioning Group (B&H CCG), through their Brighton & Hove Communities and Third Sector Prospectus (TSIP), fund Amaze and the Carers Centre for Brighton and Hove to engage with carers. Amaze and the Carers Centre work in partnership so that the voice of carers is included in the planning and delivery of services across the city.

Amaze and PaCC run consultations among families of children with additional needs on health care services which are accessed by the carers for themselves or for their disabled children ([See Annex 1: How Amaze and PaCC engage with parent carers](#)).

Information, data, suggestions and recommendations gathered through consultations are presented to BHCC and B&H CCG. As a result BHCC and B&H CCG are provided with clear intelligence about how children and young people with a variety of disabilities and their parent carers experience local services and how they would like those services to respond to their needs.

In addition BHCC and B&H CCG's understanding of the needs of disabled children and their parent carers is improved, and health and social care services are correspondingly made more responsive and targeted to actual needs. Finally parent carers feel that their views are valued and that they can influence decision making regarding health and social care 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 Annual Survey

Parent carers who are supported by or get in touch with Amaze and who want to get more involved in shaping local services for families with children and young adults with additional needs and/or disabilities are invited to join PaCC. PaCC members are offered various opportunities to get engaged, e.g. online consultations, forums, focus groups as well as be part of PaCC social media.

Every year PaCC runs an online consultation among its members. In that way we make sure everyone in PaCC has an opportunity to provide suggestions and ideas on what the forum should focus on during the coming year.

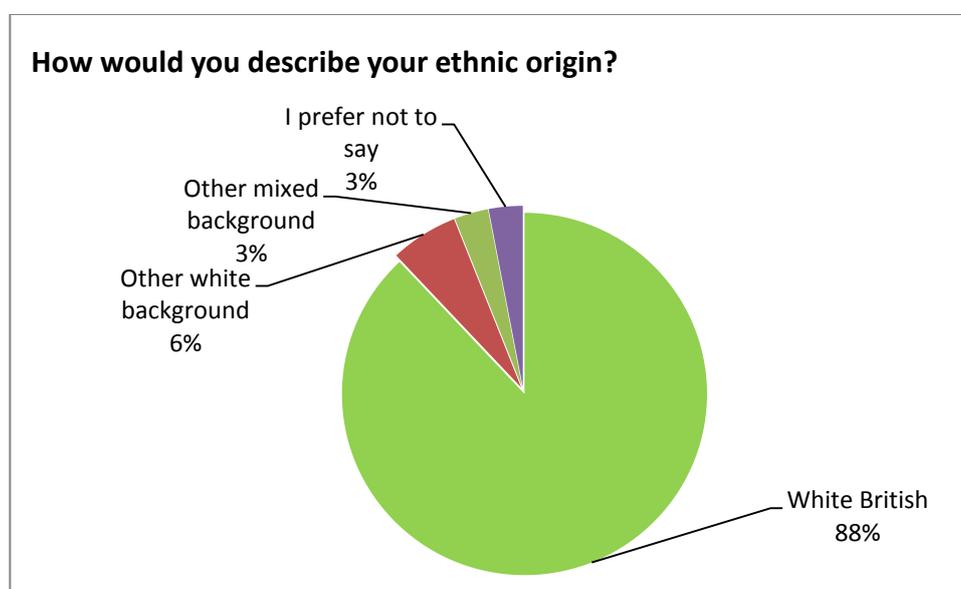
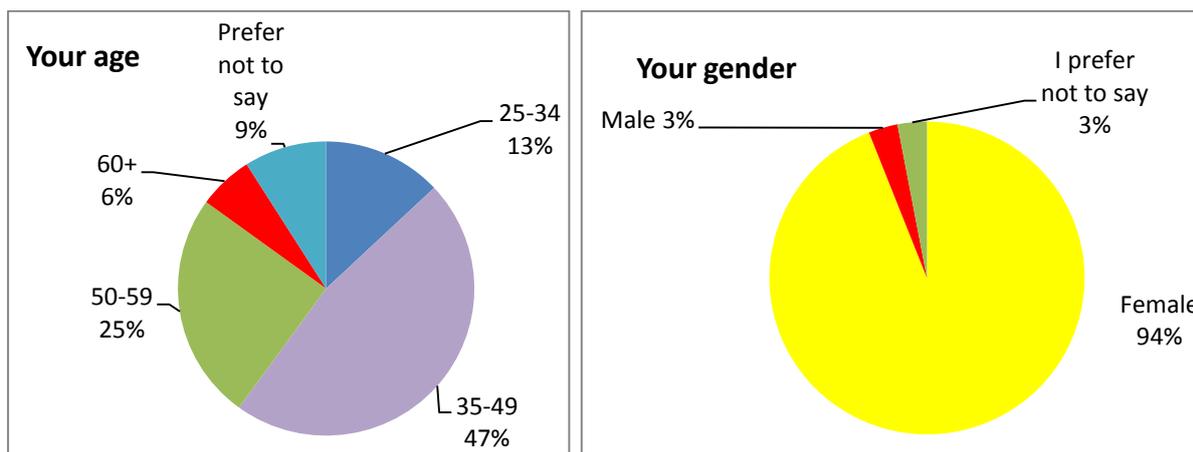
The 2017/2018 annual survey is one of the engagement activities delivered under the TSIP. With this survey we wanted to tap into the idea of engagement and how PaCC members felt about it. More specifically we wanted to explore if parent carers felt that their voice is heard and that they have made a difference on the way services are reviewed and developed.

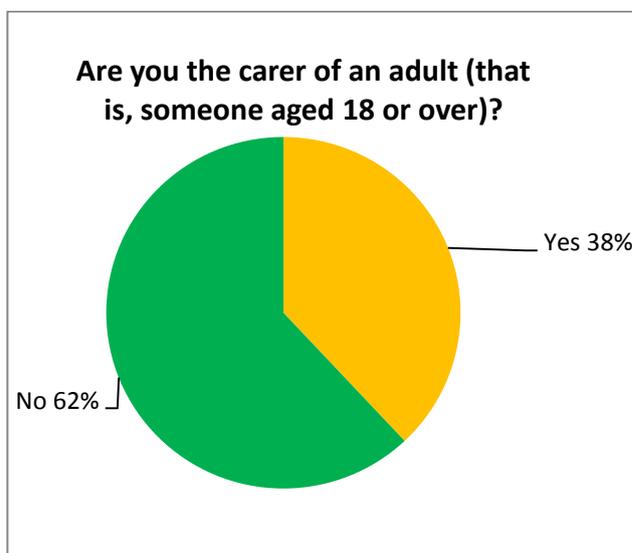
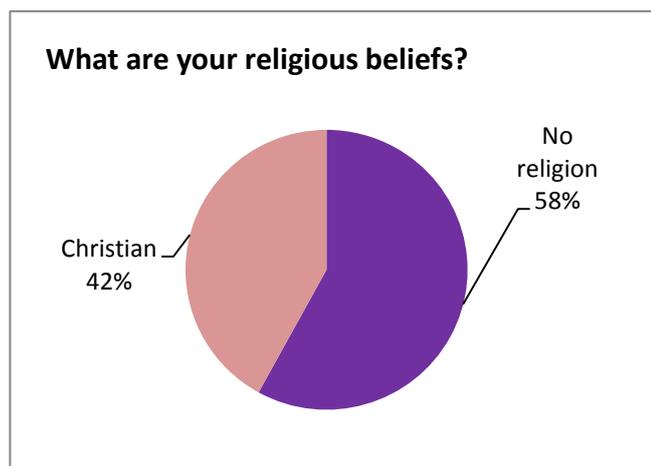
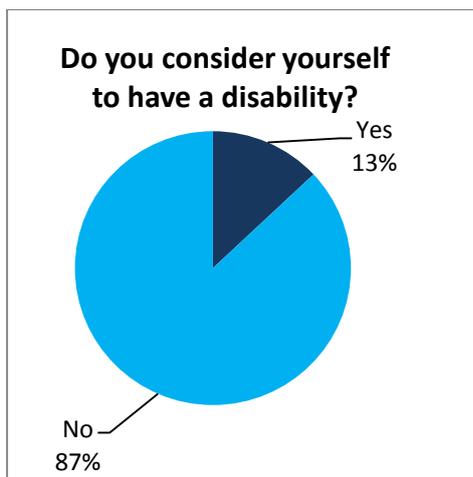
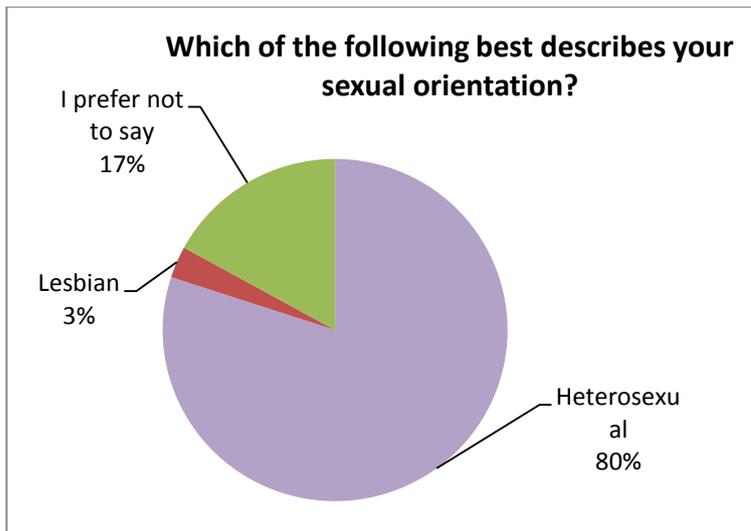
3. Methodology

To gather data and information for this consultation we used an easy to navigate and use online survey which was designed with help from the Amaze Database Manager. The online survey had a few questions with 'please select', 'tick box' options and boxes to provide extra information and feedback ([See Annex 2: TSIP PaCC survey - 2017](#)). The questionnaire was sent to all PaCC members.

We received 42 completed questionnaires which were collated into a summary ([See Annex 3: PaCC Members Survey 2017 - Summary](#)) and used to inform this report. Parent carers' contributions to this consultation are reported in verbatim to better reflect their experiences and comments.

4. Demographics from the online questionnaire

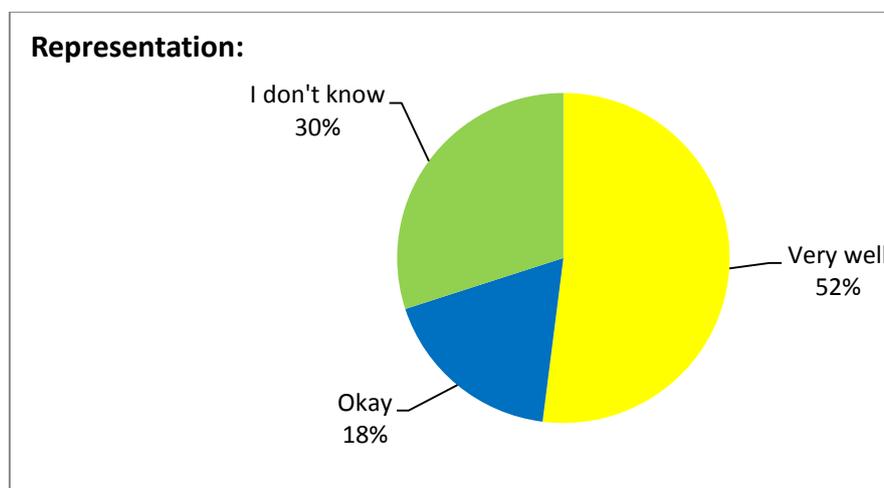




5. Findings from online survey

5.1 PaCC's representation of parent carers' views

First of all we wanted to know what members thought about PaCC representing their views. To the question - *'PaCC is the local parent and carers forum representing families with children and young people with additional needs in Brighton and Hove. We try to input views and influence developments so that services for our children are improved. How well do you think PaCC currently represents the views of parent carers in Brighton and Hove?'* - respondents told us:



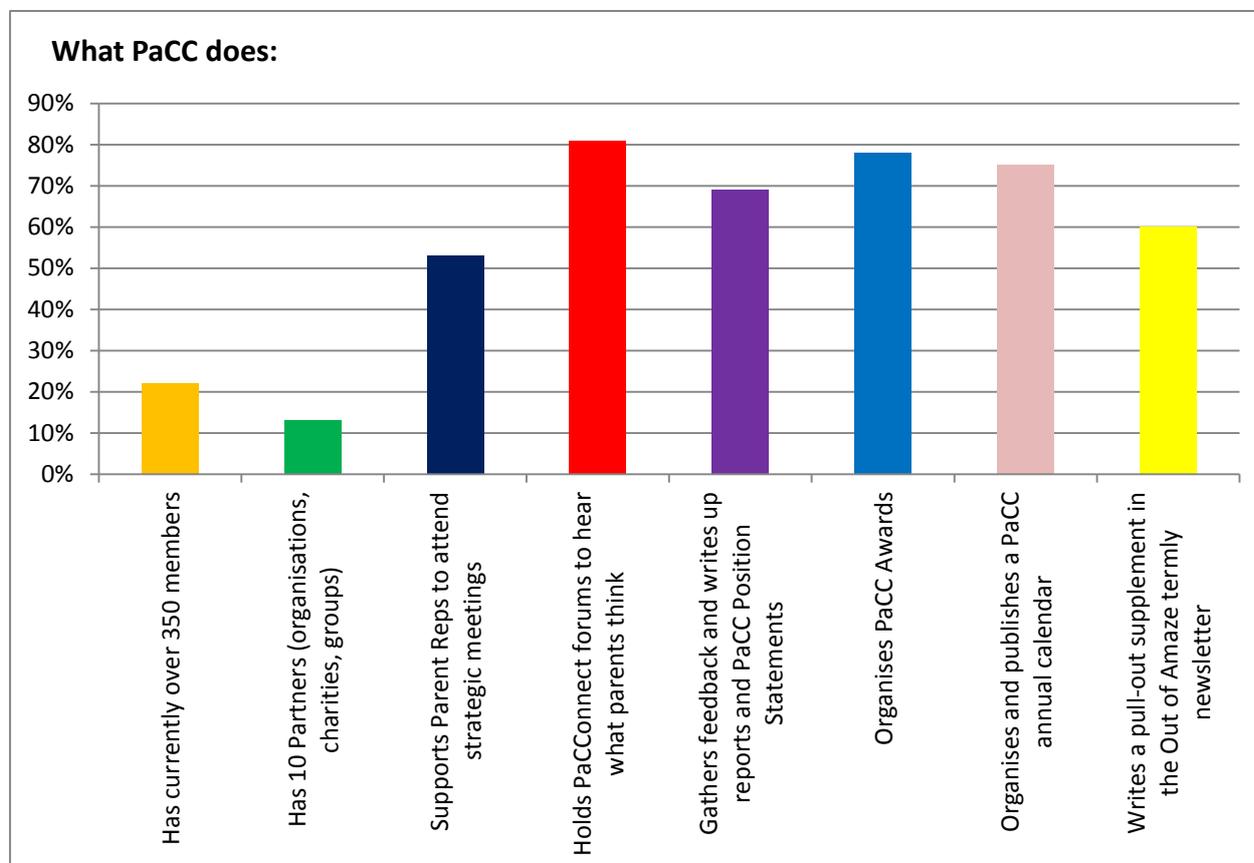
Over half of respondents stated that PaCC represents their views very well whilst 18% think that PaCC does okay when it speaks for them. Interestingly 30% of respondents stated that they don't know how PaCC represents their views. Whilst the majority of parent carers who completed the online survey are happy or satisfied with PaCC's representation, a third is not sure about it.

PaCC provide feedbacks and updates on its various activities through its website and FB closed group. PaCC also informs parent carers on its activities through the Amaze termly newsletter where PaCC has a distinctive four page pull-out.

Since the consultation was launched PaCC has also started to 'communicate' with its members by a quarterly ebulletin. However findings from this question point out that **PaCC needs to improve the way it informs and keeps in touch with its members.**

5.2 What PaCC does

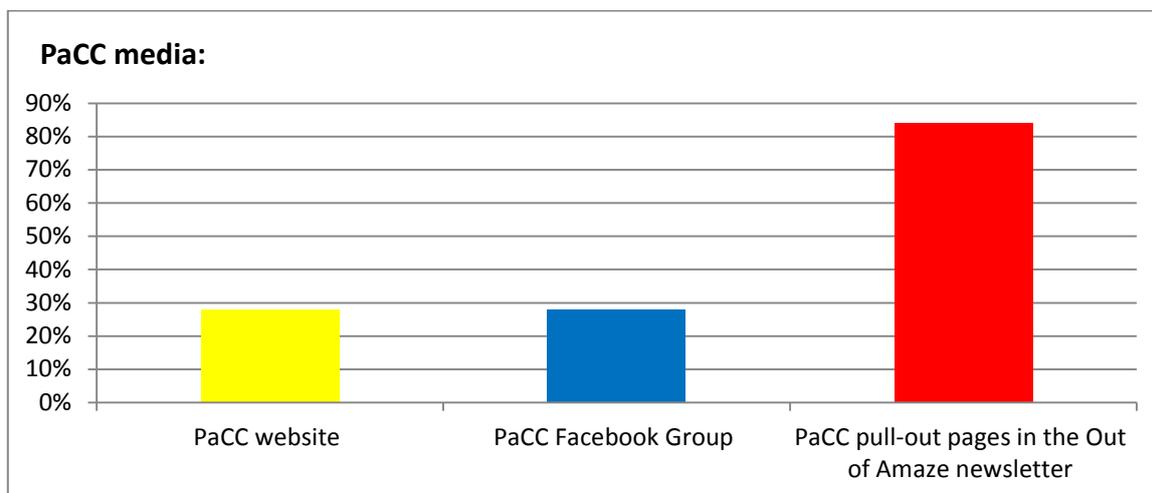
PaCC runs various projects/activities and we wanted to know how much the forum members are aware of them. To the question - 'PaCC works in a number of ways. Did you know that PaCC (tick all that apply)' – parent carers fed back:



Respondents to the online survey reported a wider knowledge about what PaCC does and nearly 70% are aware of the fact that the forum carries out consultations and reports and does provide feedback. 80% of the respondents know about PaCCConnects, a very valued and successful activity where parent carers can meet professionals and be engaged around specific services and/or topics. A small percentage, just over 10%, is familiar with the fact that PaCC has 10 Partners, parent carers groups and small charities, which have representatives on the PaCC Steering Group (SG). **Following the finding it was decided to have a dedicated space on the PaCC ebulletin to promote its Partners.**

5.3 Use of PaCC communications

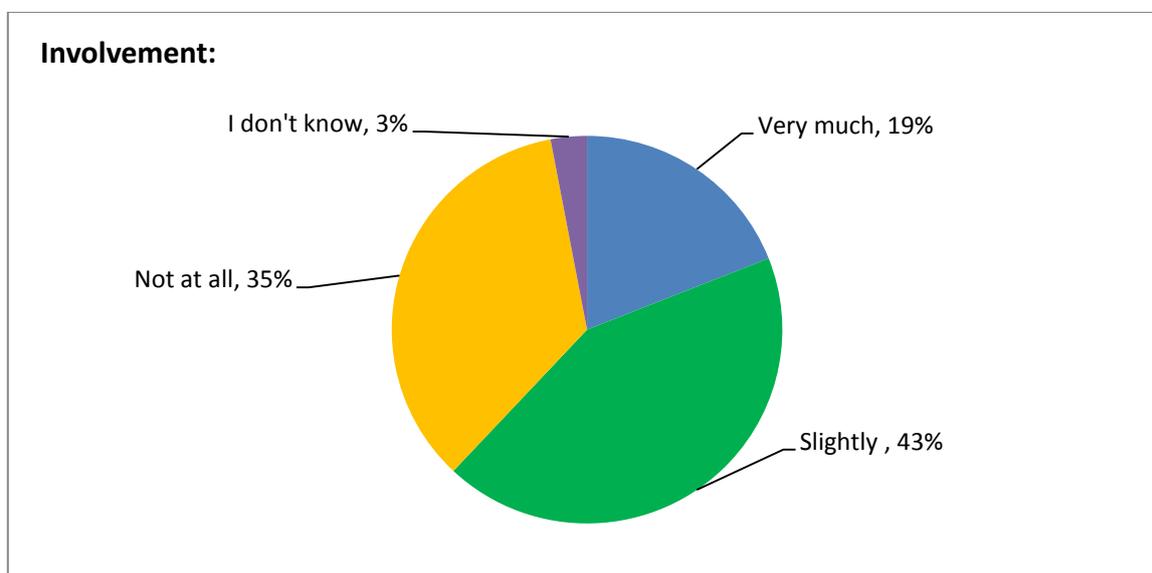
The way PaCC communicates with its members using different media has changed throughout the years. To the question - *'Have you accessed/used our (tick all that apply)'* – respondents fed back:



PaCC pull-out supplement on Amaze termly newsletter was redesigned three years ago. The new improved layout clearly illustrates what PaCC does and provides feedback on some of its engagement activities. Nearly 90% of respondents report reading the PaCC pull-out. A smaller percentage, approx. 30% have used PaCC website and/or PaCC FB closed group. **PaCC should, after taking in to consideration capacity, increase the use of its social media.**

5.4 Involvement

One of PaCC's aims is to improve the way parent carers are involved in how services for their families are planned and delivered. To the question - *'Overall, how involved do you feel in having a say on how education, health and other services for your child are provided and on how they work?'* – Respondents stated:



With this question we wanted to explore how parent carers felt about involvement on services for their families. Only 19% of respondents think they are fully involved, whilst 43% felt slightly involved. A third of parent carers who completed the survey reported feeling not involved at all.

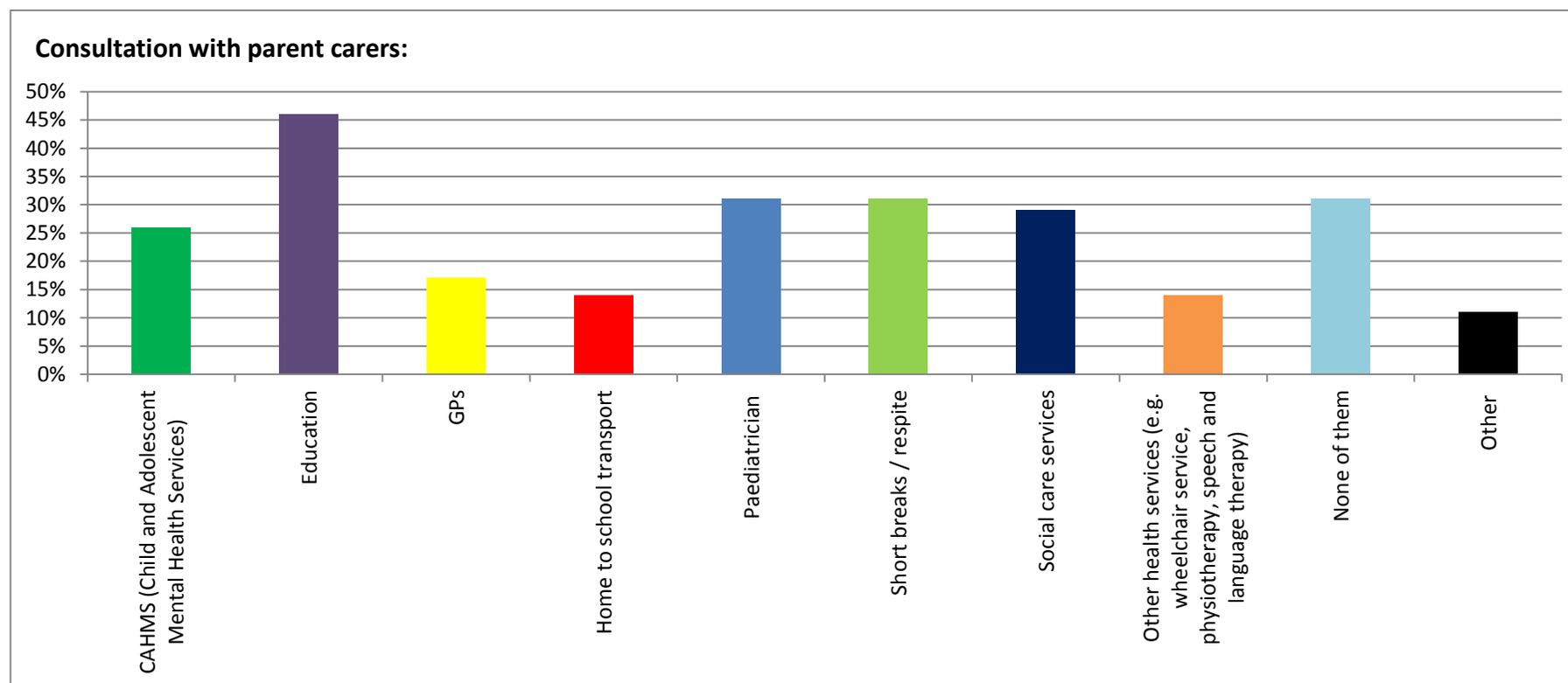
Active engagement and participation are quite complex activities, for example a person can be engaged by being informed about something, or being able to provide feedback, or a more in depth engagement could be that the person is first of all informed and then asked to participate on a focus group or forum.

The Special Educational Needs and Disability (SEND) Code of Practice 2015 introduced the concept of 'co-production', an ongoing dialogue between parent carers families and the Local Authority (LA). It stipulated 'a joint approach to evaluation, review and ongoing improvement, these co-production relationships need to be planned for and sustainable'. Parent carers' voices are included from the planning stage, not just as a feedback exercise <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25> .

PaCC believes that co-production is the way forward and during the past two years much progress has been made to reach that level of working relationship. PaCC is committed to making sure the LA subscribes to that idea and that feedback on any improvement and/or changes following co-production is provided to parent carers. **PaCC to inform its members about the idea of co-production and the benefits of it. PaCC to publicise PaCC's co-production statement. PaCC to make sure the LA commits to co-production by signing the co-production statement.**

5.5 Services and parent carers' voice

We wanted to find out which services, from a parent carer's point of view, are more actively seeking their views and ideas. To the question 'Which services do you think seek the input of parents and carers? (tick all that apply)' PaCC members replied:



Over 45% of respondents reported that education services do actively involve parent carers. Only around a third of respondents think that CAHMS, paediatricians, short break/respite services and social care services pursue parent carers' involvement. In addition a third of parent carers feel that none of the services do actually engage with them.

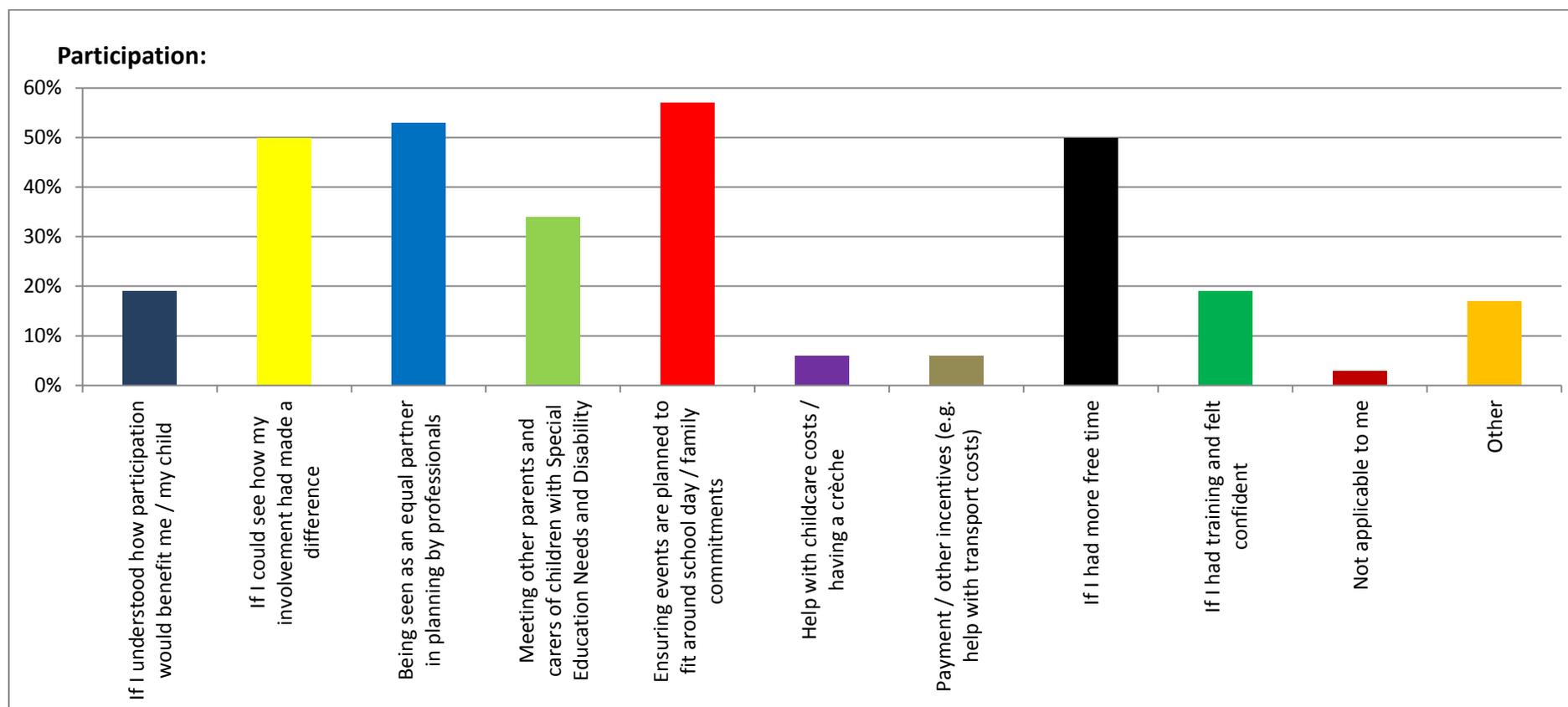
The finding is worrying because parent carers should be at the centre of how services are planned and provided. Whilst co-production is the optimum of engagement, and more challenging to achieve, other levels of engagement should be put in to practice. Seeking input from service

users should be properly promoted. A parent comments – *‘Parents are good at offering input, unsure how well services actively listen, often wonder if it's just window dressing’*

PaCC and Amaze, through the TSIP, are part of the ongoing engagement across the city and both organisations have organised consultations and forums on health and social care services during previous years. PaCC actively engages parent carers, as for example through its Partners; a respondent underlined how important parent groups are on seeking their views - *Mascot Parent Support Group* – mASCot is one of PaCC Partners. PaCC collates feedback, suggestions and ideas and present them to the LA when attending board meetings. **PaCC to reiterate importance of co-production when attending board meetings and to make sure recommendations from consultations and forums are taken in to consideration and acted upon.**

5.6 Improve parent carer involvement

PaCC wants parent carers to be fully engaged with how services are planned and commissioned and we also want our members to be more involved. We asked 'If you don't feel involved in developing services, which of the following would persuade you to get more involved in parent / carer participation? (tick all that apply)' parents said:



Most of PaCC activities happen during term-time and within school hours. We are aware that we should be organising some activities for people who cannot attend week days because they are at work or have other family commitments. Nearly 60% of respondents to our survey reiterated that point. One parent suggested '*Meetings at times that I am able to attend*' and another respondent '*evening when not working*'.

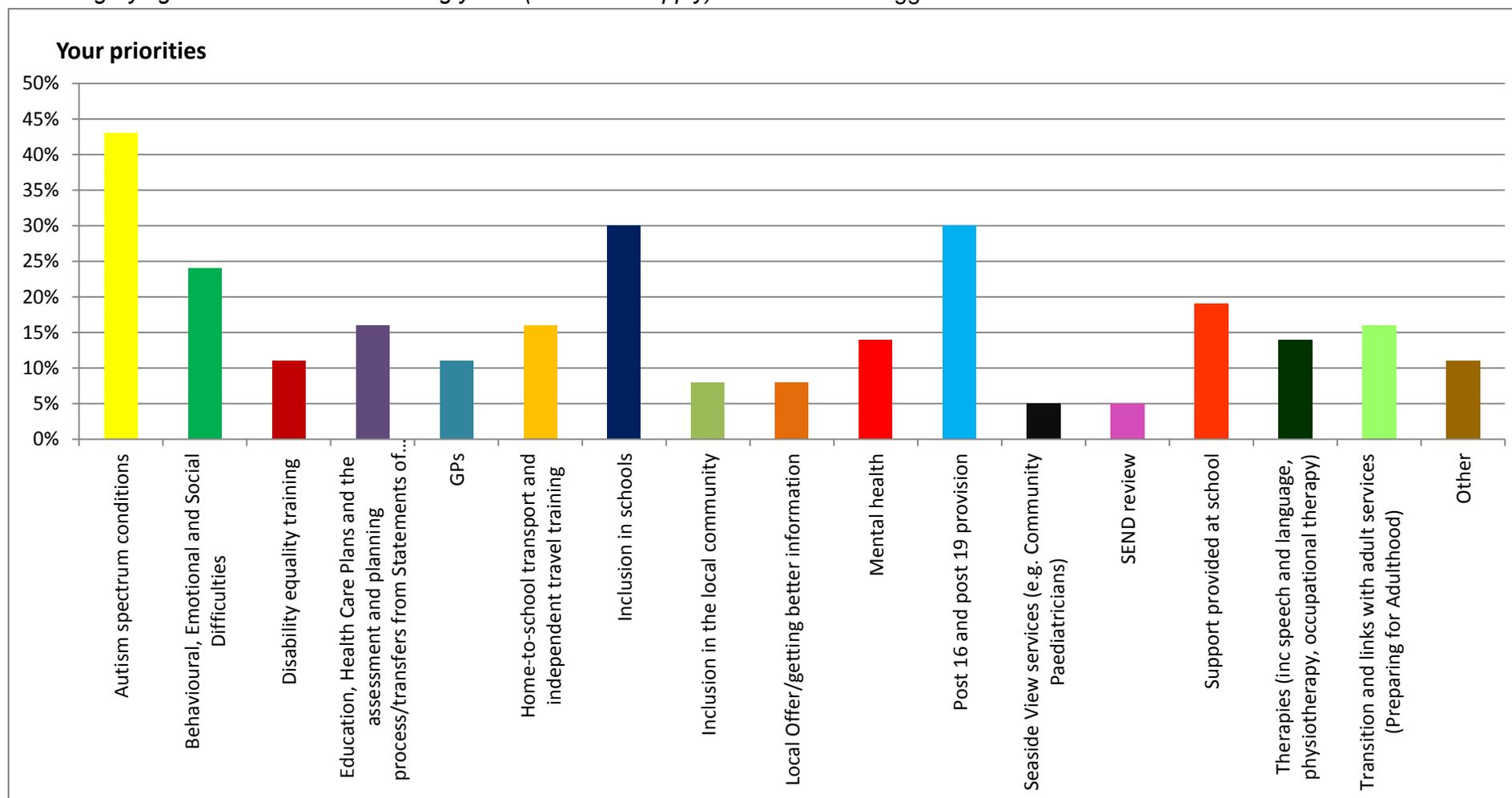
Engagement and participation, and even more co-production should bring an equal 'power & knowledge' relationship to the table. Approx. 50% of parents who completed the questionnaire would like to be seen more as an equal by professionals, and nearly 20% pointed out the need for more clarity about benefits of involvement. One parent commented *'My child is now 22 years old and has slipped through the net following new events of five years ago. No-one appears to be interested much in young adults. Even social services have refused to give me a Carers Card because my young adult doesn't want them involved in her life, despite the fact that she still has a Compass Card'*.

Other findings point out the need of providing training around involvement and building parent carers' confidence and help with childcare and travel costs. PaCC engagement events always take place at fully accessible venues; nevertheless two respondents would like *'a location that is accessible'* and *'reasonable adjustments for disabilities'*. One parent commented *'I don't need persuading, I just don't get asked! However I have ticked the elements that would make it possible for me to attend'*.

Around 50% of parent carers who completed our online survey reported that they would like to get more involved if they had more free time. PaCC and Amaze are well aware that looking after a child or young person with additional needs and /or disabilities has its rewards but is also very demanding on parent carers' own time and parents find it difficult to find time to look after themselves. While PaCC and Amaze highlight how important short breaks and respite are we also use different methods through which parents can engage with the way services are planned and delivered. **For PaCC and Amaze to carry on using various forms of engagement and to always look for innovative ways to reach out to parent carers who don't have much free time.**

5.7 Your priorities

PaCC's priorities are parent carers' priorities. Every year we run a consultation among PaCC members to find out what are the most important topics and/or services which they would like PaCC to work on. To the question 'Which 3 areas would you like the PaCC to focus on reviewing/trying to influence for the coming year? (tick all that apply)' our members suggested:



Findings from the chart above will contribute to shape PaCC's strategy for next 12 months. PaCC is already active around some of the priorities suggested by respondents. For example one of the PaCC Parent Reps sits on the Autism Working Group, and some other Parent Reps, the PaCC Chair and Vice-Chair are involved around school inclusion and post 16 and 19 provision. PaCC has co-produced with the LA the SEND review which includes the merging of special schools and the creation of a hub dedicated to children with behavioural, emotional and social difficulties.

A concerned parent would like PaCC to work on opportunities for **young people to access employment** *'My young adult is struggling to secure a job despite the help she is receiving from Scope. I'm sure there is discrimination going on with some of her job applications. She was on an Apprenticeship but lasted only 7 months when the college concerned kicked her off the apprenticeship. She was working a 37 and half hour week and got behind with the homework. The only type of employment she's had since Oct 2015'*

Two parents would like PaCC to focus on legal support and one added *'legal support & formation of teen drop in centre for therapies & formation of alternative school'*. Under the category 'Other' respondents mentioned **parent support groups, personal individual budgets** and SEN **Strategy Document 2013-2017**.

A respondent critically commented on the fact that looking after a child with additional needs and/or disabilities is, most of the time, a complex situation with many priorities *'ASC school for High Functioning Autistic Children. I think there are so many things that are interlinked - breaking this down to 3 areas is misleading. Respite /Parent Support / Transition post 16 from Primary to Secondary school are all key areas. Support for holiday SEN schemes so parents can work, and support for young people finding employment are ALL essential - asking to choose seems to me to not understand complex issues surrounding support for SEN children / YP and their Parent/Carers'*

6. Recommendations

- PaCC to improve the way it informs and keeps in touch with its members
- PaCC to have a dedicated space on the PaCC ebulletin to promote its Partners
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- PaCC to use finding/priorities from the report to shape PaCC's strategy for next 12 months.

7. Annexes

Annex 1: How Amaze and PaCC engage with parent carers

Annex 2: TSIP PaCC survey – 2017

Annex 3: PaCC Members Survey 2017 - Summary