Carers’ assessments and their needs – December 2017

Report Summary:

With this report Amaze and PaCC wanted to find out how parent carers and their families experience the assessment process to identify their needs and then if they are provided with the services that they need to support them in their caring role. We also asked parent carers for their ideas and suggestions on what can be done to improve their life as a carer.

Amaze and PaCC worked closely with the Carers Centre for Brighton and Hove to identify this topic and to design the survey questions, as we wanted to pick a topic that would provide useful intelligence about the needs of parent carers and carers of adults and if/how these are being identified by means of an assessment.

This consultation was done as part of our engagement work with the local Clinical Commissioning Group (B&H CCG) but the topic identifies issues and concerns which cross health and social care processes and services, provided in some cases by Brighton and Hove City Council.

The legislative framework around carer’s assessments is complex but in essence the Care Act 2014 strengthened the right for carers of adults to have an assessment of their own needs as a carer and the Children and Families Act 2014 introduced an equivalent right to a carer’s assessment for parent carers of under 18s and for young carers. The right to a parent carer assessment is separate to the duty to assess needs of the child but can be carried out alongside this as part of a holistic family assessment.

Some families who are assessed within social care (Early Help/Social Work) get their needs assessed within the Strengthening Families Assessment (SFA). The SFA is intended to be carried out every 6 months and was designed specifically to ensure that all the assessed needs of a family were contained within one document.

We sent the survey to parent carers of 0 to 25 year olds on the Compass disability register. Respondents told us that 81% have never had a carer’s assessment and 71% have never been offered a social care assessment. Of those who have received an assessment only 30% said the assessment was recorded and written down.

Whilst we cannot be sure that every parent carer who responded to the survey would be eligible for a carer’s assessment, the survey results suggest that many eligible carers are either not getting any assessment or where the child/family is assessed, it is not clear to the family that this includes a carer’s assessment.

Our findings show the majority of parent carers are receiving support from various charities and community groups, their family and friends. Some receive support from public sector organisations.

Parent carers want more counselling for themselves and their children/young people. They would like more information and advice on what's available for them and their families.

Parent carers would like to be able to access more training and courses to support them as carer, and they would also like more training to be offered to professionals to better support children and young people with special educational needs and disabilities (SEND).

Parent carers say they need more respite, including activities and support groups. Parent carers and their families benefit from befriending and peer support and would like more of this.

Parent carers want to see an end to a system that reacts to crisis instead of preventing them.

As a result of this consultation we are recommending that:

- **It is clarified which parent carers are likely to have their needs assessed, how often, and by whom and for this detail to be promoted on the Local Offer**
- **We ask that all professionals using the SFA are identifying if there is a carer in the family and include their needs of carers in their assessments as the Children Disability Team (CDT) say they do at Seaside View**
- **CDT to improve their communication with carers to explain that their needs are being assessed as part of the SFA**
- **The Local Authority to clarify the aims of undertaking a formal carers' needs assessment to both professionals and families including all carer's needs to be taken into consideration and for the assessment to be recorded**
- **The Local Authority and CCG to make sure that professionals and organisations which provide carers assessments and follow on services are financially supported and their funding is ring-fenced**
- **Secured, ongoing financial support to those charities and voluntary organisations which provide support and advice to carers and their families – including more investment in information and advice as well as cost effective befriending/peer support, support groups etc. that draw on the use of volunteers.**
- **Increased investment in the provision of counselling services for carers and their families**
- **Carers to be provided with more information on what's available locally through various media including the Local Offer website**
- **More training to be offered to carers, e.g. how to better support their child/young person and themselves and to mainstream schools staff, teaching assistants and teachers, to help the inclusion of SEND children**

- **Reversal of current policy of budget cuts on critical (preventative) services so that more short breaks and other social/group activities are made available**

- **Recommendations and suggestions from this report are used to feedback on the Brighton and Hove CCG 'Caring Together Care Programme – Preventative Services & Community Care' (Ca-To)**

This consultation was carried out in partnership with the Carers Centre for Brighton and Hove. It explored the needs of parent carers and carers of adults and if/how these are being identified by means of an assessment. In addition to this report a table collating recommendations from Amaze and PaCC and The Carers Centre for Brighton and Hove will be circulated.

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

The PaCC, hosted by Amaze, is a city-wide engagement group with over 340 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 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 and disabilities 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 are targeted to actual needs. And 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. Assessment of parent carers and their families' needs

Previous consultations have highlighted the enormous demands that looking after a child with disabilities and/or additional needs brings.

In 2014, as part of a survey on mental health and wellbeing, Amaze asked parent carers how they would rate their current state of happiness. A third of respondents rated it as less than 5/10 (10 being the higher score and 1 the lower) and stated that caring responsibilities, finances, relationships, housing and employment, among other issues, contributed to how they felt *(See Annex 2: Mental Wellbeing Survey Results for Report).*

Findings from Amaze's report mirrored similar ones from a national survey carried out in 2011 by Contact, formerly known as 'Contact a Family', a charity for families with disabled children. Contact found out that families with disabled children faced an overwhelming combination of financial, emotional and practical pressures and, without information and support, found it difficult to cope and became isolated. To reduce the social isolation caused by lack of support the report **recommended *'a distinct carers' assessment that considers a parent's ability to provide and continue to provide care for their disabled child or children'* and '*provision of services to meet any assessed needs'*** *(See Annex 3: forgotten_isolation_report)*

During the past few years there have been quite few changes in the way support and services are provided to families of children and young people with disabilities and/or additional needs. In 2014 a new Children and Families Act and a new Care Act kick-started a huge transformation. Section 3 of the Children and Families Act led to the SEND Code of Practice, detailing local authorities, health bodies, schools and colleges' duties for children and young people with special educational needs and disability (SEND), whilst Section 5 amended the Children Act 1989 to introduce a duty on local authorities to carry out parent carers' needs assessments for parents of disabled children (under 18). At the same time the Care Act 2014 introduced a strengthened right to a carer's assessment for those caring for over 18s; a child's needs assessment for young people approaching the transition to adulthood and a child's carer's assessment for parent carers of young people 'in transition'.

The Children and Families Act 2014 underlined the importance of the wellbeing of the parent carer and the welfare of the child/young person. It also established how people's care and support needs should be met, setting out that any assessment of a disabled child should take into account the needs of the rest of the family members, including parents and siblings, and consider their needs as a carer and capacity to continue with caring. In addition some siblings that share in the care of their disabled brother or sister may be identified as a 'young carer' and so have their own right to an assessment.

The Care Act details how social care should be provided to anyone over 18. It also introduced a duty on LA to carry out a Child's Needs Assessment or CAN for young people approaching 18. The assessment should look at any social care that the young person might be eligible for once they are 18 and older. The assessment focuses on the young person's needs and aspirations and should be linked with the consideration about preparing for adulthood that starts in the Year 9 annual review for young people who have an Education Health Care Plan (EHCP). Parents can ask for their young person to be assessed but LA is not obliged to provide a CNA if they think the young person will not need adult social care *(See Annex 4: What the Care Act means for young people with support needs – page 13, Out of Amaze, October 2015).* Parent carers of young people approaching 18 can also ask for a child's carer's needs assessment that looks ahead at their needs as a carer once they are caring for an adult. The aim of both these assessments is to ensure a smooth transition from children's to adult services.

Regardless of whether a carer is caring for a child or an adult, the aim of a carer's assessment is to consider the impact of caring on the carer and also to examine what the carer would like to achieve in their day-to-day life, for example study, work and do more socially. The assessment should determine a carer's eligibility to services and either provide advice and information as to what's available, including support and services from local voluntary organisations or a 'support plan'. Basically a carer's assessment should be seen as an opportunity for the carer to tell services what they would like to receive so that looking after a child and/or adult is made easier. And as a result of the assessment the carer may access the necessary health and social care services, or be provided with a 'direct payment' to purchase the services that they need.

Our understanding of current, local, practice within the Children's Disability Social Care team is that the carers assessment is contained within the Strengthening Families Assessment (SFA). The CDT say the SFA was designed specifically to ensure that all the assessed needs of a family were contained within one document. This is rather than spread over a number of documents which might be confusing and problematic. As such, there is not a separate carers assessment document. The SFA is an assessment document which is updated every six months.

A recent Contact report 'Caring More Than Most', August 2017, underlined the fact that *'disabled children and their families are at a significant disadvantage in many key aspects of life including their economic situation, health, employment and housing'.* The report found out, among many other things that **a quarter of parent carers provide over 100 hours of care every week**. In the light of those findings Contact demands more provision of health and social care services, for example short breaks, therapies, personal care, home help and so on. The charity states that increasing provision of services can only be achieved by reversing the national and local trend of policies which focus on funding cuts and reduction of already insufficient services *(See Annex5: caring_more_than_most_exec_summary or go to https://contact.org.uk/caring-most for full report)*

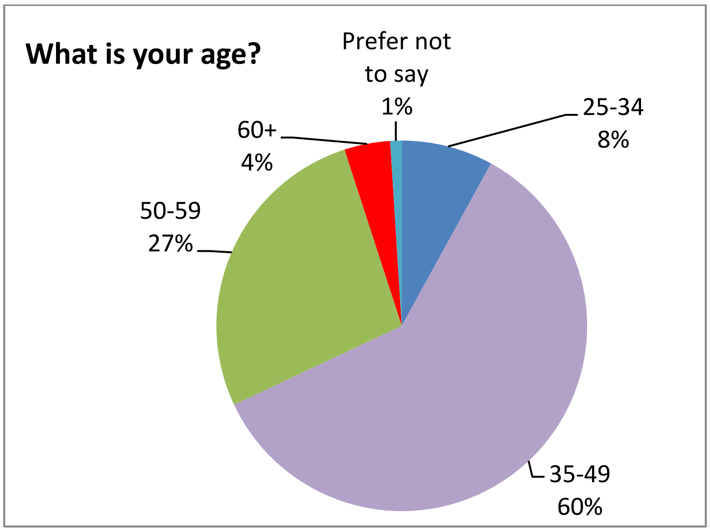
With this report Amaze and PaCC wanted to find out how parent carers and their families experience the assessment of their needs and whether they are then provided with the services that they need to support them in their caring role. We also asked parent carers for their ideas and suggestions on what can be done to improve their life as a carer.

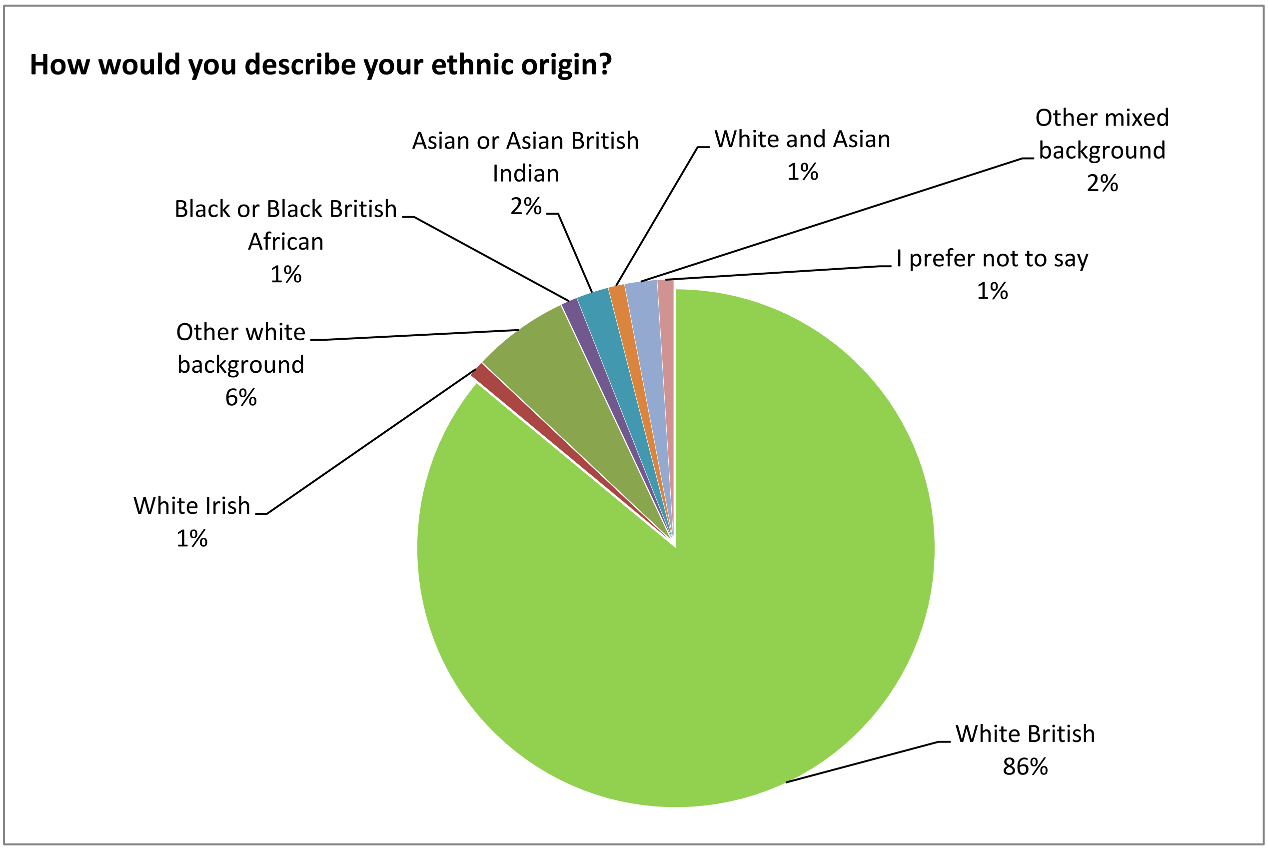
3. Methodology

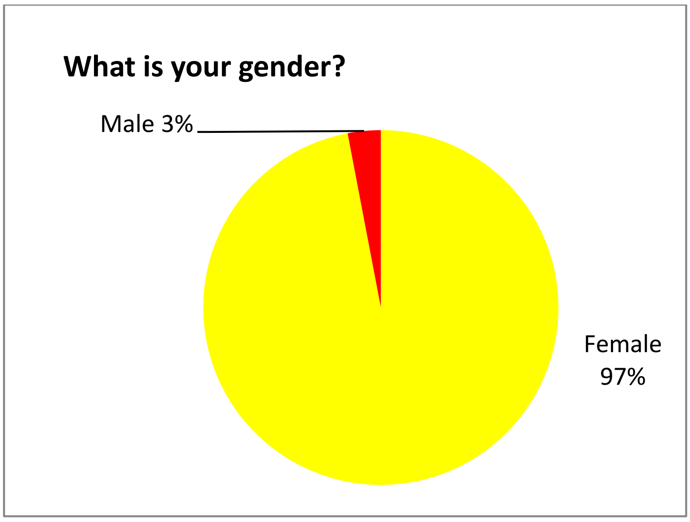
To gather data and information for this consultation we used an easy to navigate and use online questionnaire which was co-produced by us and Carers Centre and then designed with help from Amaze Database Manager. The online questionnaire had a few questions with ‘please select’ and ‘tick boxes’ options and boxes to provide extra information and feedback *(See Annex6: CCG Carers Assessment Survey).* The questionnaire was sent to all parent carers whose children/young people (0 to 25) are on the Compass Register. All children and young people on the Compass are either in receipt of Disability Living Allowance (PIP if older) or have an Education Health and Care Plan.

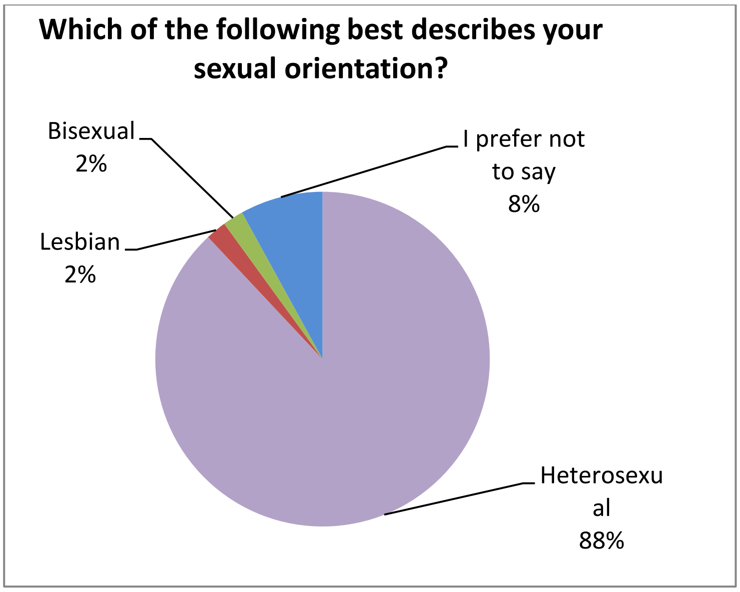
We received **113 completed questionnaires** which were collated into a summary *(See Annex7: CCG Carers Assessment Survey - Sharedexplore - Public-view)* and used to inform this report. The high number of responses indicates straight away the importance, urgency and need that parent carers place on carer’s assessments. Parent carers’ contributions to this consultation are reported in verbatim so to better reflect their experiences and comments *(See Annex 8: Carers Assessment Survey – comments)*

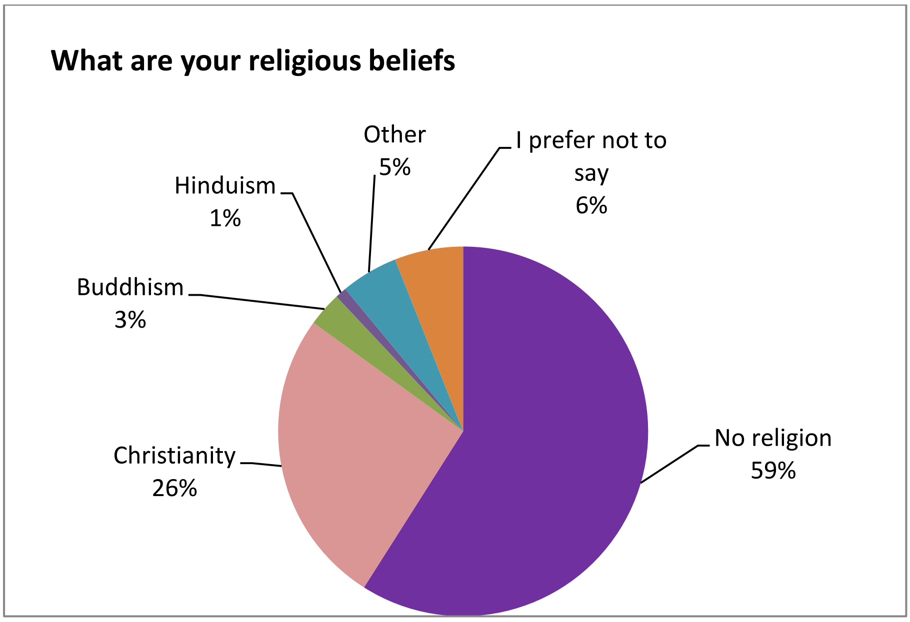
4. Demographics from the online questionnaire

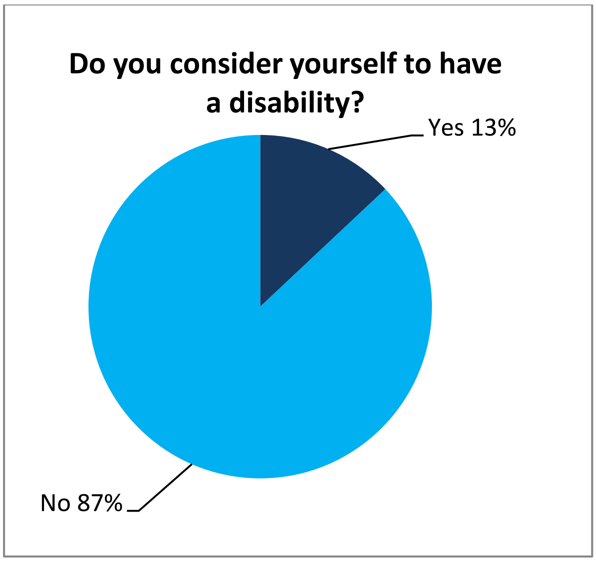


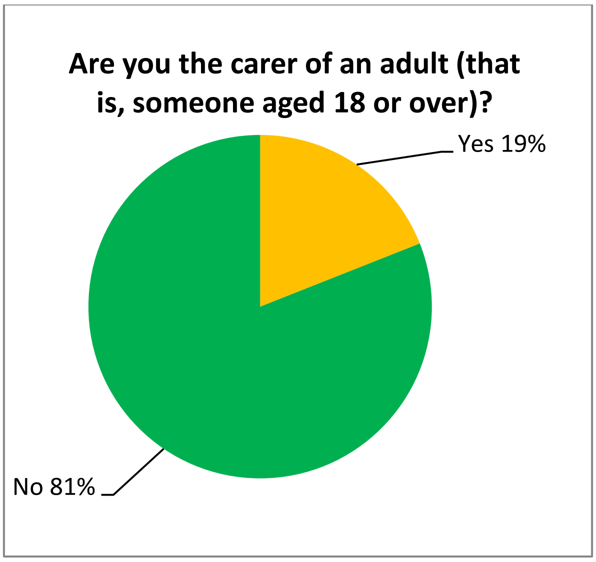

How would you describe your ethnic origin?
Asian or Asian British Indian 2%
White and Asian 1%
Other mixed background 2%
Black or Black British African 1%
I prefer not to say 1%
Other white background 6%
White Irish 1%
White British 86%


What is your gender?
Male 3%
Female 97%


Which of the following best describes your sexual orientation?
Bisexual 2%
Lesbian 2%
I prefer not to say 8%
Heterosexual 88%


What are your religious beliefs
Other 5%
I prefer not to say 6%
Hinduism 1%
Buddhism 3%
Christianity 26%
No religion 59%

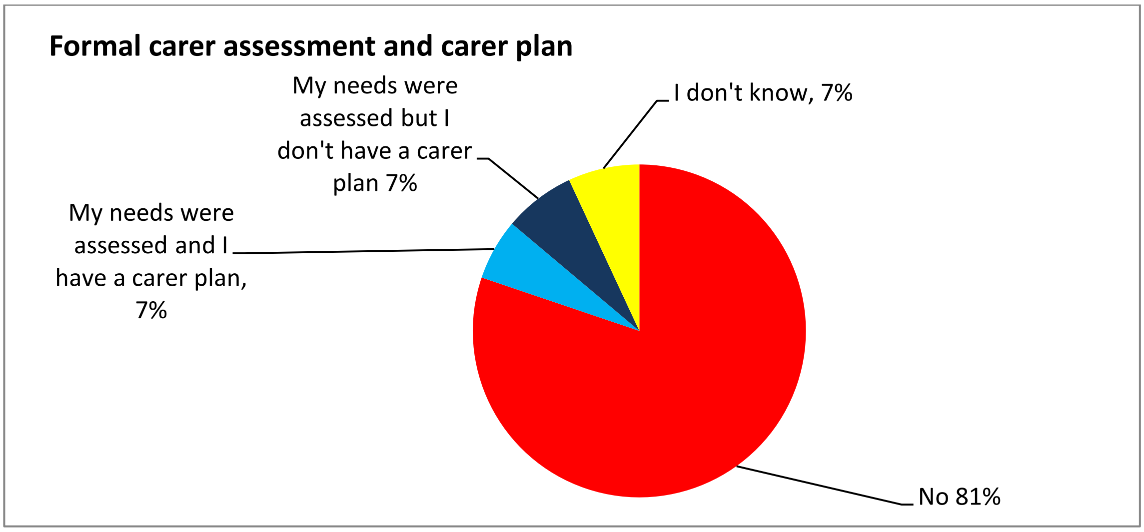

Do you consider yourself to have a disability?
Yes 13%
No 87%


Are you the carer of an adult (that is, someone aged 18 or over)?
Yes 19%
No 81%

5. Findings from online questionnaire

5.1 Formal carer assessment and carer plan

A carer's assessment is a discussion between the carer/s and a trained person either from the council or another organisation that the council works with. To the question *'Have your needs as a carer been formally assessed by a professional in the last year and have you got a carer plan as a result?'* respondents told us:



The **overwhelming majority of parent carers** who responded to our online questionnaire, **81%**, **reported that their needs as carer haven't been assessed at all**. The Children and Families Act 2014 introduced the provision of parent carer's assessments however the legislation is not very clear on who should get one and how proactively each LA must identify those parent carers within their area who have needs for support. A parent reported *'I get no support as a carer. I was told by Children's Services there was no point having a carer assessment as there was nothing available'*

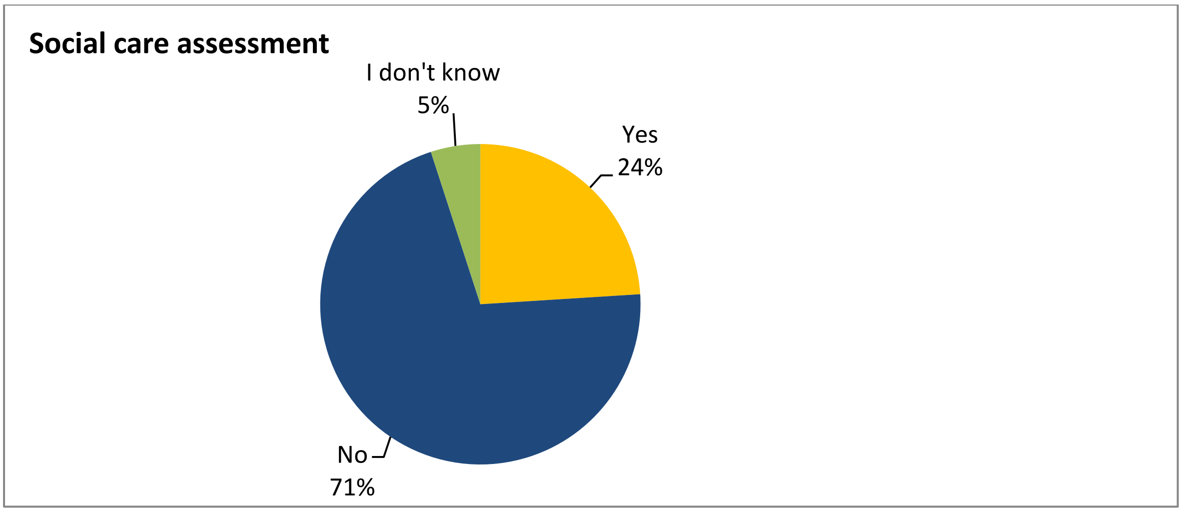
It also brings up the issue the Act intended to tackle, that is the **wellbeing of the parent carer and the welfare of the child/young person not being taken in to consideration.** As a result parent carers may not be receiving the support and information around physical, mental and emotional wellbeing which they should be entitled to, clearly demonstrated by our respondents, *'really concerned that we don't know who to talk when we feel that we need some emotional support'* and *'the pressure on me as a working single mum/carer is immense. I would like more support in accessing any help I might entitled to. I don't have time to do this'*.

Isolation, underscored by so many reports, takes its toll among parent carers, *'support for myself as a carer as I feel so isolated and don't know where to turn. Advice about services available to my child and support to get him at school'*. A parent observes *'I feel unless you search for help, and even know what help you need there is not one place I know of or have heard of that you can go to that would help with an umbrella of information, if you're not in a social circle of people in the know how are you supposed to know where to go?'*

However once the carer asks for support, the outcome sometimes is not what the family was hoping for, a parent commented *'In the past anytime we as a family asked for support we were instead scrutinised by Social Services, despite there being no reason for this or simply offered parenting courses such as Triple P. We have never been offered any support relating to our son's disability'*

5.2 Social care assessment

Next we asked parent carers about the social care assessment and to the question *'Has a professional carried out a social care assessment for your child/young person and family in the last year?'* respondents told us:



Whilst a few more families seem to have received a social care assessment, **the majority of respondents, 71%, haven't been offered one**.

As mentioned earlier, the law around who should receive social care assessments is complex. Looking at children (under 18s), there is a duty under the Children Act 1989 to safeguard and promote the welfare of children who may be "in need". Being "disabled" is one of the defined reasons for being "in need". Children that have additional needs below the threshold of a disability may also be "in need" if they are unlikely to have a reasonable standard of health or development without the provision of services. This would suggest that many, if not all, of the parents who responded to the survey are caring for children who could or should have a social care assessment. And some will meet the more stringent criteria for assessment by the Children's Disability Team to see if they should be provided with services under either Section 2 of the Chronically Sick and Disabled Persons Act 1970, and/or under the Children Act 1989.

For adults (18 and over) eligibility is based on identifying how a person's care and support needs affect their ability to achieve relevant outcomes, and how this impacts on their wellbeing. Local authorities must consider whether the person's needs are due to a physical or mental impairment or illness, if they make them unable to achieve two or more of a list of specified outcomes and as a result there is likely to be a significant impact on their wellbeing. Again many of the survey respondents caring for young adults age 18 and older will be caring for someone eligible for adult social care assessment.

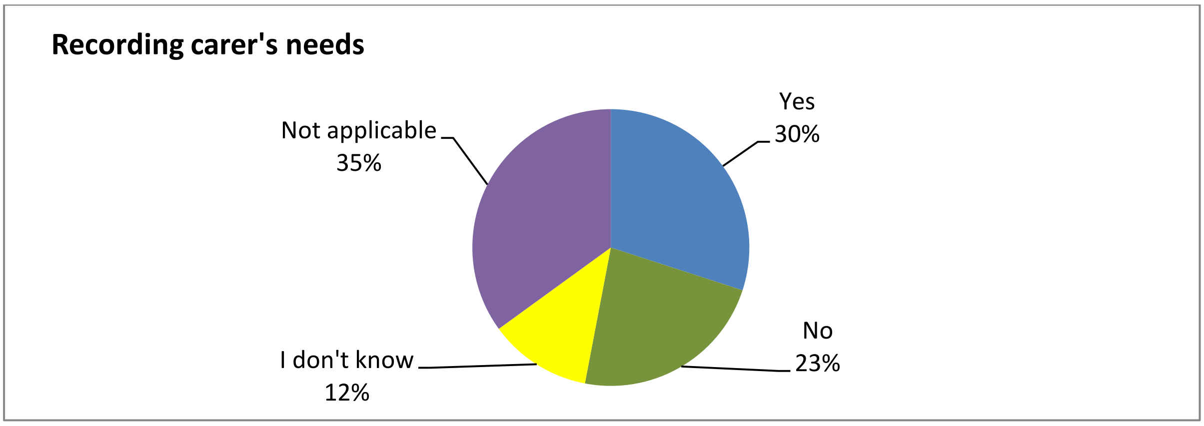
One parent comments *'I didn't even know that I was entitled to an assessment and no professional has ever even suggested that we need a social care plan for my son. Everyone seems to just assume that I will do everything!'*

The impact of not getting an assessment for the carer and the child is enormous, *'not being able to even access a carers assessment as fall between gaps in services. My child has significant additional needs (dx developmental trauma), I'm her sole carer, live a very restricted and isolated life and receive no support'*

The Children and Families Act 2014 introduced the right for carers and their families to have an assessment so to focus on prevention and move away from providing support and services at point of crisis. By ignoring the positive impact of preventative intervention parent carers have to deal with emergency after emergency as illustrated by one of our respondents in this case talking about health and education services assessment rather than social care, *'I think the Seaside View and CAMHS service needs to be improved and doctors need to listen to parents and send them for assessments at an earlier stage in life.* ***I knew my son had some difficulties from a very young age and asked the doctor for an assessment.*** *I was told he was too young and he wouldn't be assessed until he was 5-6years old! At school he struggled and I pushed from reception for him to be assessed. It was only when he started falling behind at school that they sent him for an assessment. He struggled for 3 years and was punished for his lack of concentration and inability to take things in with no support. I finally managed to get him assessed in year 3 and after 1-1 support and different strategies of learning put in place for my son that he was more able to learn.* ***His assessment has taken a long time, we are finally waiting for our last appointment with a psychologist at CAMHS to confirm that he has ADHD and ADD . We were told there is an 8month waiting list for this! That is too long for a child and parent that are struggling to learn and get more support. I will not get any proper help until I have this diagnosis****. In fact the only help I have had is from you fantastic people at Amaze that gave me a Compass Card, it helps a lot with days out and keeping my very active child busy at an affordable rate'*

5.3 Asking and recording carer's needs

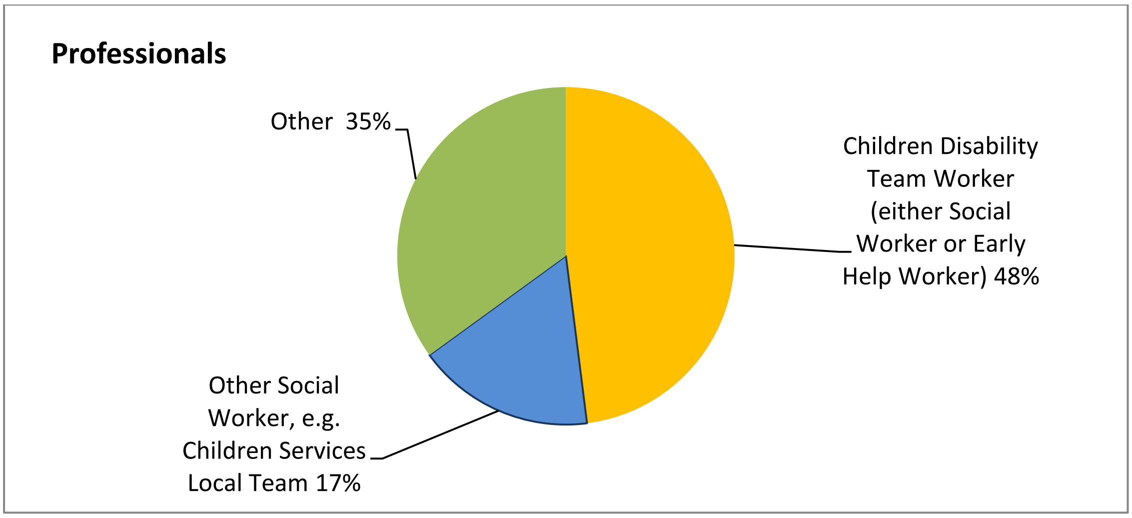
In order to explore in depth the previous findings we asked our parent carers *'If you answered yes to Question 2, did that include asking about and recording your needs as a carer?'* Respondents told us:



The Children and Families Act 2014 requires every assessment of a carer's needs that has been carried out to be recorded and written in to a document. The findings above indicate that only 30% of assessments carried out follow that procedure clearly. Where there has been a holistic assessment of a family that includes a disabled child, the parent carer's needs may well have been considered and assessed but it appears that this is not recorded such that the parent is aware of this.

5.4 Who carried out the assessment

Carers' needs assessments should be carried out by a professional, so we asked parents *'If you replied yes to Question 1,2 or 3 who carried out the assessment?'* Respondents told us:

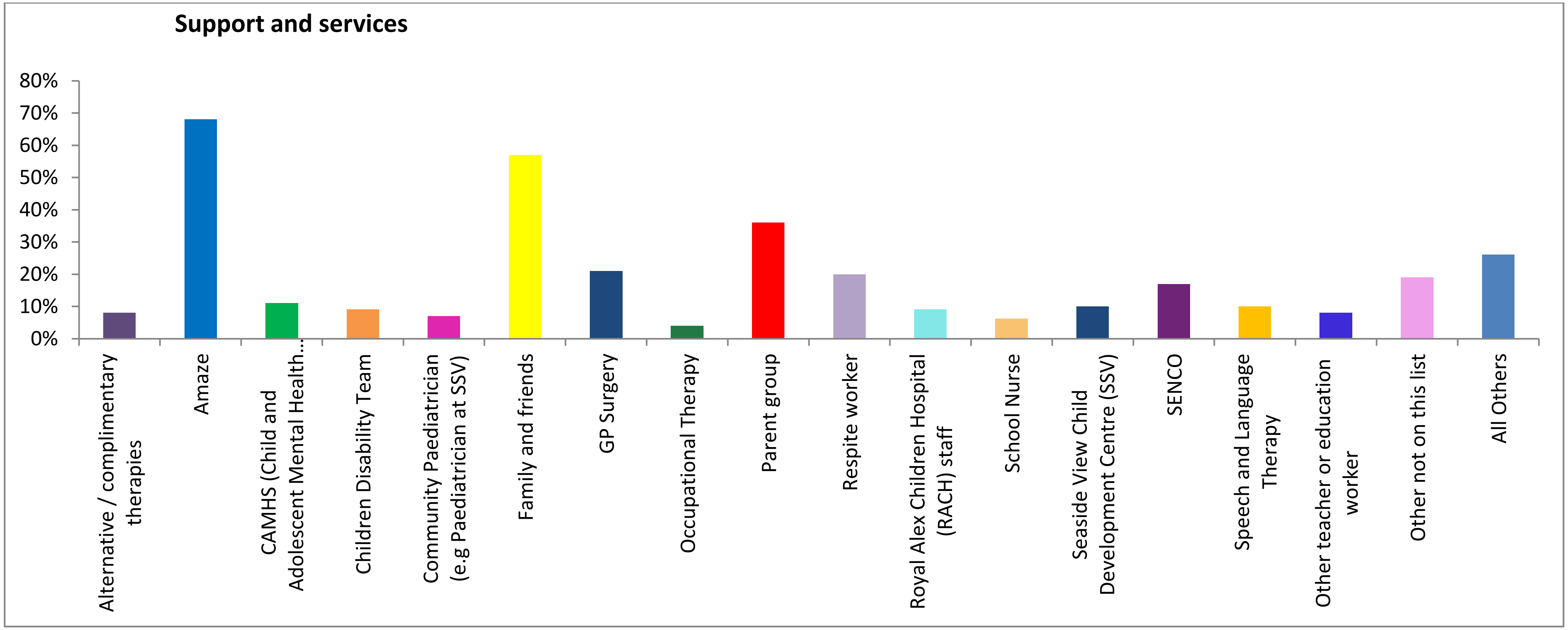


Children Disability Team is the most reported service that carried out the assessment, and that is the case in **48% of those who received one.** This is to be expected as Childrens Disability Team workers would carry out the social care assessments of the disabled children who meet their criteria, which is the most likely group of respondents to be able to identify that they have had a social care assessment. However a parent commented, *'under resourcing of Children's disability team and the short breaks service - both are at crisis point and this causes us extreme worry and stress'*

Other professionals included Adult Services, Adult Social Care Team, Brighton & Hove Inclusion Support Service (BHISS) family worker, Seaside View Social Worker (presumably in fact from the Childrens Disability Team), Adult Disability Social Worker, Adult Social Care and Transition Worker.

5.5 Support and services already in place

With this question we wanted to find out which services parent carers, not their child and/or young person, are currently receiving. To the multiple choices question *'What support and/or services already support you as a carer?'* respondents told us:



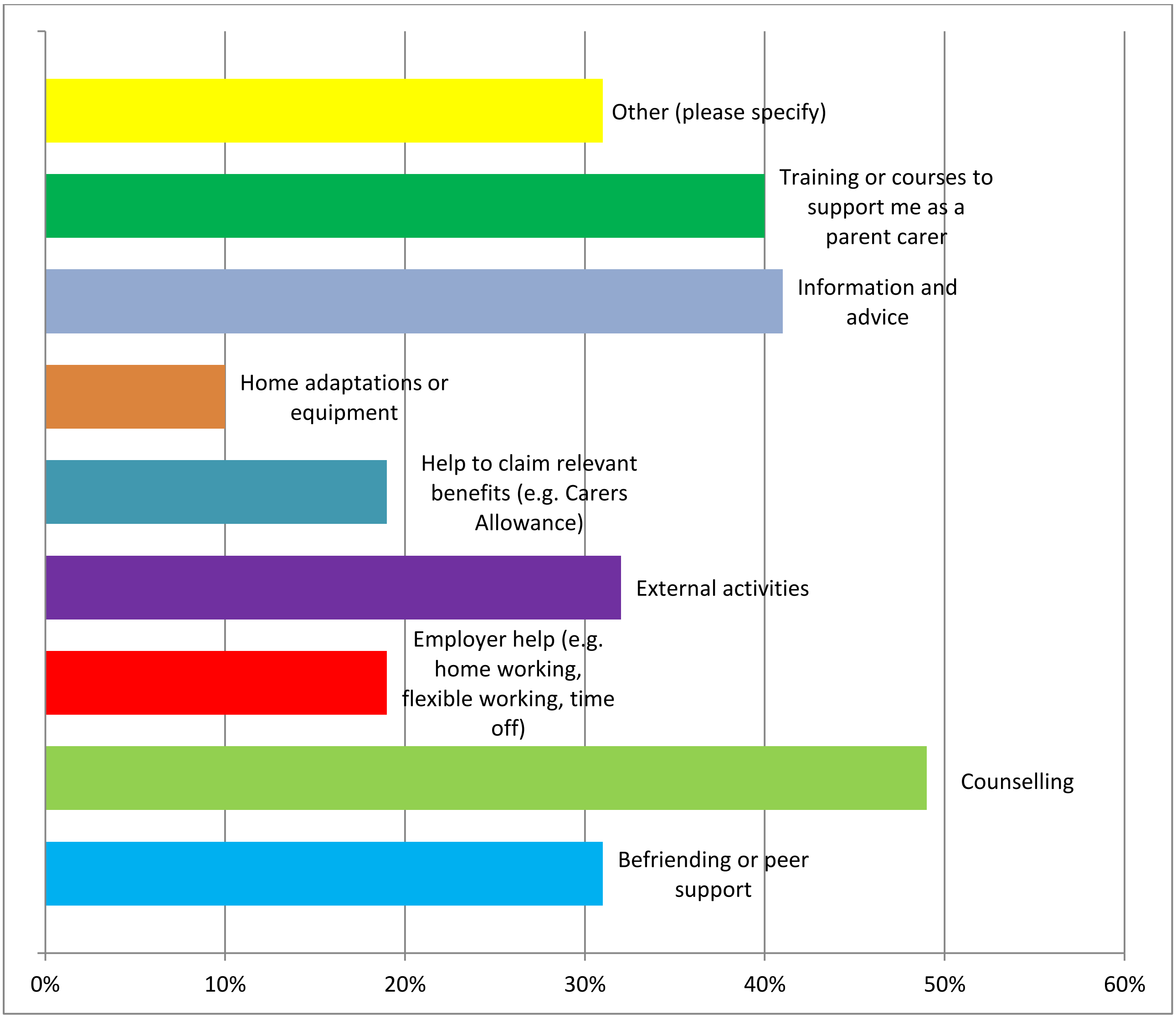
Our respondents reported to access support and services from **a great number of organisations and/or people**. Interestingly the organisations which seemed to provide most of the help, support and advice are from the voluntary sector/charities/community groups, as for example **Amaze which 68% of respondents** mentioned, **or parent groups, for example mASCot, T21, Brighton Pebbles, Face2Face (now also part of Amaze) indicated by 37% of respondents**. Many **parent carers, 57% are supported by family and friends**, whilst **20% report accessing support through respite organisations/workers, as for example Extratime, Barnardos, Crossroads and PAs.**

Among organisations from the public sector, intended here as those organisations that are owned and operated by the government and exist to provide services for its citizens, parent carers report receiving different forms of support from their **GP, 21% of respondents**, **SENCO, 17%, CAMHS, 11%, and Seaside View, Children Disability Team, RACH and Speech and Language Therapy supported by approx.10% of respondents.**

For a full list of organisations and people please see *Annex 7: CCG Carers Assessment Survey - Sharedexplore - Public-view.*

5.6 Support and service needed

Aware that many parent carers tell us they are not receiving enough, or not at all, support and services, we wanted to hear from them what they would like more of. To the multiple choices question *'What do you need more of to help and support you in your caring role?'* respondents told us:



Parent carers want to be able to access **counselling**, in fact **nearly half of the respondents mentioned it**. Counselling is one way to support and sustain parent carer's wellbeing and the child/young person's welfare, however it is clear that families crave for more, a respondent noted the '*Inability to now be referred to CAMHS since new system has been put in place.* ***Unbelievable waiting time to access basic counselling*** *(even though something more is needed) for children with serious issues'* A parent commented, *'knowing how to access* ***free or affordable counselling*** *to process the ongoing difficulties'* whilst another respondent added '*caring for two children, one with Tourette's Syndrome and one with Crones Disease, leaves me* ***exhausted and sometimes depressed. I would appreciate counselling or even a person i could email for support'***

A carers assessment, when carried out, focuses on the family as a whole, , including siblings, *'**sibling support** – our son needs counselling and support due to the impact on his life through worry about his sister (who has autism)'*

More information and advice was requested by 41% of parent carers who completed our questionnaire, '*knowledge about what services are available. I had no idea about the services in previous question'* and another parent suggesting *'more information about how to meet my child's changing needs. More training and more information on where to get help'* This is very important taking in to consideration the aim of the assessment which is to provide advice and information to what's available, including support and services from local voluntary organisations. One of our parent suggested *'named 'go to' person (just one!) to help find info/offer support/ideas. Helping with my mental health – made redundant from a very fulfilling job. Now due to problems at school, have to apply for Carer's Allowance as cannot commit to another PAYE job at present'.* Amaze is currently jointly commissioned by the Local Authority and the B&H CCG to provide an information, advice and support service to parent carers but parents usually have to wait to be called back from their helpline service and case work support is only offered to the most vulnerable families. So despite 68% of respondents saying they had been supported by Amaze, it's clear they feel more is needed.

40% of respondents would like more training or courses to support them as carers, and not only but also *'better training in mainstream schools (teaching assistants and teachers) to help the inclusion of SEND children'.* In the past Amaze has been funded by the Local Authority to provide some parent carer training courses, but their funding has ceased. This financial year the CCG is funding some 'Insider's Guide' courses which aim to build to resilience and knowledge of parent carers but we know demand for more courses and workshops is high.

External activities and respite would help many families to be able to cope better, and **32% parent carers would like to be able to access it** or benefit from it more often. Some respondents see respite as essential - a lifeline, *'not being isolated from society. Getting more help, as night respite or short break (3-5 days). I am a single mother with no family in England. I had my break for 4 days only (2016) once for last 11 years. It was my relief, when I came back after 4 days holidays I felt much better emotionally and physically. It will be great to have a grant or funding for me to do it again, so I can pay a PA to stay in my house with my child while I can go away. I dream about it again'*

Many parent carers rely on and access support from community and/or voluntary groups which provide **befriending or peer support** – see section 5.5 on 'support and services already in place'. For many parents who feel isolated one of the positive outcomes of meeting people who share the same experiences and challenges is to feel they 'are not the only one’. One respondent comments: *‘network of parents I got to know in various setting with similar children’.* **A third of respondents to our online questionnaire would like to see more befriending and peer support**, *‘befriending would have been really helpful when the children were younger’.*

Impact on caring for a child with disabilities and/or additional needs is felt on many levels, as a parent describes *‘long term extreme stress and drains on my time and energy, plus having to deal with stuff I find especially difficult means I am barely managing to provide the basic for my daughters with ASC, for whom I have always provided exceptional care and engagement in the past, including fun activities and social connections. Concerned now for my mental health (stress, insomnia, memory loss, physical symptoms, overload) and the fact I can’t quite get it together for basics such as food shopping and dealing with admin at the moment. I’m in financial difficulty and yet end up having to get takeaways to feed my daughter (e.g. fish & chips, pizza). I need help to sort my life out, some troubleshooting, practical help and bills reduction, and then put some new helpful structures in place. Stop this downward trajectory’.*

Befriending and peer support are invaluable as they provide an opportunity for parent carers to meet and talk to other parents who have been there and also find out more about services available in the city. A parent suggested making **support groups more accessible by expanding time and days when they take place**, ‘*all support groups/ coffee mornings etc. run whilst I'm at work so I can't attend. Can feel a little isolating at times; feel as if I'm not learning as much as I could to support my child’*

Some respondents to our consultation would like **more opportunities for their child and/or young person to be able to also access befriending and peer support**, *‘my son to access the community, social groups with appropriate peers, friends. Getting regular time off for me from caring’*

Many reports highlight the fact that looking after a child with disabilities and/or additional needs means that parents are not able to work full time or at all. As such, many families experience poverty which is also exacerbated by recent changes to the benefits system. **19% or parent carers** who participated in our online survey **suggested better (flexible) employment opportunities** and **more help to claim relevant benefits would be helpful**.

A parent observed, *‘I'm worried that my son won't get an EHCP* (Education Health Care Plan) *that secures help for some years. I'm sad that I've made the decision to leave my job because after school childcare at my school would require a 1:1 TA. When I add up parking costs, fuel costs and additional childcare, it's not worth going to work. I worry that my daughter misses out on time with me because her brother needs so much supervision’*

Parents are worried that the new benefits system will further deteriorate their economic situation and as a result have an impact on their mental health, one respondent summarises their own scenario, *‘transition to universal credit coming soon, child’s PIP under review, other youngest child on low rate DLA for medical condition, worried about possible return to work place/finances/ just diagnosed with moderate depression’*

In addition to poverty some families are at the forefront of the housing crisis, a parent commented, *‘permanent housing in a house. Our temporary accommodation is in a flat with no garden. With a child that is easily distracted by noise and has bundles of energy we need* *a quiet home and a garden to burn off energy. We also need stability and to settle, we can't do this when we are in temporary accommodation'.* Housing shortage means that some families live in crowded or unsatisfactory accommodation, a parent suggests: *'getting a house with an extra bedroom because of difficulties with sharing bedroom and an upstairs toilet'.* **Home adaptations** were mentioned by 10% or parent who completed our questionnaire.

5.7 Other pressing and important issues

With the final question *'What are the most pressing and important issues that you would like to see improved or are you worried about? This could be about services/support for you as a carer or for the child/young person you care for'* we wanted to hear from our families which issues were most important from them.

Responses have been used throughout this report as and when it was felt they were relevant. In addition to the support and services listed on section 5.6, respondents to our survey also talked about other issues and made some suggestions on how improve their quality of life, for themselves and their families.

Some families would like **a different approach to the way services and support is provided to them**. One parent remarks that, *'It seems that once you have a diagnosis and have been registered as a carer you are just left to it. No-one checks up to see if you/child are OK. You are in the system e.g. the doctors surgery knows but there is no **proactive follow up, reassurance or check-up'***

Many parent carers report **a system that reacts to crisis instead of preventing them,** a system that instead of resolving problems, it creates a series of additional issues. The following comment summarises others collated by our survey, *'there are no services to support carers unless you are at breaking point. I have been told that as we cope as a family we can't access any additional support. Services wait until families are in crisis and then offer support which is hard to access and slow to arrive. This puts pressure on services as rather than preventative intervention all services are accessed on an urgency basis. I get support from my son's school and from parents and I volunteer at a group set up to support parents of children with ASC. My son's **speech and language support is non-existent** and we have been told we won't receive any **OT support** for him unless we pay for it privately. I would suggest **a yearly check-up clinic for parents with children with disabilities which could be attended by multiple parents where concerns can be discussed and where parents can be signposted or referred to any appropriate support groups.** I would also suggest that speech and language support for children is impossible to get yet if my son is still non-verbal as an adult **this will cost more** in terms of support as an adult than if he were able to function in the community with some language**. I would advise there needs to be some longer planning as there is in other areas of the NHS and investment in preventative support for parents'***

Families who have children on the Autistic spectrum would like more support to be provided once the assessment is carried out, a parent noted, *'total lack of support for our child between stages 1 and stage 2 ASC assessments. Identifying a child has Autistic traits, coupled with severe anxiety, and only offering a stage 2 diagnostic assessment with no* *interim support is a failure of care. It is neglect, if not child abuse, to identify a child has severe needs and do nothing to help that child or family. Our child broke down.* ***This was entirely predictable given his identified needs that were unsupported'***

To avert the above many respondents suggest **a check-up system** whereby a family's needs are regularly monitored, *'all families who receive a diagnosis of autism for their child, especially those in mainstream education need practical support at home and respite not just training courses for parenting. We need checking in from SSV or CAMHS to see that we are ok; most of us only ask for help at crisis points because it's only then that service involvement is triggered and even then it's not always offered or is patchy.* ***Lead professional to keep in touch with families to check they are managing before crises occur. Buddy scheme for more able ASC children to access activities without their parents always having to supervise and manage their independence. Sessions for ASC children around issues that affect them e.g. managing friendships, bullying, independent travel, careers advice.'***

We could have included the need of more **respite** under some of the support and service listed on section '5.6 Support and service needed', however as many of the comments from our online survey pointed at the importance and lifeline implications of it, we decided to have a specific paragraph for respite, see below. In addition PaCC will be issuing an updated PaCC Position Statement on the Brighton and Hove budget 2018/2019 stating the necessity to remove all planned savings to short breaks budgets which will be available here http://paccbrighton.org.uk/what-we-do/pacc-position-statements/.

Whilst some parent carers and their children benefit enormously from the opportunities offered already, many would like to be able to access more short breaks: *'PAs PAs PAs More holiday club time at Extratime'* and also *'respite and help for ASD meltdowns'*

Some parents lament the limited offer, *'there's a lot of talk and promises when a child is born and found to have disabilities but a few years down the line very little support is offered to parents. Most importantly respite to free parents for a 24/7 caring role. Also the quantity of this is care is important such as 3 hours from Crossroads really doesn't meet the needs of a carer. Respite centres have long waiting lists and usually only take terminally ill children. Severely disabled don't seem to count. Childcare providers are struggling to meet the needs and staff aren't always willing to take a role of a one to one. It took us over a year to find a nursery for my daughter.* ***More trained staff to work with children would really help in day care settings or agencies such as Crossroads'***

Other parents worry about the ongoing demands of caring and what the future holds for them and their young person, *'it gets harder not easier as they get older. Less time in school /education, dread what is beyond. No help outside term time with transport /activities. No time for myself, always on call. Very isolating stressful and exhausting.* ***Need reliable help getting to from activities. Befriended /buddy scheme with competent adult not just a willing 6th former. To take out for a few hours. Transport training. Cookery training. Many courses run over school college time &/or can't get to them. Proper work experience opportunities'*** **Transition** was mentioned by many parents. '*I worry about the future for my children and how services will support them into adulthood'*

Some respondents ask for a better provision of **educational setting and improved communication between health professionals**, a parent explains, *'the issues that increase my stress and negatively impact on my wellbeing as a main informal carer for my son include: Lack of support for children at primary school with a SEN and cuts to the numbers of TA's working in schools. Lack of empathy/understanding from teachers in both primary and secondary towards children with a SEN. Seaside View/The Alex & G.P surgery - general lack of coordination/communication between health professionals, no-one taking a holistic approach encompassing both SEN & health needs. The high thresholds needed to be provided with an EHCP and the ongoing parental monitoring required to ensure it is followed within educational setting.*

Consistent communication and support both at primary and secondary schools could reduce stress level for parent and child, *'better understanding from schools. All staff are well meaning and supportive, but there is a lack of true understanding. They see a child who appears to cope, but doesn't feel at all comfortable and so skips school far too often. The effect is stressful for us both. I should maybe step up my level of communication with them but have struggled to do that at secondary school (the situation was very different at primary...with the daily contact)* ***I would like to see a school system where a child (with ADHD) can be themselves and not have to conform to a system that makes them feel uncomfortable. I know that's a big ask! and things happen in baby steps'***

The ongoing reduction of services available is felt by the families and compensated by **charity voluntary sector organisations**, *'having services cut from my child's school like her INA* (Individual Needs Assistant)*. I feel that because my daughter's diagnosis was in 2016, during a time of change for BHISS that I was forgotten about. I was seen by a specialist health visitor once and never again. Any other support I tried to get usually came with an 8 month waiting list. There's just no help out there for the parents. Especially if you have a more high functioning child. The only support services I know of now are provided by charities like Amaze. ASC is so broad the support needs to be specific and gender needs to be a focus.'*

As mentioned above, Amaze is currently jointly commissioned by the Local Authority and the B&H CCG to provide information, advice and support service to parent carers. **Nevertheless one parent suggested more advice and support should be provided by professionals from the public sector**, *'we have an 18 year old daughter who has learning delay. She goes by taxi to Sussex Downs College in Lewes by taxi. She has not made any friends. She won't go out on her own and won't be left in the house on her own. Our worry is, how as parents do we support her to become more independent, also* ***what professionals to we turn to for advice and support?'***

If a parent carer's wellbeing and child/young person welfare are at the centre of the assessment then **provision of mental health services needs to change** too. One parent says: *'CAMHS – is a disaster happening or waiting to happen.* ***All roads lead there and yet there is such enormous underfunding*** *that they place themselves in adversarial relationships with parents in order to force them off the lists. Also, kids being forced out of education in to home schooling to save money - so unsupported, isolated and without MH support'*

Many respondents point out that **receiving support when they are at breaking point is not acceptable**, again our families would like a system that prevents instead of ‘reacts’. One parent suggests, *‘CAMHS seems to help only in a crisis; they are too slow to respond in giving support to stop the situation deteriorating.* ***I would like to see at least annual visits to the school by the health professional to check the right support is in place and to advise school workers. I would like to see talking therapies available for my son****, the voluntary provision has disappeared. I do not trust using private therapists with my child's wellbeing. I would even be happy to make means tested contribution to future provision of this service’*

Stress and isolation can be prevented by providing support and advice when it’s needed. Proper carer’s assessment or better, whole family’s assessment could prevent that. The assessment needs to be ‘an opportunity for the carer to tell a professional what services what need to receive so that looking after their child and/or young person is made easier’, otherwise parents will feel that, *‘when you have to organise all the support for yourself - through PA's etc - it's really difficult sometimes. It's also hard to find PAs sometimes - we're OK at the moment, but there's always back of my mind anxiety about it. Thinking about the future worries me. Health professionals with their own agenda (I'm sure with the best of intentions) foisting their own worries onto me is a HUGE issue - when I see so many of them and they are all concerned their own pet things, and highlighting potential issues in their own areas - I see the whole picture and I already have enough to worry about without worrying about the "what ifs" and "why don't we just do a set of health investigations into this" when it's totally unnecessary - and then they say things like "oh don't you want my help?" and I feel like I have to say "of course" otherwise it might get taken out on my daughter - or what's happened twice now "you know she could DIE if there is a problem and we haven't uncovered it?" for god's sake it's just inventing more problems and issues where there aren't any and making us feel like we're bad parents if we don't do as they say... e.g. "how is she?" "she has a cough. we've spoken to doctors about it and she is having medicine" "she shouldn't be having a cough this long" "yes, which is why we've seen doctors about it and she is taking medicine" "we need to investigate further, I'm making a referral to [whoever]" "it's under control, she has seen 2 doctors" "are you telling me not to? because she could die." "no no, I'm not saying not to, if you think that's really necessary" "yes she's going to have blood tests and referral to specialists and hospital therapists and [bla bla]". This happened last week. Profoundly disempowering and quite frankly, bullying’.*

6. Recommendations

- **It is clarified which parent carers are likely to have their needs assessed, how often, and by whom and for this detail to be promoted on the Local Offer**

- **We ask that all professionals using the SFA are identifying if there is a carer in the family and include their needs of carers in their assessments as the Children Disability Team (CDT) say they do at Seaside View**

- **CDT to improve their communication with carers to explain that their needs are being assessed as part of the SFA**

- **The Local Authority to clarify the aims of undertaking a formal carers' needs assessment to both professionals and families including all carer's needs to be taken into consideration and for the assessment to be recorded**

- **The Local Authority and CCG to make sure that professionals and organisations which provide carers assessments and follow on services are financially supported and their funding is ring-fenced**

- **Secured, ongoing financial support to those charities and voluntary organisations which provide support and advice to carers and their families – including more investment in information and advice as well as cost effective befriending/peer support, support groups etc. that draw on the use of volunteers.**

- **Increased investment in the provision of counselling services for carers and their families**

- **Carers to be provided with more information on what's available locally through various media including the Local Offer website**

- **More training to be offered to carers, e.g. how to better support their child/young person and themselves and to mainstream schools staff, teaching assistants and teachers, to help the inclusion of SEND children**

- **Reversal of current policy of budget cuts on critical (preventative) services so that more short breaks and other social/group activities are made available**

- **Recommendations and suggestions from this report are used to feedback on the Brighton and Hove CCG 'Caring Together Care Programme – Preventative Services & Community Care' (Ca-To)**

  This consultation was carried out in partnership with the Carers Centre for Brighton and Hove. It explored the needs of parent carers and carers of adults and if/how these are being identified by means of an assessment. In addition to this report a table collating recommendations from Amaze and Pacc and The Carers Centre for Brighton and Hove will be circulated.

7. Annexes

Annex 1: How Amaze and PaCC engage with parent carers
Annex 2: Mental Wellbeing Survey Results for Report
Annex 3: Forgotten Isolation Report
Annex 4: Out of Amaze Oct 15
Annex 5: Caring More Than Most
Annex 6: CCG Carers Assessment Survey
Annex 7: CCG Carers Assessment Survey – Report
Annex 8: Carers Assessment Survey - comments