



How Brighton & Hove Community and Voluntary Sector supports parent carers' mental health and wellbeing – May 2016

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

1.2 What PaCC does

The Parent Carers Council (PaCC), hosted by Amaze, is a city-wide engagement group with over 286 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs. PaCC also has 8 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 to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve health, social care and education services for disabled children.

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 the termly newsletter and through social media.

2. Wellbeing Service, Community & Voluntary Sector and parent carers

By April 2017 B&H CCG will have completed the re-commissioning of primary care services which support adults who experience mental health problems; one of those services is the Improving Access to Psychological Therapies (IAPT). The IAPT service supports adults with mild or moderate mental health problems who are registered with a Brighton and Hove GPs. The service treats patients experiencing common mental health disorders such as depression, panic disorder, generalized anxiety disorder, simple phobias, post-traumatic stress disorder, health anxiety, social phobia, body dysmorphic disorder and obsessive compulsive disorder.

To inform the re-commissioning, the local CCG asked Amaze and PaCC to consult with PaCC partners and Amaze expertise on what sort of services and activities they provide which directly or indirectly improve parent carers' mental health and wellbeing.

Information and suggestions from the consultation is going to contribute to a better provision and organisation of wellbeing services in Brighton and Hove, including professionals been more aware of what's available in the city and more confident on how to access services provided by those organisations (*See Annex 2: Reaching traditionally excluded communities*).

Amaze and PaCC annual surveys, which focus in part on the impact of caring for child with a disability, special or additional needs on the mental health of his/her parent carer, highlight the fact that caring for a disabled child puts incredible strain on the mental health of parent carers.

Analysis of our parent carer surveys received during 2015/16 showed that 69% of parent carers report that they have experienced physical or mental ill-health as a result of their caring role (*See Annex 3: Amaze Parent Survey 2015*). In a more in depth analysis in 2013 we found:

- 22% of parent carers responding to our survey told us they hadn't had a single day or even an evening off from caring in over 6 months. **14% have never had an evening off from their caring role.** This increases to 36% who have never had a weekend off and 58% who have never had a full week's break from caring.
- **71% of parent carers feel that they don't look after themselves well enough or are in fact neglecting themselves. This increases to 85% if the parent has disabilities or additional needs.** The corresponding figure for carers of adults ('Caring for Others' survey) was 42%.
- 27% of parent carers felt they had enough time to look after themselves, compared to 58% of carers of adults, and we think the reasons for this should be further investigated but we know that parent carers feel overwhelmed with the needs of their child(ren)/siblings/ partner/household etc. such that their own needs fall off the bottom of the list.
- **86% of parent carers spend none, or not enough, of their time doing things they value and enjoy. 20% feel socially isolated and this increases to 35% if the parent carer has disabilities or additional needs.** A further 53% of parent carers don't get enough social contact.
- **Only 33% of parent carers usually get a good night's sleep, and this drops to 15% if the parent carer has disabilities or additional needs.**

- Given these results, it isn't surprising that **58% of parent carers feel depressed, anxious or stressed some of the time and a further 18% feel that way all or most of the time - this last figure rises to 42% if the parent carer has a disability or additional need** (See *Annex 4: Survey 2013 Analysis Report*).

Our survey in 2011 showed 76% of respondents have experienced mental ill-health as a result of their caring role (See *Annex 5: 2011/2012 parent carer survey analysis report*)

More recently, in April 2014, as part of our ongoing engagement with the local CCG, we ran a consultation on what parent carers thought it was important for their own mental health and wellbeing or for that of their children (See *Annex 6: Mental Health and Wellbeing - views from parent carers of disabled children*). The consultation highlighted the need for more support in form of activities, advice and free or low cost counselling for parent carers and more provision of respite. In addition parent carers' feedback that many Amaze services did indeed support their mental health and wellbeing.

PaCC partners report many gaps in support for parent carers, many of whom are taking medication for depression and anxiety, due to the stresses of their caring role. Parent carers deal with ongoing high levels of stress, caring for medically complex children or those with mental health problems and challenging behaviour. As well as physically caring for their children, parents must coordinate health, social care and educational support and appointments, often while caring for other children and trying to maintain themselves in paid work.

3. Methodology

For this consultation we designed a brief questionnaire which was sent to PaCC partners (See *Annex 7: Voluntary sector, mental health and wellbeing*). We received some feedback from a community allotment and we also looked at a recent evaluation of Compass Card service, one of the services run by Amaze.

4. Findings

4.1 In your role with the group or organisation your work/volunteer with, do you provide/organise any support/service around parent carers' mental wellbeing?

Most of respondents to our consultation provide or organise services which in one way or another support parent carers' who experience mental health problems. Others provide services that aim to prevent the onset of such problems.

One organisation, Extratime supports parent carers by providing **respite for severely disabled and challenging children and young people**. Provision of respite supports parent carers' mental health and wellbeing. A worker from the organisation clarifies: '*In case of concern about the mental health of a parent carer then the staff would suggest that they contact their GP or Amaze for advice and support and if the concerns were more serious they would contact the child's social worker*' (<http://www.extratimebrighton.org.uk/>).

Another organisation, Barnardos provides **short break care** which they see as a key to a parent carers' sense of wellbeing and mental health. Short break care is the cornerstone of their service. Their model of **family-based short breaks** provides a systemic family support intervention. Evaluation and feedback received from parent carers evidences the way in which short break carers skilfully and sensitively support the whole family in so many more ways than simply providing a break. '*Short break carers form helpful*

alliances with parent carers that can be supportive in addressing particular issues in relation to their child, as for example dietary, behavioural, personal care and independence skills. This can help to increase parental wellbeing and reduce potential stressors’.

In addition parent carers benefit from Barnardos’ provision of short break carers and **home support workers** in terms of informal emotional support and thereby contributing to their overall resilience and wellbeing. Parent carers are also supported through the Parent Carer Consultation Group which provides a space in which parent carers are listened to and engaged with and their voice embedded in the service.

(<http://www.barnardos.org.uk/fosteringandadoption/fostering.htm>)

A Befriending service for parent carers is offered by the local Face to Face scheme run by Scope. *‘The project has a team of trained volunteers, all parents of disabled children themselves who offer emotional support to parents, particularly around the time of diagnoses’.* The project works with parents who have significant mental health difficulties, who feel low and struggle to come to terms with their child’s disability. Around 60% of parent carers outreached by the project are on anti-depressants. *‘We are clear to define our role, we are not counsellors but we can provide peer support and a listening ear’* (<http://www.scope.org.uk/support/services/befriending/about-face-2-face>)

Brighton Pebbles, a community group, recently run a survey among their families and found out that 42% of respondents reported that they live with mental health issues and 58% stated they were unable to work due to caring commitments. The group runs different activities, for example **monthly lunches** for parents, mainly mums but dads can attend too. These are places where people can get together and chat about anything that’s bothering them or just meet up with friendly people. The group also organises a **sewing and craft group** at their office based at Emmaus, in Portslade. *‘Some of the mums realised that they had a shared love of sewing and so people come together once, twice or three times a week to sew (or do any crafts) and chat to each other. It’s great to have a space to go to, then it isn’t reliant on someone opening up their house and it means that people can drop in when they fancy’.*

In addition Brighton Pebbles run a **carer’s boot camp exercise session weekly**. They hire the hall at the Manor Gym and hire a personal trainer who puts everyone through their paces. The benefits of exercise on mental wellbeing are well documented and they think it’s a great idea to get everyone moving in a fun session. The community group recognises that *‘just being part of a supportive group and going out in a group to day trips and activities is incredibly helpful as you aren’t alone when your child kicks off and everyone helps each other – it helps to build up confidence and self-esteem and helps with the ‘can do’ attitude’* (<http://brightonpebbles.org.uk/>)

Gardening activities are offered by The Magic Garden, a community allotment for parents and carers situated in Hollingdean. People don’t need to have experience or knowledge about gardening and growing vegetables and parent carers can go every week or just drop in when they can. *‘Gardening and growing vegetables is not just good old exercise but is also very beneficial for your mental health and wellbeing. It helps you relax, get some fresh air while meeting other people ... and don’t forget that tasty salad!’* (<http://bhfood.org.uk/the-magic-garden>)

Financial discounts and incentive to children and young people are offered by the Compass Card Brighton and Hove. A recent evaluation of the project brought to light not just the financial aspect of families being able to enjoy leisure activities but also the huge impact on reduction of stress and people’s mental wellbeing: *‘I think the main changes are in terms of mental wellbeing. Having a Compass Card has reduced feelings of*

isolation and increased our sense of pride in seeing our son achieve new things and gain confidence and new friends. On the whole I think the Compass Card has given the whole family much more confidence and a strong sense of feeling part of a community' (See Annex 8: Compass Card Evaluation November 2014 Summary).

The card is issued to all children and young people aged 0 to 25 who are registered on Brighton and Hove's 'children's disability register' which is called The Compass. Amaze manages the disability register or database for Brighton & Hove City Council.

(<http://amazebrighton.org.uk/services-and-support/the-compass-card/what-is-a-compass-card/>)

Amaze's DLA Project uses a team of volunteers to **support families complete the 40-page DLA/PIP benefits application**. An independent evaluation (in 2012) of the project found that (in addition to the obvious financial benefits estimated to be about £3m per year or £8k per family) the service should be considered by commissioners as a highly effective mental health intervention for carers of disabled children as it helps validate their experience and begin to boost and support their resilience and self-esteem, in addition to providing obvious financial benefits. The researcher also concluded further research on the relationship between having additional parent carer responsibilities and poor mental health should be considered with a view to identifying what earlier support could be provided to families to build their resilience and reduce periods of depression, anxiety and stress (See Annex 9: DLA Report).

(<http://amazebrighton.org.uk/services-and-support/advice-brighton-and-hove/help-with-dla-claims/>)

4.2 What do you think is the best way to ensure that professionals working with parent carers' who experience mental ill health are aware of what is available in the voluntary sector and know how to access those support/services?

- To establish a more dual family based approach to adult mental health and caring for a disabled child. This model of greater joint working between adult mental health and Children's Services would offer a more integrated, holistic approach. It has happened but it can be patchy.
- To update and inform professionals about support and service provided by community and voluntary sector. Often if a professional is working with one family who has benefited from those organisations in some way, they can then pass information on to other families. Some organisations do get referrals from a range of local services but there is a need to make sure professionals know about the vast range of parent groups and projects available.
- The 'Local Offer' should hold all the info on all local services for children and young people. It could be very hard for each individual worker to know about every service in the city, and how it might support individual parent carers. Having knowledge of key organisations which can signpost parent carers to the best services would possibly be the most practical route. Amaze's website and Through the Maze handbooks also provide a useful directory that many professionals also find useful.
- Professionals to have community and voluntary sector organisations' leaflets and business cards to give out to parent carers.

4.3 Do you think there are gaps in mental health provision for parent carers' families that the voluntary sector would be well placed to deliver and why do you think the voluntary sector is well placed to offer these services?

- Not all parent carers are part of a parent carer community/support group or are aware of so many groups and communities. The benefit of a parent led group is that they are aware of lots of the issues facing families, because they are in the same position themselves and hence are well placed to deliver services. However more secure statutory funding for community and voluntary sector organisations is needed so that the services offered are less dependent on very uncertain and increasingly competitive grant donations from various places.
- There is a lack of or minimal provision of therapeutic support for the siblings of disabled children and that is a major gap in mental health provision across Brighton and Hove. Whilst generic sibling support groups in schools can be helpful as a first tier of provision, a sibling may need opportunities for more intensive, personalised intervention which could avert more chronic mental health problems from developing in adolescence. For example, Barnardos are piloting a spot purchase therapeutic provision for the sibling of a disabled child using the skills base of their staff and also specialist knowledge of SEND to support the young person, and Amaze recently piloted running a sibs group with money from the Mental Health Innovation fund. This was very well received and demonstrated a large unmet need.
- Some parent carers receive little in terms of respite support. Recent research by Extratime showed a need for twice as many after-school club places per week to meet current demand for this service. Whether the voluntary sector or the statutory sector supports them, somebody needs to do it. Investment in support for parent carers will enable them to better manage their situations and support and care for their children for longer and more effectively. Most parent carers try to 'just get on with their lives', absorbing the stress of caring for their children with little opportunity to think about the impact it is having on them and the implications for their futures. The rate of relationship breakdown in families with disabled children is much higher than for those with 'non-disabled' children. More effective support might enable these families to stay together.
- In some situations, parent carers may be more willing to accept support from voluntary sector organisations as they may have suspicions of statutory services, associating them with children being taken into care or adults being sectioned. We hear from families who are very happy to access the Information, Advice and Support service at Amaze as it is located outside of the council and so is seen wholly independent and impartial. In comparison we hear from families in other local authority areas who don't access the corresponding 'in house' service as they are not considered independent/impartial enough.
- For support to be meaningful and effective it needs to be ongoing, for example a fixed number of counselling sessions may not be enough, and flexible to fit around childcare and work commitments. Voluntary sector organisations may be seen as more flexible and responsive to individual needs. But without secure funding at a reasonable level to support some core costs, these organisations will not be able to provide the required level of service.
- Parents can refer into Seaside View for counselling but only if their child is 'under' Seaside View and many parents aren't but still need support. Parent carers need

more free counselling as a lot of our families are on low incomes that they can access regardless of who is managing their care (CAMHS, the RACH etc.)

- Provision of childcare to parents accessing counselling.
- Parent groups and activities are a brilliant way of improving mental health outcomes for parent carers and more support is needed to ensure these continue. All are run by volunteers, are cheap to deliver and have marked positive mental health outcomes in terms of parents feeling less isolated, better able to cope and more positive about their future.
- Secure funding for more inclusive and discounted leisure activities and partnership working between Amaze and leisure organisations so that activities are targeted and welcoming to families where there are additional needs.

7. Annexes

Annex 1: How Amaze and PaCC engage with parent carers

Annex 2: Reaching traditionally excluded communities

Annex 3: Amaze Parent Survey 2015

Annex 4: Survey 2013 Analysis Report

Annex 5: 2011/2012 parent carer survey analysis report

Annex 6: Mental Health and Wellbeing - views from parent carers of disabled children

Annex 7: Voluntary sector, mental health and wellbeing

Annex 8: Compass Card Evaluation November 2014 Summary

Annex 9: DLA Report