



## *'I go around in circles'*

### **Integrated care for children with special education needs and disabilities (SEND) and their parent carers - June 2014**

---

#### **1. Introduction**

This consultation on integrated care originated from Brighton and Hove City Council (BHCC) and the local Clinical Commissioning Group (CCG) efforts to have a more organised and joined up delivery of health and social care services for the most vulnerable people living in the city, including parent carers of disabled children and young people. The driving force behind it is the 'Better Care' Fund announced by the Government in June 2013 which promotes the development of a system where health and social care system work closely together (<http://tinyurl.com/q9qy3ul>). Brighton and Hove Better Care plan will focus on delivering integrated care to people who are 'frail', not just elderly people but also people with complex health needs, people who are homeless, carers and children and young people with special education needs (see Annex 1).

The aim of integrated care is to have a holistic approach to people's care needs by placing people at the centre of their own care plan. The vision is to have services delivered to those individuals who have multiple or complex needs in the community and in people's home; services which will be flexible and offer more choice. A direct effect of this new strategy will be a more person centred services with less demand on A&E, admissions to hospitals.

Amaze and PaCC work closely with BHCC, for example some our staff and Parent Reps sit on strategic boards and groups across the city. We are also one of the local CCG's 'Engagement Gateways' where our role is to consult parents and carers of children and young people who have additional needs or disabilities on different health care issues. Our work enables parent carers' suggestions and ideas to be taken in to consideration when health services are planned and commissioned for their children with special educational needs and disabilities or them as carers.

We are aware that parent carers and their children need advice or support from a number of different professionals and organisations. Integrated working means that all professionals involved with providing care should work together as one team to give families the support they need. For example at Seaside View Child Development Centre there is an integrated disability team which provide support to children and young people with special educational needs and disabilities co-locating health and social care services for some.

We also believe that a parent carer's experience of services cannot be understood in a vacuum but it has to take in to consideration and constantly refers to the role of caring for a disabled child or young person. Caring for disabled children makes demands on families over and above those usually expected of other families. On 2013 Amaze carried out a survey of parent carers in Brighton and Hove which highlighted the extra demands of caring for disabled children when adequate support and resources are not provided. A staggering 66% of respondents said they provided 20 or more extra hours a week over and above their usual parenting duties and 15% said it was 100 hours or more (see Annex 2).

Caring for disabled children has an impact on parent carers. The Contact a Family report 'Forgotten Families' pointed out that carers are twice as likely to suffer ill-health as those not providing care. More specifically the report revealed that:

- 72% of parent carers experience poor mental health such as anxiety, depression or breakdown,
- 65% feel isolated frequently or all the time,

- 56% reported that the cause of their isolation is due to lack of support from statutory services,
- 54% say that not having the time or money to do things that other families do makes them feel isolated,
- 49% reported feeling so unwell that they have asked their GP for medication or to see a counsellor,
- 21% say that isolation has led to a break up of their families or marriage (see Annex 3).

Both reports revealed the fact that parent carers are particularly vulnerable to poor health outcomes, as one of the respondent to our consultation pointed out: 'Our problems stem from the complexity of our son's needs.'

## 2. Methodology

This consultation was carried out by online survey and a small focus group. Some data from previous consultations and reports carried out by Amaze and PaCC are also included.

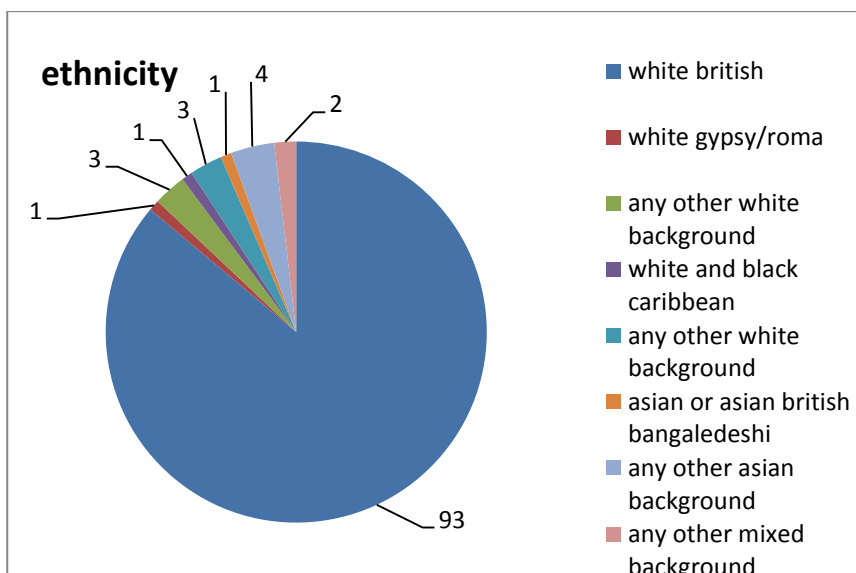
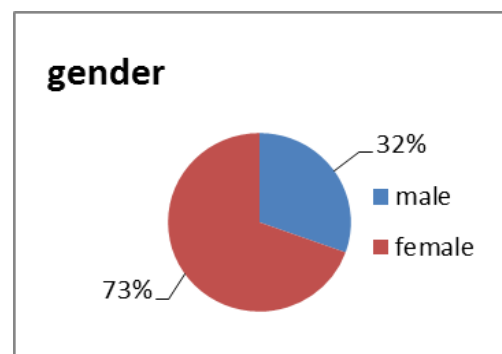
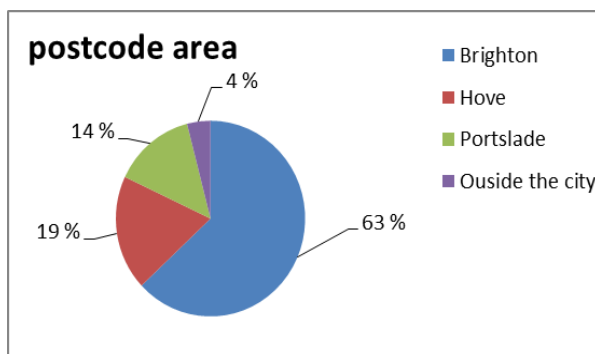
The CCG provided us with some standard questions which we adapted to better suit parent carers' experience and knowledge. We looked into parent carers' experience of accessing multiple services and asked for their feedback on:

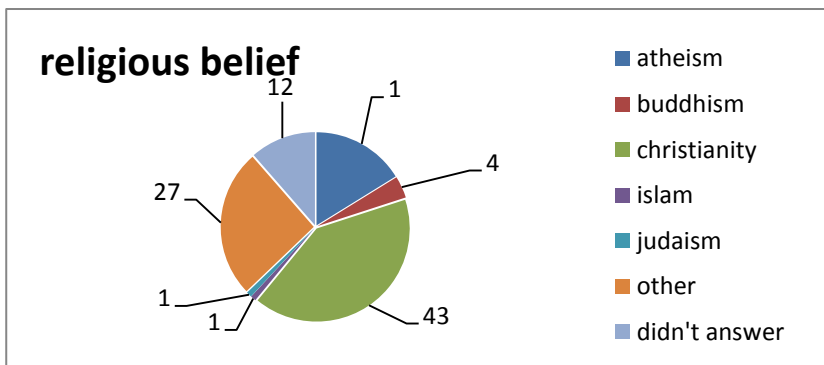
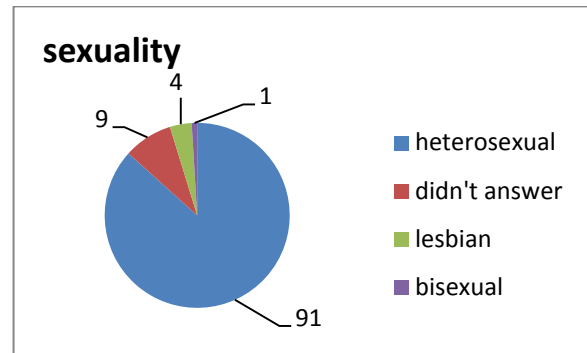
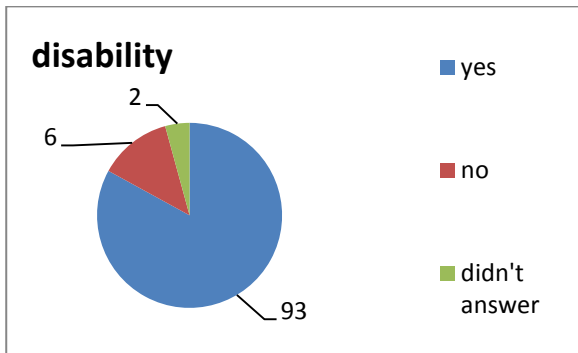
- What worked well?
- What didn't work so well?
- What are the problems/barriers to a better integrated health and social care system?

The Summary of Recommendations are organised in a way that refer directly to 'what will be different?' from the BHCC and CCG briefing paper-Better Care plan: integrated care (see Annex 1)

## 3. Demographic

We decided to look in to the needs of parent carers and also young people in the transition group that is 16 years and above who are heading towards adult services.





#### 4. What we found out from our transition survey and our focus group

##### What worked well ...

###### a. information

When asked about **awareness of agencies that provide support and information** for both carers and their children the majority of respondents said that they are aware of agencies providing social care support including organisations which can **signpost** them, as for example Amaze or other community groups.

'Good because Social Worker was excellent & really listened to parents/child to get right level of funding for packages'

'I heard about other services through Amaze' and 'Amaze is a brilliant source of information, advice and support'

Parent carers are very satisfied when **organisations support them or signpost them** to other services/organisations that can help with their needs, which sometimes can be life-savers. Two parents spoke about Local charity Assert that supports adults with ASC and their families. They appreciated the advice and leisure opportunities Assert provides.

Respondents agreed that **community and voluntary groups are a source of information and help**, and very helpful when they work in partnership with others.

The same satisfaction was registered when **main stream services referred parent carers to other organisations**, as for example professionals at Seaside View Child Development Centre were very good at pointing people in the direction of Amaze or further help/advice.

The majority of respondents also reported a good index of **satisfaction in relation to information and support received**. People liked those **services that provide continuity of staff and staff that are dedicated and well-meaning**. A third of respondents were aware of health care organisations.

'Generally we feel well served by the variety of health and education professionals involved and that we can go for advice when we need it'

'We feel well supported with a number of people we can turn to SENCO, SENCO at new college, Teacher of deaf, school careers adviser etc.'

'I had support from other parents from mASCot (a local organisation that support families who have children with an Autistic Spectrum Condition) whose children have moved on'

Respondents benefitted **from information sessions and from printed material** as for example booklets and handbooks. Nearly half of the respondents found out information by themselves while 12% said from other parents carers or friends, 7% from their local school or college, 5% from the Internet and 4% from other agencies.

'Did my own research and planning with the help of the Carer`s Centre'

When attending meetings the majority of carers reported that social and health care were discussed, same percentage mentioned changes to benefits while a third mentioned housing options and leisure activities.

A carer commented that 'It would be too long a meeting if benefit changes, adult health/mental health & leisure discussed, but separate meeting for these would've been good'

#### **b. Particular and knowledgeable staff**

**Getting information, advice and support and signposting** was valued positively when passed on by knowledgeable and professional staff.

'She (the social worker) really knows her stuff'. 'You never feel like she's fobbing you off'. 'She's very calm, you feel like she's on your side, but she's very professional'

'The Adult Social Care Supported Employment team were brilliant though. They signposted us to the benefits adviser who is part of the council's welfare team'

Parent carers reported the **excellent service received from receptionists** who always passed messages on efficiently. Receptionists were also very **welcoming to families and included the children and young people** when they visited the unit. Parent carers praised **friendly and approachable staff** that are very understanding and **had a real grasp of carers and children's difficulties**.

**Key-workers and specialist health visitors**, active at Seaside View, are well received. However they are a very small team of two and many families, who have multiple professionals involved with their child, were left without a key- worker. Key working and key workers are valued as a way to coordinate family support. Through regular contact key workers improve the quality of family life by ensuring quicker access to support and benefits reduce level of stress, and greater empowerment. With changes happening around SEN the situation could get more complicated as many more parent carers will need support to navigate the new system.

A good professional is:

'Someone supportive, with a good knowledge base as an expert, and willingness to build relationship and care and understand. Also they were part of a wider service our family uses, so not working in isolation'

Parent carers like **professionals who are very 'knowledgeable' and 'empathic'**, those who 'go the extra mile' and who 'treat carers as equals' in their child's care. **Good services are those which are very patient centred and those which treat patients as a partner**, not someone to be told what to do.

The majority of respondents are happy when their GP asked regularly how 'their' health was as the main parent carer. **GPs also got involved in much needed referrals** for respite. Parent carers

reported GPs asking if they got enough respite and if they could write letters to support their access to more help.

'My Doctor has been very approachable, understanding and helpful and put me in contact with people to help over the years'

Also GPs provide good support when they know the family and its history. Some parent carers reported that their **GP was very holistic, seeing the family as a whole and gave 'carers' support**. This approach was highly valued and respondents appreciated practices that **de-stigmatise and reduce isolation and include whole family/siblings**.

## What didn't work so well ...?

### a. Eligibility

Our consultation in relation to adult social care pointed out that **only 20% of respondents know about information on what's available and eligibility criteria** while **50% don't know about it**. Only 19% of parent carers report having a clear understanding of the resources that may be available to their child through adult social care.

### b. Lack of joined-up care

Some participants to our consultation commented on the **unsatisfactory support from Social Services when not 'joined up'** and sometimes don't offer what it is needed. It seems that unless seen as 'not coping' the person won't get any help, even when requesting support. Some services don't share information, even when that information is crucial. **Communication between different professionals was often poor**.

Parent carers of disabled children access a great number of services and because of that people become sometimes find the process very confusing:

'Names of things change all the time so confusing, may well have had social care assessment, but who knows!'

'The number of meetings you have to attend, repeating the same thing over and over again. It takes a huge effort providing information to professionals and it begins to feel pointless. If the information provided doesn't lead anywhere, result in something positive happening, if it's not looked at properly or used. You feel 'what's the point?'

'I feel I have no one to talk to or help me and my personal let down is I don't drive so I can't easily get to places that had meetings out of Brighton'

As a result of not joined-up services parent carers find themselves going over the same story again and again which created a sense of frustration and disheartened feeling. Parent carers told us that this can be really irksome. Some noted that taking their child's 'most recent letter' helps but even this didn't totally prevent the repetitive process.

'I go round in circles waiting so much time for meetings/interviews/phone calls'

'Unless your child is extreme need you don't get a look in with Social Services. Then anything we need has to be thought of and dealt with by parent/carer. Unless there are tons of professionals in the equation you're overlooked, not taken seriously. Being able to constantly do this is very hard, depressing. Not much progress'

'Progress has largely been due to my persistence in ensuring the right communication between all services involved so everyone had the correct information'

### c. Information, contact and feedback

One respondent comment highlights the need of proper information and advice: 'Problem is less advice or lack of it than the limitation of options available'

For parent carers who have to attend so many meetings to **be kept in the loop and feedback are paramount**, however that is not always the case. Some respondents commented that there have been situations where not proper information was passed on to parent carers who felt left in the dark.

'I have never felt supported either for my child's needs or my own. We have had to fight and struggle alone not just with his condition but also the financial implications'

Sometimes also **professionals are not fully informed on what's out** there for parent carers and their children with special needs or **how to make referrals**. As a result parent carers feel they are not taken seriously unless another organisation acts as advocate for them.

'They didn't explain why they did not give this to us. They keep you in the dark. It was a really bad, horrible experience. I think because I'm not from this country they don't take me seriously. I don't think they treat everyone fairly. They never listened to me unless I had the support from Amaze'

Another respondent commented: 'Matters were further complicated when we didn't hear back from them, they said they sent an email but we never received it. This led to misunderstandings on both sides'

After sitting through yet another meeting with a professional a parent commented: 'I never heard anything back from her'

Some respondents felt that **GPs sometimes lacked knowledge about specialist services**. Parent carers reported having to 'fight' to be referred to specialists or that GPs knew nothing about the variety of specialist services which might be available. Parent carers may find visiting their GP so stressful and demoralising that they avoided taking their young person to their GP.

Some people feel that **GPs they don't recognise how much care and support a parent carer provides to a child or young person with special needs**.

'My GP wasn't helpful when I've been at the end of tether, just told 'keep going', 'doing really well' and 'get on with it'.

### How can problems/barriers to a better integrated health and social care system be overcome?

Respondents would like **a more joined-up support**, for example mental health properly connected to ASC (Autistic Spectrum Condition) assessment in order for people not to be stranded between them with no help from either.

Some respondents would like to see **services that deal with the 'whole'** not just point of crisis 'triggers' as well as more information shared with parent carer.

Some respondents raised the issue of parent carer's needs not been taken enough into consideration. **A dedicated professional who provide ongoing, dedicated support** can make a big difference, and so a service that respond well and they know what's going on and they respect parent carers.

'More recently we've had really good support from Adult Social Care when my son had a mental health crisis. They acted respectfully and quickly. We've been fully involved. She always did what she said she would'

Some respondents pointed out how important is to feel included and informed.

'Professionals that involve parent carers and keep to their promises are good'

Parent carers would like to access **services that take in to consideration, and include the whole family**. For example a respondent commented on the transition stage:

'To have a truly person-centred plan, a holistic approach to keep everything in people's minds  
A proper Transition worker, who has the time, can do their job. Someone who is really there who responds to things in a timely way'

**Clear and easy to understand information** would be very beneficial and so **more feedback**:

'To provide easily accessible information about provision. Don't keep people in the dark.  
More transparency'

More **awareness is needed for help and support services that are available**. Some respondents suggested that professionals should have a comprehensive understanding of disability and the issues families face and that they need to be deeply empathetic. **Parent journey training** which are taken up by some professionals should be made mandatory for all professionals, including consultants. This would greatly improve communication between health professionals and families and reduce complaints.

'Informed professionals aware of the problems faced by the whole family'

**Communication needs to be improved between the multitude of professionals and parent carers should be routinely copied in to any correspondence** and should be routinely given details of eligibility criteria and waiting times. Some parent carers are happy to receive information via website; however there is a need to take in to consideration access to online technology by some people and not others. In those cases leaflets and booklets would be more appropriate. The majority of parent carers prefer to speak to someone who is knowledgeable can pass on the right information and signpost.

As many parent carers of disabled children and young people have to rely on extra financial support - it costs three times more to bring up a disabled child - some respondents highlighted how important is to **ensure families with disabled children are accessing all the right benefits**.

'Nationally about half of those eligible don't claim DLA. Could the CCG consider providing some financial support to Amaze's very successful DLA project which supports families'

Many respondents emphasised **the need for increased community support throughout health services**. For example, a specialist paediatric epilepsy nurse would be cost effective in the long run, reducing stays in hospital and greatly reducing stress levels in family members looking after children with very complex epilepsy. Also, the disability liaison nurses in adult services are making a huge difference to the experience of adults with learning difficulties in hospital. The same post for paediatrics would greatly improve the experience of young people and their families in hospital. This would reduce complaints and even reduce hospital stays as this valuable professional can give advice over the phone too.

Another idea to improve communications between services could be like the Disabled Children's Acute & Community Liaison Group who is looking in to improving that by producing an All About Me document that would be carried with the disabled child and their family (see Annex 4).

**Services should 'talk' to each other** more:

'Can Social Care do anything to help NHS staff with their understanding of the issues around transition and what needs to be done to support children in transition?'

Some respondents would like to see **more home visits given routinely to children with disabilities and SEN** who find it difficult to successfully visit the surgery.

More thought must be given to **out of hours GP services** to allow families that have difficulty accessing the services during the day time to go to the GP when the surgery is also less busy.

## 5. Summary of Recommendations

- **What will be different? (see Annex 1 for points 1, 2, 3, 4)**

*1) The community & voluntary sector will play an active role in supporting people to stay well; the independent care sector and the local community and voluntary sector will be encouraged to be active partners in service delivery; more people will be supported in a community setting.*

**Our parent carers value community and voluntary sector support and benefit from mainstream services signposting them to other organisations.**

*2) There will be an emphasis on reabling care, including the use of assistive technology to support people to maximise their independence.*

**Our parent carers would like to receive clear and easy to understand information in order for them to be able to choose what options are best. Use of technology will have to take that in to account.**

*3) Individuals will be empowered to direct & personalise their care and support based on their individual needs; care will be co-ordinated in a single place to ensure service users and carers only need to tell their story once; Care Co-ordinators will take responsibility for active co-ordination of care for the full range of support (from lifestyle support to acute care); service users and their carers will be listened to and drive the model of care.*

**Our parent carers would like to see:**

- **How integrated care relates to children and young people with special educational needs and disabilities**
- **A care system that see the family as a whole and that includes children too**
- **Parent carers to become partners, to be fully involved in finding the best care support which take in to consideration what they would really like to receive**
- **Parent carers and young people to be able to access information on different formats**
- **Provision of, when possible, face-to-face support**
- **A better communication system where parent carers are better informed on what's going to happen next and when**

*4) GP Practices will be at the heart of co-ordinating a person's care with support from a multi-disciplinary team; access to professional support will be available 24/7.*

**Our parent carers think that it would be a good idea to:**

- **Extend the key-working system so that parent carers feel understood and supported**
- **Provide ongoing training on parent carers journey**
- **Create a more joined-up health and social care system**
- **Enable professionals to have knowledge of services available for parent carers or be able to signpost them to the right organisations using the 'Local Offer'**
- **Facilitate cross referral between different agencies and organisations so that children and young people with special educational needs and disabilities and their parent carers receive the best health and social care**
- **Create a working culture where collaboration, share of expertise and best practice becomes the norm**
- **Create a system where GPs or paediatricians act as hub of advice and referrals, as they are the first point of contact, and who share information with other professionals**
- **Provide home visits to children and young people with special educational needs and disabilities so that parent carers and their children can receive a more person-centred care**

Annexes:



- 1) Better Care plan: integrate care Briefing paper
- 2) Analysis of the Amaze Parent Carer Questionnaire July 2013
- 3) Forgotten Families. The impact of isolation on families with disabled children across UK
- 4) This booklet is All About me