



Partnership Outreach Pilot to Parents/Carers (POPP) of Disabled Children Evaluation Report

Contents

	page
1. Introduction	1
2. Project Aims	2
3. Summary of Outcomes/Outputs so far	3
4. What we found out about families with disabled children in these neighbourhoods	4
5. What we found out about outreach work in deprived communities	7
6. Recommendations for funders and the Voluntary and Community Sector	13
7. Appendices	
A. Full Findings from Moulsecoomb	15
B. Full Findings from Hangleton & Knoll	19
C. Full outputs table	23
D. Case Studies	24
E. Background and Pilot Methodology	27
F. Glossary of terms	30
G. Acknowledgements – funders and staff and volunteers involved	31
H. Databridge (OCSI) Report and maps	32
I. Publicity Flyers	36

1. Introduction

Amaze is a city-wide charity working to support parents/carers of children with disabilities and special needs. The charity is subcontracted by Brighton and Hove City Council (BHCC) to manage the city's register of disabled children which they do with considerable success, compared to other local authority areas, as families trust their independence to hold their information confidentially. Families are provided with a discounted leisure (Compass) card and are then hooked into other Amaze services such as telephone helpline, education/benefits/transitions casework, resilience building and parenting skills workshops/training etc.

Despite this success, Amaze estimates it is in regular contact with only 54% of the total population of disabled children and their carers. In order to further understand its reach, sophisticated data analysis was carried out as part of the Databridge project (**see appendix D**) to try to pin point areas of under-representation. Despite Amaze data being able to evidence that it already had significantly higher contact with families in the more deprived wards in the city – namely Moulsecoomb, East Brighton, North Portslade and Hangleton and Knoll- the results indicated there were still many children with disabilities living in these more deprived areas whose parents/carers were not getting

any support from Amaze. Two of the highest ‘undercounts’ were the Moulsecoomb and Knoll estates. As a result of this new insight, Amaze approached the two community development organisations working in those neighbourhoods to see how they could develop a new partnership outreach model to identify new parents/carers, better understand the needs of their disabled children, and better signpost/support them to access the city-wide and local services which were set up to help them.

The Hangleton and Knoll Project is a resident-led Community Development, Youth work and Adult Education Charity operating in the ward of Hangleton and Knoll and has been established for 30 years. This area contains 15,000 people and is made up of two local authority Housing estates and a mix of social and private housing. Super output areas across the ward are identified as in the top 10% nationally when measured on the index of multiple deprivation (IMD). Hangleton and Knoll has high numbers of children living in single parent families and in poverty.

The Trust for Developing Communities (TDC) is a city-wide organisation delivering community development work across Brighton and Hove and Sussex. As well as delivering training, its aim is to support local community groups and develop them to flourish and represent their neighbourhoods in their own right. Moulsecoomb is one of the Trust’s core areas for community development work. With a population of around 3,000 people Moulsecoomb is within the top 5% areas of multiple deprivation nationally, child poverty levels are almost 60% and disability living allowance claimants are double the City’s average.

The approach we followed to deliver the Partnership Outreach Pilot for Parents/Carers (POPP) of disabled children is described in **appendix A-D** but, in brief, comprised door knocking and linking up with existing community groups followed by facilitated coffee mornings with the aim of establishing regular, local, peer support groups. We wanted parents to feel safe, be listened to and get the specialist advice/help they need and become more engaged with local and citywide services.

2. Project Aims

See Appendix E for full background and aims but in summary we hoped that the partnership of a city-wide community of interest/specialist advice/support organisation and the community development organisations with knowledge of the target neighbourhoods would lead to:

- i. Increase in the use of Amaze services within the groups identified as currently out of reach.
- ii. Parents feeling more confident and resilient to cope in their caring role.
- iii. Increased Compass registrations - with associated financial savings (we estimate the leisure discount card saves the average family £650 per year) and other health and well-being benefits of undertaking more physical and leisure activities, and other benefits of being on the Amaze mailing list and included in our aggregated statistical reports/analysis for commissioners
- iv. Support establishment of new, sustainable parent carer support group (if desirable)
- v. Parents feel less isolated and more empowered in their neighbourhood (more informed about local services available for them and their children).
- vi. Parents in group supported to feed into relevant consultations affecting them themselves or their views consolidated and presented by Amaze or PaCC representation at key strategic meetings e.g. views fed up to Link/Healthwatch, Disabled Children’s Partnership Board etc
- vii. Parents in group supported to be part of local decision making about local services or their views consolidated and presented by local community development organisation at key local meetings – encouraged to join the Local Action Teams (LATs) or local Patient Participation Group (PPG) etc

- viii. We will ensure support group is sustainable and if required, can set up as own (finances, constitution etc.)

3. Summary of Outcomes and Outputs so far

The POPP clearly demonstrates the power of partnership to deliver value for money, effective outreach for Amaze. This ground-breaking project has enabled some specialist advice and help to be given directly to families in the heart of geographically isolated and economically deprived communities and is beginning to build knowledge and understanding in the partner community development organisations (staff and volunteers) of the needs of disabled children and their carers and what services are available to them.

This Project recognises that where parents/carers face multiple issues they are less likely to have a voice and receive the services that they require. Parenting a child with special needs is hugely challenging and can be completely overwhelming when coupled with other difficulties (such as financial, housing or mental health problems). The families identified by this project are some of the most vulnerable in our local area. This shared desire among partners to ensure equity of provision and enable the development of local support has driven this project and led to some very clear outcomes for parents and their families

The POPP found parents on the estates in Moulsecoomb and Hangleton & Knoll facing multiple deprivation with high levels of mental health needs and low levels of resilience and capacity to access the services they need. Parents feel both socially and geographically isolated and are often coping alone with their children, who have significant additional needs.

Door-knocking exposed a high density of parent carers in both areas. In Moulsecoomb we knocked on 1500 doors and spoke to 200 people of whom 52 had a child with special needs (25%) In Hangleton & Knoll, we knocked on a further 1800 doors and spoke to 300 people of whom 34 had a child with special needs (11%).

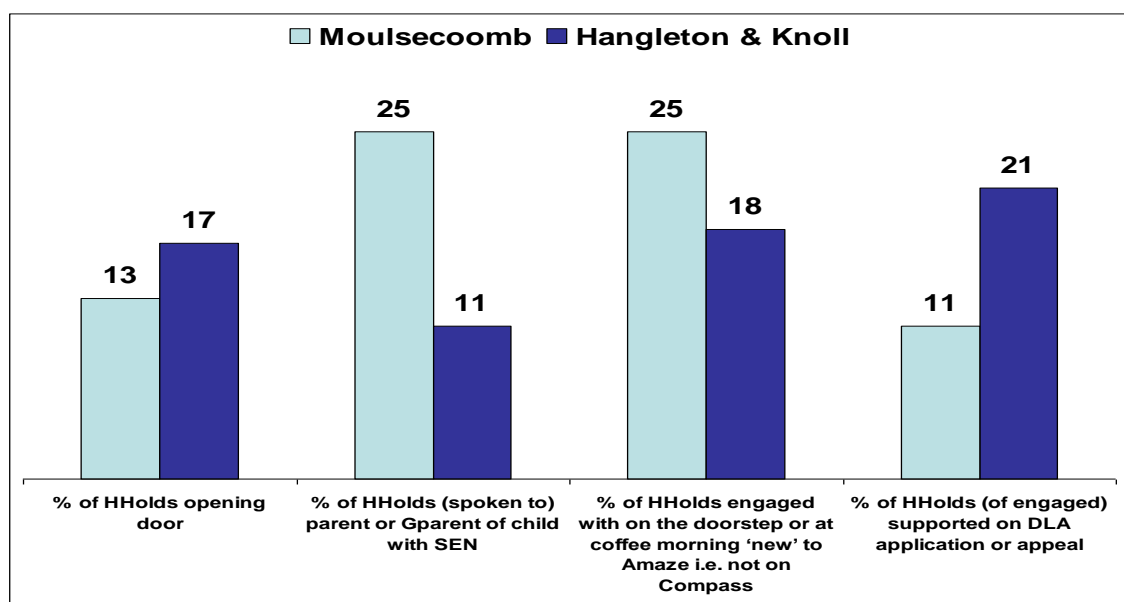
We found that parents were keen to meet and share their stories but we underestimated their need for specialist Amaze casework, information and advice. We also underestimated the time that it is going to take to establish sustainable, parent/carer-led, groups due to the high levels of vulnerability among the families who engaged with us during this pilot.

This project has enabled us to develop a model that is not only innovative but easily replicable with other city-wide 'community of interest' organisations looking to improve their reach in the City and a model that we will seek to develop and expand jointly. We also hope our findings can help inform the Health and Wellbeing Strategy on emotional and mental ill-health.

In the last 6 months, the POPP has already managed to deliver significant outputs, see below (for full table **see appendix C**). The Project in Moulsecoomb commenced in May 2012 and in Hangleton/Knoll in October 2012.

“Single parents need support there’s no time to rest and hand the ropes over...”

	Moulsecocomb	Hangleton & Knoll
No. households 'door knocked'	1,500	1,800
No. households opening door	200	300
No. households spoken to identifying with being the parent or grandparent of a child with SEN	52 (25%)	34 (11%)
Coffee Mornings held	4	2
No. parents/carers attending coffee mornings – helped so far	7	25
No. of those engaged with on the doorstep or at coffee morning 'new' to Amaze i.e. not on Compass	13	7
No. supported (or to be supported) to complete a DLA application or appeal against a decision on DLA	6	8
No. supported to join the Compass	11	6
No. new parent carer volunteers from the community supporting coffee morning.	1	4



We are also beginning to identify many positive outcomes for parents/carers who have been identified and are now getting involved with the POPP which, if sustained, will have a longer-lasting impact on these families including:

- Sense of belonging to community of other local families with disabled children.
- Reduced isolation, increased sense of support network.
- Access to local neighbourhood representation structures and activities.
- Increased self-confidence and resilience from having information/support to access right services for child.
- Improved outcomes for the CYP with disability:
 - Help sorting child's statement/education placements
 - Help accessing services e.g. CAMHS (Child And Adolescent Mental Health Services), housing officers, keyworking,
 - Improved school attendance levels

- Support with assessment process ensuring that the CYP get the help they need and help to access appropriate community activities
- Increased take up of leisure/sporting/cultural activities via Compass Card membership benefits
- Improved health and well-being of carers.
- Improved family finances - via access to DLA project. This may be through new claims, help appealing claims that have been turned down or increasing the rate of DLA e.g.: from middle to upper). Assuming we supported 15 new families to successfully access DLA benefit, this will bring in at least £450,000 to those families (average award £10k p.a. per family for average 3-year period). This may also involve signposting the family to other benefits advice (e.g. one family are thought to be eligible to a higher rate of working tax credits).
- Improved family finances - via access to Compass Card - average financial savings equivalent to £650 p.a. per family.
- As parents/carers become more resilient they will begin to feel more able to become engaged with service design/delivery and evaluation. Service user participation will lead to improved services, better allocation of scarce resources and fewer complaints. Through the project, we have also been able to signpost parent carers to the help they need.

We are keen to identify some additional capacity to allow us to evaluate more keenly these outcomes; including asking all parents attending the new groups to complete a baseline questionnaire about how they think they are coping, which can then be redone in 8-9 months time.

4. What we found out about families with disabled children in these neighbourhoods

So far we have found that families with disabled children living in Hangleton and Knoll and Moulsecoomb are:

4a. Families are Facing Multiple Deprivation

The majority of the 86 families we spoke to during this POPP relayed they were experiencing a number of difficulties often compounded by having a child with a disability or special need or directly connected to the huge challenges this brings. We have witnessed a real 'concentration of deprivation' in the two pilot areas. Grouped together these can be classified as 'multiple deprivation' factors and include factors like:

- More than one child with a disability
- Parent with disability/mental health problem/long term health condition
- Unemployment/living solely on benefits/low income
- Single parent
- Poor housing
- Experiencing domestic violence
- Lack of social support/inclusion

Most families have reported feeling very isolated as a result of having a child with a special need/disability coupled with financial pressures, transport and housing issues, mental health issues and family breakdown. Some described feeling that their whole family felt excluded, not just their child who has special needs, including siblings.

Families have expressed high levels of anxiety about the cuts and changes to welfare benefits, including Disability Living Allowance (DLA) eligibility, and "how they are going to cope". Mothers reported feeling under pressure to "do the right thing" and worried that they were in some way responsible for their child's difficulties. Dads were also widely affected: in one family, the father had given up work in order to support his son with his very challenging behaviour at school. Another

father had not applied for another job after being made redundant due to the pressures on the family of bringing up a daughter with a life limiting condition (he also has caring responsibilities for his wife who has been diagnosed with ME). Obviously, having two parents out of work, or the main income earner out of work, has long-term and far reaching impacts on the family's economic situation and emotional wellbeing.

The anecdotal findings from the POPP mirror other national and local evidence. National evidence shows it costs 3 times more¹ to bring up a disabled child and over 40% of disabled² children live in or on the margins of poverty. City-wide we know many disabled children live in the poorest parts of the city, in particular Moulsecoomb and Bevendean (12%), East Brighton (11%), Hangleton & Knoll (7%), North Portslade (7%) meaning their health outcomes are likely to be further reduced.

4b. Significant needs of parents/carers, which evolve over time (parent carer journey)

So far the POPP has brought Amaze into contact with some 20 new families. However, we have also been reconnected with families who have been in touch with Amaze in the past (and been on the Compass) but a long time ago for a one-off intervention, but have since not been in touch or 'forgot' that Amaze may be able to help. This is an indication of the level of vulnerability as many parents are presenting with complex and chaotic lives.

Parents have appreciated the face-to-face contact at the coffee mornings and talking to each other. Indeed, many of these families who were already known to Amaze had 'new' live issues concerning their child with a special need or disability or a sibling they were now concerned about. The coffee mornings provide a different 'forum', giving parent carers a space to consider and discuss issues they may not have explored when receiving an alternative Amaze service. Parents/carers have said it would be helpful if there could be a way for Amaze 'check in' on existing clientele – to prompt them to see if they have any emerging or new concerns. Clearly this would require additional helpline capacity as the service is hugely oversubscribed currently.

4c. Identifying needs and signposting to the right agency

In Moulsecoomb, community development workers linked families in with other sources of support (e.g. low-cost counselling at the Women's Centre in the city centre) and in HKP siblings were referred into youth team activities. This ability to signpost is really important. Educating neighbourhood workers about which issues are best picked up by Amaze and jointly thinking about the optimum referral routes for other issues is vital. This could be addressed by developing a short training course for neighbourhood workers who are working in partnership with Amaze through the outreach project.

In both areas, parents/carers had a high level of mental health needs. Going forward, it would be beneficial to link to mental health community organisations and examine how they work in specific communities and how we can link families into their services. Likewise, we uncovered a high level of housing issues. Parents complained about outstanding repairs on their council properties (and not being able to access the relevant help) and issues with housing. For example, in Moulsecoomb, one Mum and Grandma share the care of their son/grandson, aged 8. Mum lives in Moulsecoomb in a two-bedroom house, Grandma lives in Hove in a two-bedroom house. They want to live together but a solution has yet to be found.

¹ *Paying to Care: the costs of childhood disability* by Barbara Dobson and Sue Middleton in 1998.

² Children's Society report called *4 in Every 10* (Oct 11) states that 4 out of 10 disabled children now live in poverty. They estimate this to be 320,000 children nationally. Of those, 110,000 are experiencing extreme poverty.

4d. Parents/carers experience very low resilience levels

Many parents reported finding it hard to cope with multiple pressures in their lives. One parent said “It’s just one thing after another and I don’t know how I am going to keep going.” This low level of resilience coupled with significant demands on their time and high levels of need has shown very few parents/carers are ready to engage yet in the setting up of a support group, let alone any further engagement with city-wide health service development etc.

4e. Parents/carers face difficulties accessing city-wide services

Some of these families feel very cut off from city-centre delivered statutory and other services. Parents reported that the cost of travelling to Brighton prevents them accessing services, training and events. The issue of dealing with their children on public transport was also raised and the fact that from Hangleton and Knoll it can take an hour to reach the town centre means that people feel unable to manage that journey. Travelling with a child with a special need or disability can be very challenging and many residents do not have a car. Geographical and social isolation were both raised in Hangleton and Knoll and Moulsecoomb.

Many stated that they find there are practical barriers to accessing Amaze e.g. phoning the helpline takes a lot of courage/energy (one parent in Moulsecoomb described ‘building up’ to the call). Due to limited resources, the helpline is only staffed 17.5 hours per week and callers are generally asked to leave a message and they are called back. Several parents reported that they did not leave a message and never found the time (or confidence) to call again.

4f. Many families with a child with SEN are fragmented

We met at least 10 single-parent families. One family in Moulsecoomb are seeking support from Relate due to relationship difficulties as a result of coping with their two children with special needs.

In addition, grandparents are presenting as main carers across both areas. Many more spoke to us on the door about their caring role in their children and grandchildren’s lives.

In Hangleton and Knoll, one parent reported that her two daughters were living with her sister as they could not live with her due to her elder son’s unpredictable and aggressive behaviour. At the second coffee morning one of the two grandparents that came was looking after her disabled grandchild as her adult child has tubular sclerosis and is in residential care. The issue of siblings and the lack of ability to meet their needs was a theme in Hangleton and Knoll. Several parents described the impact of dealing with a child with special needs leaves little time for their brothers and sisters. Better links are needed with The Carers Centre ‘Young Carers Project’ and youth activities in both communities.

We also met at least 2 adoptive parents/carers.

4g. Late diagnosis makes it difficult for families to access the right services/support

Having to wait for a diagnosis and ‘navigate’ the system was a recurring theme. Parents reported having to wait months and even years for a diagnosis and so a huge delay in early intervention and support which impacts on outcomes for a child or young person later in life (and impacts social care and education budgets). One family (in Moulsecoomb) described how her child had been flagged up by one teacher in year 1 but was only just being assessed in year 6. This was a sibling of a child with significant ASC (autistic spectrum condition) difficulties and the parent felt she was ‘fobbed off’. Another mother reported that she had had to push for intervention for her 6-year-old son. Her 15-year-old daughter has a diagnosis of ASC and she has had concerns about her son for several years. The team at Seaside View child development centre were about to discharge her until she insisted on further intervention and he is now being seen as part of the ‘autistic pathway’ and will be subject to further assessments. There was a feeling from one parent carer (in Hangleton and Knoll)

that her background meant that instead of an ASC diagnosis she was accused of not being a good parent and that there were 'attachment issues' and that this judgement hampered and delayed the eventual diagnosis of her child.

Concerns about transition to adulthood and adult services were raised by two families at the event and one door-knocking in Hangleton and Knoll. One parent of a child living on the Knoll and attending a special school reported they had received no transitions advice, support or information despite her child being 16.

Many families felt their child's school was not able to cope with their needs/behaviour and their child had been sent home/given an informal exclusion as a short term solution to the lack of diagnosis and associated additional support.

Late diagnosis issues were compounded by a significant percentage of people attending the events who had children with health problems.

5. What we found out about outreach work in deprived communities

Our initial POPP project plan set out to pilot the provision of outreach in Moulsecoomb and Knoll estates with the assumption that 7-8 months would be sufficient to identify and support groups of families with disabled children, not previously known to Amaze, to come together, be supported to access the appropriate services and for their groups to become self-supporting in the longer term

A summary of what we have learnt is below:

5a. Need realistic budget for meaningful engagement

These are not 'hard to reach' communities – they are 'seldom heard from' as engagement is generally high-cost and labour intensive. If investment is not made in their engagement, they will not be engaged and their voices left unheard. Engagement with this group requires a pro-active approach, it is simply not enough to use traditional methods and it is pertinent that because of this the voices that probably most need to be listened to are hidden. These are the families that could benefit most from early intervention, yet because of complex barriers, they are not accessing the support they need and are eligible for.

This £9k POPP project budget (kindly provided by the BHCC and Link/CCG) has been insufficient to cover the costs of these two pilots in full. In reality the early stages of the pilot has cost more in the region of £15,000. In addition, we didn't factor in the need to provide on-going maintenance funding to continue to support the initial outreach advice and support needed by these families, nor the cost to provide on-going facilitation to ensure the continuation of the new support groups including the maintenance of family contacts and links to other local groups/networks. This gap in funding has been met to date by additional input from Amaze, TDC and HKP.

5b. Value for money achieved through city-wide specialist agency working in partnership with community-based organisation

Amaze has not previously been able to afford to carry out outreach work in targeted neighbourhoods. This work would have been far more expensive as a solo project as we would have needed to set up a lot of systems and, more importantly, the project would have taken much longer and required greater resources if we hadn't been able to link in to existing networks and trusted relationships in both communities.

The model of a specialist (city-wide) 'community of interest' organisation working in partnership with community development organisations has achieved real savings/synergies by using established links and relationships in the community keeping costs low and increasing our reach/impact.

“We’d like alternative treatments/health care for our child on the NHS”

The ability of partners to harness and support volunteers in the medium to long-term to support this work also makes for a very sustainable model.

5c. Partnership working needs trust and time

We also underestimated the amount of management time that the POPP would require. We took a very collaborative/partnership approach but have learnt that there needed to be one manager ultimately responsible for the project in each area. Our learning is that this should be the manager on-site in the local community and there should be regular project team meetings to ensure all partners communicate what's going well/not so well and plan ahead. All staff involved in the POPP need to have clearly defined roles/responsibilities.

We have had to acknowledge that working in partnership in new communities takes a high degree of trust and flexibility to change culture and working practices in order to best meet the needs of the project in hand. This clearly requires additional managerial capacity but also commitment and leadership and collaboration at all levels of the organisation.

5d. Door knocking/promotions processes

From the outset we were keen to incorporate time and resources to getting out in both areas to physically knock on doors and speak to residents as a proactive way to come into contact with families who may be completely isolated and not engaging with other services/school. This is the traditional approach within neighbourhoods and is the only way to reach the most isolated residents who will only respond to face-to-face contact. It's also a very good way of getting a message out into a community's networks. In each area we spent around 60 staff hours to speak to people and distribute flyers.

We identified the streets to door knock from the original data analysis work (see **appendix F**).

We believe door-knocking was very effective and the only way to reach some parents. In time we believe this will serve us well as families will remember that face-to-face interaction and we hope will be encouraged to get more involved over time. In Moulsecoomb in particular, most of the people we contacted didn't know each other and we were not building on existing contacts. This is perhaps evidence of how isolated residents are in the area and how little support residents draw from their neighbours. Face to face conversation is far more effective than just a flyer and was the best way to establish relationships. Both areas benefitted from attendance at events where the parent was already known to the CD worker

We found the door-knock also to be very successful in terms of relationship building on the 'door-step'. We met one family with a 5-year-old with a visual impairment claiming DLA but not on Amaze's Compass database. She did not come to the coffee morning but very positive engagement took place and we are confident of involving the mother at a future date. Another mother, who attended the fourth Moulsecoomb coffee morning, said that she had 'built up the confidence' to come. She was visibly moved when talking about her child as the family had just been told that he would 'not live independently'. She said that she appreciated the opportunity to talk to others 'in the same position' and discuss concerns about on-going support from Seaside View with the Amaze worker.

In Moulsecoomb we followed up practitioner contacts after the event and had a very positive meeting with Moulsecoomb Primary's Family Support Worker. She is directly targeting families who may benefit and through links with Moulsecoomb Primary School we will do a 'leaflet' drop outside the school gates prior to the next coffee morning. As projects in both areas develop, we will continue to target Schools and other practitioners working in the area to network their local contacts. This relationship building takes time and worked best when we were able to involve other practitioners at the planning stage building a feeling of 'ownership' of the project.

“We want to know what local activities are available for our children. There's nothing for them to do.”

In Hangleton and Knoll we had more time to prepare (as the second pilot area) and were able to outreach to the Children's Centre staff and other community groups as well as being able to place an advert in the local newsletter prior to the first event.

Going forward, it is also important to consider targeting families with a preschool child with SEN. These are new to the system and may be at a very difficult stage post-diagnosis. There is a citywide focus on Early Intervention, coordinated by Seaside View child development centre. Amaze will explore how we can work in partnership with Seaside View as well as strengthening links with nurseries and PRESENS (Preschool Special Educational Needs Service) in order to identify families in these communities and encourage attendance and engagement.

5e. Staff/Volunteer training, increasing knowledge, capacity building

Without increased capacity/resources to allow Amaze helpline staff to attend POPP outreach sessions on an on-going basis, we have recognised the importance of the capacity building/training for the CDWs. This will enable them to better understand what services Amaze can provide to families and support them to access these (especially the helpline) and what other agencies/organisations may be able to assist with. With improved knowledge, CDWs on the ground will feel more confident/empowered to signpost families to the right agencies earlier in their relationship.

We are seeking funding to host a day's training for all staff and volunteers involved in the POPP to gain a better understanding of what services/support are available from a range of providers for disabled children and their carers. This staff training is something Amaze could provide and we could build in some basic training/knowledge on the principles of building resilience which they can use when working with families. If we can evidence the value of this, we would suggest this model could be used by other city-wide community of interest groups.

We recognise the importance of ensuring all staff involved are familiar with (and have attended training in) Child Protection and Vulnerable Adults policies and that these need to be aligned across partners to ensure a consistent approach is achieved.

5f. Service delivery is required before engagement can happen

It does appear that parents need a lot of support before they are able to run their own group and get more engaged. The first coffee morning event in each area was well funded and resourced to include 3-4 Amaze helpline/casework advisors specialising in benefits, education and transitions advice but there was no budget for on-going support which illustrates a real gap in our thinking/planning.

As such Amaze is hoping to identify some funding for an Amaze 'Outreach Parent Support Worker' to attend one coffee morning a month in each location until March'13 with the aim of continuing to advise/support parents with individual queries where possible, or support them to access support from the relevant Amaze/or other service, and to continue to support the local CDW on the ground to promote the on-going groups and provide information about Amaze services where necessary.

The hope is that once parents feel able to regularly attend their new local parent support group, they will feel more inclined/supported to engage with the development of services in their local area and then ultimately feel able to join the Parent Carers' Council (PaCC).

5g. New groups take time to 'storm/form/norm'

In Moulsecoomb, a clear evolution of the coffee morning has been seen since May. At the initial two coffee mornings, parents needed intensive advice, signposting and support. By the third, parents started to chat amongst themselves and 'share' stories, intelligence and tips. Families have shared that they are not able to go on holiday or access days out easily and so they are keen to explore

"It's been good to talk to others in the same position..."

opportunities for day trips as a group. One mother said that her 12-year-old, who has emotional difficulties, has 'never been on holiday'. Parents/carers came up with their own ideas and unanimously agreed that they really needed a 'night out' for the mothers to have a 'break'. The mothers present at this coffee morning do not 'go out much' and there are financial barriers (childcare etc.) as well as emotional ones.

In Hangleton and Knoll, there have been two follow up coffee mornings post the event. Attendance is much higher in this area reflecting the much larger population and also wider mix of families attending. As well as families new to Amaze who are very vulnerable, the coffee mornings have attracted parents who currently access support from Amaze but who welcome the opportunity to get together with families who are in the same situation. At the follow up meeting the parents insisted on a December meeting (we had planned the next meeting for January) as they did not want to wait so long.

The Hangleton and Knoll community workers had more established links with parents/carers from existing work and these volunteers formed part of the planning group from the start of the project and door-knocking with Amaze and HKP staff. There are now 4 volunteer parent carers who are involved in all stages of the planning and delivery of coffee mornings. We hope that this core group might form the basis of a committee as we go into 2013 and therefore it is likely that we will achieve a constituted group in Hangleton and Knoll first.

A group is already established in Hangleton and Knoll called 'Hangleton Fun for Families' and HKP are working with them on developing their group to have the ability to offer more inclusive trips and increase the opportunities for low-cost days out for parent carers. The Chair of this group has an autistic son and is a volunteer on the HKP POPP.

In Hangleton and Knoll parents have already asked for a series of talks themed around issues such as communication and behaviour management. This is something that Amaze hopes to be able to offer in both areas as themes emerge in Moulsecoomb too.

On-going support groups need facilitating carefully, to ensure we keep up the momentum and engagement of these families. This requires on-going CDW time. For example, numbers attending the Hangleton and Knoll coffee mornings are significant (25) and it is already a challenge to keep case notes up to date. We will train CDW staff and volunteers to be able to take notes as it is vital we capture all the data to best support parents.

We are also keen to engage existing parent support groups (The Parent Carer Council (PaCC), the 'parent voice' work stream within Amaze has 'partnered' with several parent led groups such as Pebbles and Sweetpeas) that support children with SEN and disabilities about what has worked/not worked for them and how they started/barriers to development. We could also see if one of these groups would support the development of the new, local parent carer group in conjunction with the CDWs. This sort of peer to peer learning would be invaluable and very empowering.

We would like to link new parent support groups to PaCC so that at some point these new groups will become the PaCC partners of the future. Parents/carers may feel able to join PaCC and become more involved in at a city-wide level. Similarly we would like to link the new support groups to representative structures in their own neighbourhoods such as Local Action Teams, Community Forums and Patient Participation Groups. This would enable them to build relations with other community groups with complementary aims.

5h. BME involvement

Sadly no parents have yet attended the groups in either area, from BME backgrounds. This is disappointing as the Hangleton and Knoll team visited the Multi-Cultural Women's Group and the Moulsecoomb team visited the Bangladeshi Women's Group, both explaining the background to the

"Some health visitors are good, some aren't. There needs to be better consistency in their service."

POPP and publicising the new support groups. One member said she would bring two of her friends along who had children with Special Educational Needs (SEN) but they didn't come, but with further engagement opportunities she may. This is an area that needs further on-going work and it is likely to be a 'slow burner'.

We understand city-wide parent carer support groups (such as Sweet Peas and Pebbles) are having more success attracting BME families as they are often introduced through a health visitor or speech and language therapist (SALT). We need to do more work linking up with health visitors, SALTS and health visitors to build these relationships so that they can 'refer' families to the POPP groups. One barrier is often the need for an interpreter and this is an area that would benefit from discrete funding.

Our next step will be to ask the established groups (the Hangleton and Knoll Multi-Cultural Women's Steering Group and Moulsecoomb Bangladeshi Women's Group) for their advice on how to identify families with disabled children in their communities and offer to run a separate/subgroup coffee morning for families needing interpreters, which could then become part of the main support group once initial needs/concerns have been discussed. Feedback is that a face to face support group without offering interpreters will not succeed in attracting the most vulnerable BME parent carers.

5i. On-going roles for POPP

We have learnt that HKP, TDC and Amaze need to provide an on-going resource to attend the monthly coffee morning/support groups whilst they are still so new in formation and parents have so many pressing concerns/problems. **See 5g)** above.

One model would be to ask trained Amaze helpline staff to go on a POPP rota and attend these meetings in turn as part of their 'helpliner' role. But demand for Amaze's helpline is huge and at present we can't take these staff out to work on the POPP (**see 6e** below). We are seeking funding for an 'Amaze Parent Support Worker' to attend follow up groups, supporting the CDWs on the ground. They are needed in addition to the CDW as they can listen empathetically to the parental concerns from their own experience of being a parent carer and can suggest services/support to access and help signpost/refer the parents to these. We need to consider whether this person should be provided with an Amaze mobile phone so families can easily make contact with them for support.

To ensure sustainability of this work, we need to identify some resource to deploy our specialist Amaze caseworkers to provide training/awareness raising for the CDW staff (see e) above so they can be armed with information/leaflets about what services Amaze offers and refer appropriate families to us. It is important to build the capacity/knowledge about Children and Young People with SEN in the neighbourhoods and this is potentially a model that could be rolled out across the City and with different target populations.

5j. Promotions/building relationships locally

We need to continue to produce the flyers promoting the POPP support groups and ask that other agencies/groups/services use the leaflets and refer relevant families to us.

It has been vital to build links with local schools, helped in Moulsecoomb by locating the meetings in the local primary school and in Hangleton and Knoll by a parent volunteer who has links with Goldstone Primary. We need to ensure we have direct contact at the schools on a regular basis and have explained the project to the schools SENCO (Special Educational Needs Coordinator). We are trialling the effectiveness of school gate leafleting at Moulsecoomb Primary School although this has also revealed the stigma felt by parents as they feel judged by other parents at the gate. Leaflets were put in the book bags at special schools but the key is to capture the very large population of children with SEN who are at mainstream school. We are working with local

mainstream schools to add flyers to the book bags of children on their SEN register and to help us promote the coffee mornings.

We need to continue to promote the coffee mornings through other channels too for instance:

- Local fun days are very well attended and an Amaze stall at these events would reach a range of local families but we need resource for this.
- Neighbourhood practitioner groups build links between services and groups. Amaze workers could join these practitioners group in target areas if resourced (e.g. Coldean, Bevendean and Moulsecoomb) or present at local representative groups such as HK Community Action.
- In both areas the CDWs are making links with GP surgeries and this will prove helpful as a referral point when on board.

There are opportunities to learn from other services such as the Carers Centre who are launching a group aimed at carers from the LGBT and BME Populations. There are community engagement parallels and lessons that can be shared such as project planning and uptake as we start to disseminate our findings.

5k. Sharing information/data about families

Staff and volunteers working on the POPP have had to learn how to work best to gather, then share appropriately (and with permission), sensitive information about each family.

For some families, this may be the first time they have shared certain thoughts or problems and we have had to be very respectful of that, whilst needing to be clear that Amaze/TDC/HKP are working in partnership and checking if they are happy for their information to be shared.

Following the first Hangleton and Knoll coffee morning the team decided we needed to create a POPP Case Notes sheet – to prompt those speaking with families to capture the necessary data/information. These case notes are now being added to the Amaze database so if families subsequently ring/access Amaze services this will not need to be repeated. A consistent approach has now been created across both areas with ‘template’ forms for ‘case notes’ and spread sheets detailing parent carer details.

As facilitated group support sessions continue we need to clarify the system for recording any information shared in group work so this intelligence can be collated and reported upwards.

5l. Planning ahead

It's vital to spend enough time project planning and to book in dates for groups to meet (coffee mornings) as early as possible, to allow for staff/volunteers/venues to be booked. Publicity then needs to be arranged and we've learnt the importance of advertising in the local community newsletters. In hindsight, we probably rushed the first event in Moulsecoomb (our first pilot site) in order to get the project started before the school summer holidays and we missed the deadline for the Moulsecoomb Community newsletter.

An advert in the Knoll Scroll and Hangleton Harbinger did result in parents attending as well as raising general awareness in the community which builds momentum over the medium term.

5m. Working with / signposting to other agencies

As mentioned in **4c) above**, the POPP has been signposting/referring families to other agencies where appropriate. Going forward, it will be important for the CDW to consider how best to link this work with other colleagues e.g. housing officers, or MIND and the training mentioned in **4e) above** would help consolidate understanding about what other agencies offer.

6. Recommendations for funders & sector

6a. Investment needs to be made in engaging with 'seldom-heard' families

See 4a) above

6b. Recognise the highly-effective and value for money partnership approach between local neighbourhood organisation and city-wide community of interest organisation

The POPP has brought real benefits for all partners – with specialist knowledge being taken into the communities and geographical/community expertise being shared with a city-wide service provider. CDWs know the unique challenges of the area and have established and trusted networks and relationships and Amaze staff understand the particular challenges facing families who have a child with a special need or disability.

Synergies are created by offering a 'lure' in terms of a specialist service/advice/support session, in a locally accessible and trusted location, then leading to increased engagement/participation/voice.

6c. Recognise that significant outcomes have been delivered already

These can be evidenced in more detail with some additional funding to support monitoring.

6d. CCG, Public Health, Stronger Families/Stronger Communities to consider joint-commissioning future engagement

The POPP is already reaching families who are 'seldom heard from' (see 4a above) and is helping to reduce health inequalities and deliver positive impacts across health/well-being, education and social care. As such we would like strategic commissioners in these areas to consider jointly funding this work on an on-going basis.

This model could be replicated across other CCG Engagement Gateways to achieve benefits from a co-ordinated approach between community development support and city-wide engagement gateway organisations.

6e. Agreement to fund an extension to POPP during 2013 and beyond

This could be via the CCG Engagement Gateway, HealthWatch commission, or other joint commissioning opportunities, and would allow us to support the development of two self-sustaining groups in Moulsecoomb and Hangleton and Knoll. This would recognise that POPPs need a bit more initial/kick-start investment recognising that after 18-24 months these groups are likely to be self-sustaining. Investment for 2013 would allow all partners to employ staff for one day a month each – at Amaze this would be a part time Amaze Parent Support (outreach) worker and at HKP and TDC this would be a contribution to their CDWs.

It should be noted that project costs have been significantly reduced by the support matched via the Community Development Commission/Grants.

In 2014 we would like to begin working in partnership with local community development consultancy Serendipity to extend this work into Whitehawk and the Friends, Family and Travellers Project to test this approach with the traveller community.

6f. Need to increase capacity for Amaze helpline.

The pilot has highlighted the need for extra capacity on the Amaze helpline. Frequently parents have said they have tried calling but as the line is engaged and they are asked to leave a message they often don't bother/don't have the courage to. Amaze has seen an 86% increase in calls in the last 5 years with no uplift in funding. Commissioners could consider if they can help find some additional resource for a very over-subscribed service. Amaze is also keen to develop new, more accessible ways, for parents to contact the Helpline – for instance being able to text the Helpline to ask for someone to call them back.

6g. Identify funding for Amaze to deliver a resilience-building course for parents/carers in each local area.

Amaze's Insiders' Guide is an 8-week course designed to increase parent carer resilience and capacity to cope with caring for their disabled child.

An independent evaluation (April 2012) of this training showed for every £1 invested in the course there is social value created in the range of £24-38. The evaluation said parent/carers reported significant changes for themselves and their families as they became, equipped, informed and confident. The resilience elements were of particular importance for parent carers coming to understand the need to attend to their own health and wellbeing in order to continue caring for their children with additional needs in the long term. Parent carer improvements in: confidence, securing more help and support, willingness to ask for help, feelings of isolation versus connectedness to others, use of new ideas and strategies in everyday situations, more positive general outlook for the future, and greater interest in joining other learning situations in the future (evidenced by pre and post measure in each of these categories).

Families attending the groups in Moulsecoomb and Hangleton and Knoll have told us they struggle to access training (and other services) in city-centre locations so often miss out on the benefits this can bring – not just the learning but the social networking/inclusion aspect too.

We would like to offer an IG course for each group at a cost of £3,250 per course.

6h. Accept that early intervention/engagement with these families is essential and saves money in the longer-term.

We know that if a child with complex needs full-time residential care as their parent carer can no longer cope with them at home; this can cost the city up to £250k per annum. Also, new figures show that the average 'troubled family' costs around £75,000 a year to support and we anticipate many of these identified in the city may have children with SEN. If we can engage these families early, and help them to feel less isolated and better able to cope, this should generate savings in the longer term.

Appendix A:

Trust for Developing Communities

– full findings and case studies from Moulsecoomb

a. Process in Moulsecoomb

Our aim was to contact residents of the fifteen streets in Moulsecoomb that the Databridge analysis had identified as having 64 children on disability living allowance that were not in touch with Amaze services.

We set up a team of staff and volunteers from Amaze and the Trust to knock on the doors of 1,500 homes in the area. Volunteers were recruited from a pool of parent carers and two were involved in door knocking. Overall the 'door-knocking team' was made up of three staff and two volunteers and they worked in teams to ensure one person knew the neighbourhood well and one could answer queries about having a disabled child.

We visited all the homes over five days in July 2012. Most visits took place during the day and the team found that in the main there was someone in the household who answered the door and was keen to talk about their child. Many residents who didn't have a child with special needs knew of another family or friend who did.

From door knocking and leafleting over 1,500 houses, approximately 200 residents answered the door and from these 52 said they had or thought they may have a child with special needs. This was just over 25% of the households contacted self-identifying as having a child with special needs.

Contact details were taken from approximately 25 families who said they would be interested in attending the first coffee morning event. Some were already on Amaze's Compass database already. Eight were not and were new families to Amaze.

We wanted to bring families with disabled children together in a local, well known venue and chose the community room in Moulsecoomb Primary School as an accessible place that most families were familiar with.

In order to meet the most pressing needs we provided immediate outreach advice from Amaze staff with DLA and transition advisors from Amaze attending. We promoted the idea of forming a new parent support group and had unanimous agreement that it was a good idea to set a group up. We also provided free pampering, tea and cakes which encouraged parent/carers to stay, chat and share experiences.

The first coffee morning was booked for July 16th so that it fell in the last week of the summer term and seven parent/carers attended. Whilst we managed to hold the event before the school holidays it fell in a busy week for the school and on a particularly wet and rainy day which meant parents were not in school for the cancelled sports day.

From this first meeting we established that many of the parents/carers attending had significant and multiple needs. We recognised that significant support would be needed to firstly meet their immediate concerns and needs and to then work with them to set up a regular support group.

b. Initial findings in Moulsecoomb

- **Grandmothers play a significant caring role.** Two grandmothers came in place of daughters who were struggling. These grandmothers were, in fact, caring for the children with special needs most of the time.
- **Parents have needs themselves.** One mother who rarely went out of the house managed to attend with support and encouragement from the door knocking team. The mother's mental health problems were significant.
- **Families are facing multiple challenges.** We found that these families have complex and multiple needs; for example many single parent households were struggling on benefits and were very concerned about forthcoming benefits changes.
- **There can be an educational impact.** Parent/carers reported that for various reasons their children were often missing a lot of their schooling. There were also concerns about their child(ren) being excluded.
- **Accessible low cost activities are needed.** Families wanted more inclusive activities and places to go for their child with special needs within the local area.

c. On-going work and findings in Moulsecoomb

Initially it was decided to try to hold a fortnightly coffee morning at the local Moulsecoomb Primary School and flyers were made and circulated to publicise the event. Three families attended the first three events and a further, new, family attended the 3rd coffee morning. Another new family attended the fourth coffee morning. The mother said she it had taken her several weeks to gain the confidence to come along. This mother was feeling upset as she had been told, at a recent appointment, that her son would "never live independently".

The families who have been attending regularly have distinct and complex needs and Amaze has had to consider carefully what on-going support it can offer them given there was no on-going budget to perform outreach work. However, one family has been able to access the DLA project and is being set up with a DLA volunteer to provide help completing the DLA application, which is a service provided in the family's home. One mother has been provided with the Amaze social work student to act as her informal support worker/advisor. The mother reports that she is finding this hugely effective and has said she feels better able to cope following this support being put in place.

The TDC team has also been able to provide information and links into other neighbourhood and city support services including the Bridge Community Education Centre and Mind.

Following these first two follow up meetings, and in order to avoid the half term break, we revisited initial contacts and also approached the school support team about referrals to the coffee mornings.

We also targeted those families living in the area who were already on the Amaze Compass with the intention of engaging families who may have been at a different stage of their caring journey, with possibly fewer immediate needs, and maybe more able to take a lead with group.

The second 'door knocking' went very well but we were unable to turn these contacts into attendance at the coffee morning, highlighting the levels of trust and confidence that need to be built for families to feel able to access services. One new family attended all three coffee mornings and this family is now able to tap in to the full range of Amaze's services. Two families had new concerns about a 'sibling' of a child already on Amaze's database and Amaze is able to help with assessment and possibly DLA in the future.

Given resourcing constraints, a monthly parent support group will be facilitated. In the New Year, when individual issues are more resolved, the group will start to look at locally accessible integrated

activities and ways of broadening engagement so that families with children who have special needs can access them.

d. Outputs/outcomes in Moulsecoomb

As a direct result of the pilot outreach project in Moulsecoomb we have achieved:

- **Three parent/carers supported to do a DLA application for their child.** There will be a likely financial output of £8-12k per annum if the applications are successful. Achieving DLA for a family has been evaluated as an important mental health intervention³.
- **Improved health and wellbeing** reported through group sessions resulting from having space to share problems and peer support.
- **Three parent/carers supported to resolve SEN concerns** about their child with schools.
- **Two parent carers given support with forthcoming meetings.** Meetings with professionals can be stressful for parents and help with planning the meeting (and writing up notes) was reported to be very helpful.

e. Conclusions and learning from Moulsecoomb

- The families we contacted through the door knocking were isolated and not part of existing community groups. This makes it more difficult to build a parent/carer support group and the community development worker visited many generic groups and services to build up contacts. The school has been very effective in introducing families and once the autumn term started the newest two families both came via school contacts. Our learning is to build strong links with school support team early on in the project.
- Families with complex needs find it difficult to commit to regular activity. It has been an achievement to now have five 'regular' families in Moulsecoomb who are committed to the group. We have found that the sessions need to be informal and unpressured and that we needed to offer information by post and email as well as through attendance at group.
- Families with several children can find it difficult to get out of house for activity. We will need to support the group to strengthen if they want to eventually constitute and fundraise independently. We are looking into how supported activity can be funded for whole families.
- Those attending the group have very specific queries regarding the support they can access and so are using group as an advice surgery because they find accessing central services and the helpline difficult. We are looking at how to improve access into central services rather than duplicating them locally.
- The group will need a range of members to be sustainable so that there are members who can take on running the group. We are approaching families who are already on the Compass to bring more experience to the group.
- Four families have so far been referred on to appropriate other service including Mind, the GP, the Bridge Community Education Centre, the Amaze helpline and Social Services.

There was significant confusion about role and remit of service providers from those families who went to the drop-in– pupil services, Seaside View, the school and the GP. One family reported that the SENCO at their son's primary school had failed to engage with Seaside View and the family had self-referred in the end. There is confusion over who can refer and

³ University of Brighton's Independent Evaluation of the Amaze DLA Project, November 2012

the family spent months waiting before taking action themselves.

We are exploring how to get some basic referral route information out to families.

- There are significant issues around transition from junior to senior school and the late flagging of a child's needs. For example families whose children are about to apply to secondary admissions are not sure if should be at mainstream school. This transition was described by one parent as 'scary' and the whole idea of moving schools perplexed parents. One parent, whose son is very unhappy and not making progress at a local primary, said, "I want to look at other schools but I don't know who to phone."

So that workers can support families we are providing them with clear timetables of this process and information about Amaze's transition work including copies of Through the Maze and Through the Next Maze - Amaze's comprehensive handbooks to services and the journey of having a child with special needs.

a Process in Hangleton and Knoll

In total 29 roads were 'door-knocked'/flyered over. Three teams of 2 workers worked a total of 15 hours between 23/10/12 and 05/11/12. We knocked on about 1,800 doors speaking to 300 people and 34 identified as having/known a child with special needs. We also identified 8 older people and gave information about older peoples groups and 5 people interested in IT learning. 18 said they would be interested in attending the initial coffee morning with 2 specifically unable to make it. There were 7 people in total involved in doing the door knock including 2 CD workers, Amaze worker, Hangleton Holistics and 3 local resident parent carer volunteers who were already involved in HK community groups.

The Project Team comprised of the 2 CD workers and Amaze worker plus Hangleton Holistics and 3 local parent carer volunteers. 6 planning meetings were held including one on the day.

Posters and flyers were distributed across the attached area to a very wide variety of venues to really raise awareness.

Hangleton Community Centre
St Richard's Church and Community Centre
Portage Children's Society
Little Ducklings Nursery (HCC)
BHIP
Hangleton Children's Centre
Sama (HCC)
Dance school (HCC)
Circus project (HCC)
Tiny Tims (HCC)
Hove Park School
Blatchington Mill School
Goldstone Infant and Primary School
Hangleton Infant and Junior School
West Blatchington Primary School
Little Lambs
Oasis Church
Hangleton GP Surgery
Burwash Road GP Surgery
Shops at Grenadier, Burwash Road, Margery Road and Boundary Road
Community Noticeboards
Hillside
Downs Park
Extra time
Drove Road
Swan Centre
Blakers
Sweet Peas parent and toddler group
Patcham House
PACC (Parent Carer Council)
Jeanne Saunders
Little Darlings
ACE

Tudor House
Link Plus
Seaside View (nursery nurse)
HK Community Groups -
Sunbeams
Fun for Kidz
Socca tots
Hangleton Fun for Families
Hangleton and Knoll Multi Cultural Women's Group
50+ Steering Group
LGBT Group

On the day of the event, one parent carer who was very anxious was collected and brought to the event with her son by the CDW. Before the event we telephoned all the parent carers that we had made contact with via door-knocking.

The kick off coffee morning in Hangleton and Knoll took place in St. Richards Church hall on 6th November, supported by a team of 4 from Amaze, 4 from HKP and 2 volunteers. **17 parents/carers** attended and were offered 1:1 advice from the Amaze advisors and HKP staff, as well as a Hangleton Holistic treatment and free tea and cakes.

b) Initial Findings in Hangleton and Knoll

- Benefits changes were mentioned frequently. One parent reported that she had her DLA stopped with no warning
- Compass forms were mentioned as difficult to fill in. Two parents had received Compass forms and had felt unable to complete them. Several parents had not renewed their child's Compass card, even though some had been sent the forms
- The complexity of applying for DLA was an issue
- Informal exclusions from school
- Lack of support from school leading to one father spending all of each and every day supporting their child in school leaving him unable to work
- Caring responsibilities for a wife as well as children
- Lack of advice and support at key transition points (junior to senior school and to adult services) raised by 3 parents
- Sibling issues and lack of local things to do
- Affordability of transport

c) On-going work and findings in Hangleton and Knoll

Parents voted at the initial event that they wished to meet again on a monthly basis and that they would like the meetings to be facilitated by the HKP and would be happy to contribute £1 to the cost of the venue hire.

The second coffee morning was held 27th Nov. CDW door-knocked the addresses of known parent carers again and utilised the school contact that emerged from previous door-knocking and circulated flyers as before.

The second event attracted **16 parent carers** of whom 8 had attended the first event. The team of parent carer volunteers all attended, helping with refreshments and making parents feel welcome. The group started to evolve as parents began to share stories with each other. The Amaze worker took all the notes which was tricky because of the numbers of parents there. In future HKP staff and volunteers need to be trained to write up case notes. Many parents expressed their feelings of isolation and of coping alone. We had drafted dates for monthly future meetings starting in January through till April but there was a unanimous demand for a December 18th meeting. This has been agreed along with the monthly dates for 2013.

We are not only picking up families with known needs who have felt unable to 'navigate' the DLA and compass forms but also new families with younger children (pre-school) who are new to the system. Also some families may be eligible for a higher rate of DLA that may then be the pathway to other benefits and support. One family in Hangleton and Knoll had had their DLA at the higher rate taken off them even though their child has a life limiting condition (as it was viewed that her difficulties are not as substantive currently). They lost their entitlement to Motability and therefore their car and their entitlement to Carers Allowance. They are fearful of appeal as they have been told that their daughter would have to appear in court. This family were able to be signposted to Amaze for further specific advice around the DLA process. Several families are very worried about the benefits changes and in losing their DLA and have questions about DLA post 16. Issues of late diagnosis were raised again with one Mum talking about her daughter who is in year 5 but is only now being assessed for having autism/ADHD. GP's were criticised by another parent for a very slow referral with Mum having to chase and wait a long time for referral to Seaside View. Another parent was not even aware of Seaside View and the role it could play with her child. There was feedback about difficulties with thresholds and access to CAMHS services and of the lack of services and support in general with mental health issues. A new parent attended, unknown to Amaze whose teenage daughter is only part time at Hove Park but whose violent behaviour is causing problems. Mum is worried and feels "there is more going on with her but the school just describes her as disruptive".

Liaison between services was raised as an issue by a family with disabled children aged 22 and 27 with special needs who have been told that their children need to move out but they are worried that Bed and Breakfast might be the only option. They are living as a family of 9 in a three bedroom house.

Parents identified behaviour management as a theme which could benefit from some additional input in future. They are really interested in having speakers. Parents also raised issues with GPs which we will ensure are fed into local PPGs and surgeries.

d) Outputs/outcomes in Hangleton and Knoll

As a direct result of the pilot Outreach project in Hangleton and Knoll and after only 2 coffee mornings we have identified

- 7 new families not in receipt of Amaze services
- 8 parent carers supported to do DLA
- 1 Compass card sign-up from a parent receiving DLA but no compass.
- 25 parents who have attended a coffee morning
- Carers Card information circulated
- 4 Parent Carers as active volunteers in Project
- Tailored advice given around issues ranging from behaviour management to bed wetting.

e) Conclusions and learning in Hangleton and Knoll

- This project was helped by existing HKP contacts and community group members with 4 parent carers who have become volunteers and have supported the door knocking and the coffee mornings.
- A couple of parents are so vulnerable that they have required collecting to have the confidence to attend.
- It's clear that this new parent group will not be ready quickly to constitute as independent, the level of need and vulnerability is just too high. However we continue to work to bring in better networked and less vulnerable parents who can both peer support but also perhaps together with our volunteers maybe form a committee. We will aim for constituting this group during 2013.
- On-going CDW facilitation and Amaze expertise is necessary in the medium term.
- There has been a demand for us to ensure we fully include Hangleton, there were not so many parents unknown to Amaze on the estate however it is felt by some parents that there is a high level of need for face to face contact.
- The issues around form filling, complexity of service provision, late diagnosis and lack of statements are indicative of the issues faced by parent carers living with multiple disadvantage. There is a clear need expressed for extra support for these parents especially when there are mental health issues on the part of the parent.
- Really reaching parents was time intensive and the project massively benefitted from having 2 CD workers and 3 volunteers supporting the outreach door-knock phase.
- The 'door-knock' following the first meeting brought in 8 new parents to the second meeting.
- To get the involvement of parents from BME communities we feel we need a separate session with interpreters. Perhaps a session where we get people to book onto as need will be very high and face to face on-going support might be better met through the existing BME mechanisms alongside the Parent Carer group.

Appendix C:

Partnership Outreach Pilot for Parent/Carers: - Outputs Table

	Moulsecoomb	Hangleton & Knoll
No. households 'door knocked'	1500	1800
No. households opening door	200	300
No. households spoken to identifying with SEN child	52	34
Of these no. dads presenting on doorstep or at coffee morning	4	2
No. parents/carers attending coffee mornings	9	25
No. of these 'new' to Amaze	13	7
Of which not pre-school	5	3
No. grandparent carer presenting	3	5
No. supported to join Compass – total	11	6
New	7	4
Renewals	4	2
No. with DLA not on Compass	1	0
No. helped with new DLA form	6	8
No. helped with SEN statement	3	5
No. helped with other forms	1	2
No. where Compass card expired (not renewed) or not joined despite invite	4	2
No. on Amaze Compass but not further engaged with Amaze:		
- For over 1 year	3	6
- For over 2 years	2	1
- For over 5 years	2	0
- Ever	3	2
No. with one child on Compass but with new sibling identified	4	0
No. not attended coffee mornings yet but are 'hot leads' to follow up	9	3
No. new parent carer volunteers for the area	1	4
No. CYP excluded from school, according to what parents told us	1	1
No. CYP on part time timetable	1	3
No. CYP problems with school refusal	1	2

Special/difficult circumstances (leading to multiple-deprivation)

Amaze is able to gather more in-depth information for families who access our DLA project (delivered by volunteers meeting with families in their own home). We are entrusted with more details about special/additionally-difficult circumstances (SCs) e.g. experiencing domestic violence, disability/mental health problem of carer, living on benefits, foster carer etc.

Analysis from this shows: 79% families had at least one SC.

30% had 3+SCs (rising to 41% in the more deprived wards including Moulsecoomb and Hangleton & Knoll)

34% had 4+SCs (rising to 45% “ ”)

Case study 1:

Family's situation (carer's needs etc.):

Parent with three children, a boy aged 15, at a local secondary school and waiting for a re-referral to CAMHS, and a girl aged 7, who is at a specialist school 'unit' and a girl aged 2.

Mum has significant mental health needs and is worried about on-going therapy (she has been doing a course of CB therapy that is about to end). She has anxiety disorder and goes through periods when she does not eat. She has not had a meeting with her health visitor for several months. Housing concerns are exacerbating Mum's mental health needs (she says her 'bathroom is falling apart' which she finds really stressful). Mum was taken in to care as a child herself and says she is 'wary' of social services. Mum says she has many days when she feels she can't get out of bed.

Details of the child with special needs and their diagnosis or needs:

Her 7-year-old daughter who has speech and language difficulties and also delayed fine motor skills. The mother reports that her daughter is passive and does not 'feel pain'. She is still in nappies. She is also worried about her 15-year-old son who has been under CAMHS (Child and Adolescent Mental Health Services) before due to anxiety issues and has been referred again. He is showing signs of OCD (constantly washing hands).

What help does the family need?

This family needs help across several areas. They need help with housing as mum needs help to get the right repairs that need to happen to her house. Mum needs support to access the right help for her little girl and 15-year-old son. Her 15-year-old is still awaiting an assessment with CAMHS. Mum describes him as 'very anxious' and 'paranoid' and 'emotionally immature'. Her little girl is well supported at a unit at the moment but is still awaiting blood test results from Seaside View. Mum will need help with the statementing process going forward. The family also needs financial help, support to get DLA for mum and for her little girl. The Compass Card will also allow them to access activities for free or at a reduced rate. The mum needs support from adult mental health services as she is worried her mental health could impact on her ability to care of her children. She is bordering on agoraphobia. She has just completed CBT with Mind but this is about to end. There seems to be a lack of a clear pathway for help and 'waiting lists are long' (mum's words).

What barriers are they facing?

This family is facing multiple barriers including financial pressures, mum's mental health problems, poor housing, difficulties parenting two children with special needs and relationship difficulties.

How did our outreach pilot help them?

Amaze was able to offer support through its student social worker (Mum did not feel wary of this as the placement was with Amaze, an organisation she trusts) and she will contact the family's health visitor. Mum reports feeling very well supported by this. Amaze's temporary 'Outreach Parent Support Worker' also enquired about a keyworker for the family (through the keyworking service at Seaside View) but the child needs to be receiving input from four different services to be eligible. Amaze is currently carrying out this 'keyworking' role in an unofficial way through the student social worker, helpline, DLA and IPS project.

What needs to happen next?

This is a family who are at risk of 'falling through the gap' without on-going support and intervention. Eventually this family could access the key working service at Seaside View as it is likely the little boy will have four health professionals involved (has two to three currently). Mum seems to really benefit from the on-going coffee mornings and is likely to engage with a support/outings group. As a result of intervention from Amaze's student social worker, mum seems visibly more able to cope.

Case study 2:

Family's situation (carer's needs etc.):

Mum and Grandma with an 8-year-old daughter with severe anxiety issues and possible ASC and a 2-year-old son with no apparent difficulties.

Details of the child with special needs and their diagnosis or needs:

Their little girl was having huge problems at home and school. She is being bullied at school, sleeps with her mother, as she is very anxious and has many 'phobias' (hair washing, scratchy clothes, loud noises). She will only eat certain foods and obsessive behaviours (she is obsessed with computer games). She has difficulties forming friendships and gets on better with children who have special educational needs.

What help does the family need:

Their concern was that they would get to the assessment (with a paediatrician and speech and language therapist) and would not be able to articulate their on-going concerns about their child, who exhibited anxiety, behavioural and social communication difficulties.

What barriers are they facing?

The family were also concerned about housing (mum and grandma provided a 'team' to support the child as Dad is not around) as they were not able to live together in a three bedroom house due to restrictions in the council's housing policy. Mum and grandma 'pool' their money (Mum works and Grandma has a pension) but struggle to get by. The little girl does not see her Dad. The little girl can be aggressive to the grandmother when stressed/anxious.

How did our outreach pilot help them?

Amaze was able to offer bespoke support to the family who were very worried about a forthcoming meeting at Seaside View, the child development centre in Brighton & Hove.

The temporary Amaze Outreach Parent Support Worker prepared a detailed history of parental thoughts. The family reported an increase in confidence about the meeting and were grateful for this specific support. This family do not currently get DLA. They believed that you had to wait for a 'diagnosis' but Amaze's DLA project lead was able to reassure them that they can still apply and this process is being undertaken.

What needs to happen next?

Nervousness about appointments and letter writing was reported by several parents and they really benefit from somebody capturing their thoughts for them. This family would benefit from counselling (mum and Grandma). The school appear to have lots of support in place. Housing is a particular issue for this family as they are living in two separate council houses (one in Moulsecoomb and one in Saltdean) and because of council red tape cannot live together (so two lots of bills and logistically very difficult). CD Project Manager to approach local councillor about writing a letter regarding this.

Case study 3:

Family's situation (parent carer's needs etc.).

Grandparent has been bringing up her grandson since birth. The child's mother has a genetic condition (as does her brother) so the grandparent also cares for both her adult children who have special needs/learning difficulties.

Barriers: This grandparent carer's physical mobility has deteriorated over recent years and she now walks with a stick. She is less able to attend city-centre (Amaze etc) events. She and her husband are worried about the future and what will happen to their grandson when they are no longer able to look after him. The family also worries about his DLA status and what will happen when he turns 16 as he is not able to manage this himself. The family are also concerned that the diagnostic process may not have been thorough enough. He has only had one of the available tests for the condition that affected his mother and uncle, for example. The family report that they have been discharged from local child development centre, Seaside View.

How Amaze has helped this family overcome those barriers: Amaze's DLA team was able to advise the grandmother on how to continue to claim the DLA on behalf of her grandson once he turns 16.

Outcomes: The grandparent reports feeling less isolated since attending the first two coffee mornings in Hangleton and Knoll and plans to attend on-going monthly coffee mornings. The key is that they are local and she can get to them. She takes great solace from listening to other families' experiences and she reports that the coffee mornings have boosted her wellbeing.

What needs to happen next: She would further benefit from a 'grandparent' focused event in her community. This family would benefit from on-going regular coffee mornings. There are other issues that Amaze can support her with such as signposting to help with 'will writing' and planning for the future. Amaze will support the grandmother to approach Seaside View regarding possible further testing.

Case Study 4:

Family's situation (carer's needs etc.):

Single-mum with significant mental health problems and agoraphobia. She has two sons and the youngest is not attending school currently.

Barriers:

Multiple-barriers. Mum has significant mental health needs. She is very worried about money and also she feels her housing is not appropriate (two bedroom house). Her son faces significant isolation. The CDW identified that this mum seemed particularly isolated and lacking in confidence so she gave them a lift to the event.

How Amaze has helped the family overcome these barriers? This family have been assigned the Amaze IPS co-ordinator to help identify what support they need. The Amaze DLA project also helped to assess that the family were getting the right level of DLA.

Outcomes: It was a huge achievement for mum to attend coffee mornings and feel 'safe' to return for a second time. Her confidence was visibly lifted. With IPS support the youngest child now has a statement of SEN. The IPS co-ordinator helped mum negotiate a package of home tuition and joint CBD in the home

What needs to happen next?

With on-going coffee mornings, we believe the POPP can make a real difference to this family. Mum trusts the team and sees us a source of support.

Appendix E:

Background and Pilot Methodology

a) Background

In 2011 the Oxford Consultants for Social Inclusion (OCSI) worked on a project called Databridge looking at how to maximise the potential and intelligence from data gathered and held at 5 Brighton based VCS organisations. Amaze participated in this project due to it hosting the City's register of disabled children – called the Compass - (a statutory duty) on behalf of the Local Authority. This Compass Database holds up to date records of approximately 1,500 children and young people with significant (in receipt of DLA or statutory assessment of SEN) disability or special need, approximately 50% of the total population.

The Databridge project supported Amaze to analyse its data against nationally available datasets, in this case the DWPs data on childhood DLA claims. It found that the Compass database held details of 55% children (under 16) of the total DLA claimants in the City – an undercount of 657 children. The analysis was able to then pin point exactly 24 Super Lower Output Areas (SLOA) – collections of streets – where the Compass undercount was greater than 10 children.

Areas in Moulsecoomb, Whitehawk and Hangleton and Knoll had the largest undercounts: 4 SLOA's in Moulsecoomb totalling 64 children on DLA not in touch with Amaze services, and 26 children in Hangleton and Knoll.

This study set out very clearly what we already knew: that whilst Amaze's management of the disability register (and subsequent membership) was frequently cited as one of the most successful in the country, we were still not reaching everyone – particularly in these more deprived neighbourhoods in the City.

This very powerful data showed our current strategies were not working for some sections of the community and Amaze decided it needed to work more closely with the community development organisations in these areas in order to change this pattern.

Amaze decided to trial a new way of outreach working in two pilot sites at opposite sides of the City and develop a partnership venture with the relevant community development teams in situ: Moulsecoomb – with the Trust for Developing Communities and Hangleton and Knoll with the Hangleton and Knoll Project.

b) Assumptions we wanted to test

We assumed that these families may be facing multiple deprivation factors alongside their child's disability e.g. parental mental health problem or own disability, poverty, adult illiteracy, English as second language etc. which may be preventing them from accessing Amaze and other services. We also assume it is unlikely these families will be engaged or participating with the city-wide Parent Carers Council (PaCC) or other engagement opportunities.

We assume that newly identified parent carers may be isolated and may need some support to cope with their own lives before they feel able to participate more fully in their community or with the PaCC.

c) Pilot aims

We know families with disabled children are high incident, high-cost users of health services⁴ as well as other services, and we all have a duty to reach out to them to find out why they are not engaging with local services. At the outset we were hoping this pilot would lead to:

- ix. Increase in the number and diversity of families with disabled children that are aware of services provided by Amaze.
- x. Increase in the use of Amaze services within the groups identified as currently out of reach.
- xi. Parents feeling more confident and resilient to cope in their caring role.
- xii. Increased Compass registrations - with associated financial savings (we estimate the leisure discount card saves the average family £650 per year) and other health and well-being benefits of undertaking more physical and leisure activities.
- xiii. To increase the number of young people with special needs attending and taking part in community based leisure and sporting activities (Compass Activities)
- xiv. Increase in the representation on the PaCC by families from the targeted groups.
- xv. Parents feel less isolated and more empowered in their neighbourhood (more informed about local services available for them and their children).
- xvi. Parents in group can feed into relevant consultations affecting them themselves or their views consolidated and presented by Amaze or PaCC representation at key strategic meetings.
- xvii. Parents in group can be part of local decision making about local services or their views consolidated and presented by local community development organisation at key local meetings.
- xviii. We will ensure support group is sustainable and if required, can set up as own (finances, constitution etc.)
- xix. Communication of successful engagement methodologies to local partner groups and the National Parent Partnership Network.
- xx. Skilling up Community Development workers on the ground.

We were hopeful that following an initial 'launch event' (one coffee morning in each neighbourhood) a group of parent carers would decide to establish themselves as a parent support group – who could then be supported by the CDW to be self-sustaining. We knew that it was likely that these groups would then need to attract further funding to continue and to provide more support to meet the needs of the particular groups once these had bedded in e.g. we thought the parent support groups may identify that they needed additional support to increase their resilience as parent carers e.g. seek funding to deliver a community-based delivery of Triple P, Insider's Guide and Looking After you training, but that this was outside the scope of the project.

d) Pilot methodology

The pilot stages were designed as follows:

- Develop clear street and route maps using the SLOA data from the Databridge report
- Door knocking and flyering in those streets over a period of 2 weeks to ask local people if they had a child living in their home who had a 'disability, health problem or was having difficulties at school.
- If yes, they were provided with a flyers or verbal information advertising the coffee morning event to take place 1 week later.
- Collection of contact details so the carers could be phoned back by the Amaze helpline and reminded about the event by CDWs

⁴ Amaze/PaCC's Talk Health Report, 2011

- Promotion of the coffee morning event via other local channels (GPs, schools, churches, women's groups, youth groups, LAT newsletters etc.)
- Initial coffee morning – with relevant Amaze and CDW staff, holistic therapy (nails, massage), tea and cakes – facilitated discussion about immediate needs of carers and signposting where appropriate
- Assess appetite for continuing parent support group (coffee morning) to then meet regularly after this

Appendix F:

Glossary of Terms

ASC - autistic spectrum condition
BHCC – Brighton and Hove City Council
CDWs – Community Development Worker
COMPASS – discounted leisure card for families with children who have a special need
CYP – Children and Young People
DLA – Disability Living Allowance
DWP – Department of Work and Pensions
HKP – Hangleton and Knoll Project
PaCC - Parent Carers Council
POPP - Partnership Outreach Pilot to Parents/Carers
SEN – Special Educational Needs
SENCO - Special Educational Needs Coordinator
TDC – The Trust for Developing Communities
VCS – Voluntary and Community Sector

Appendix G:

Acknowledgements

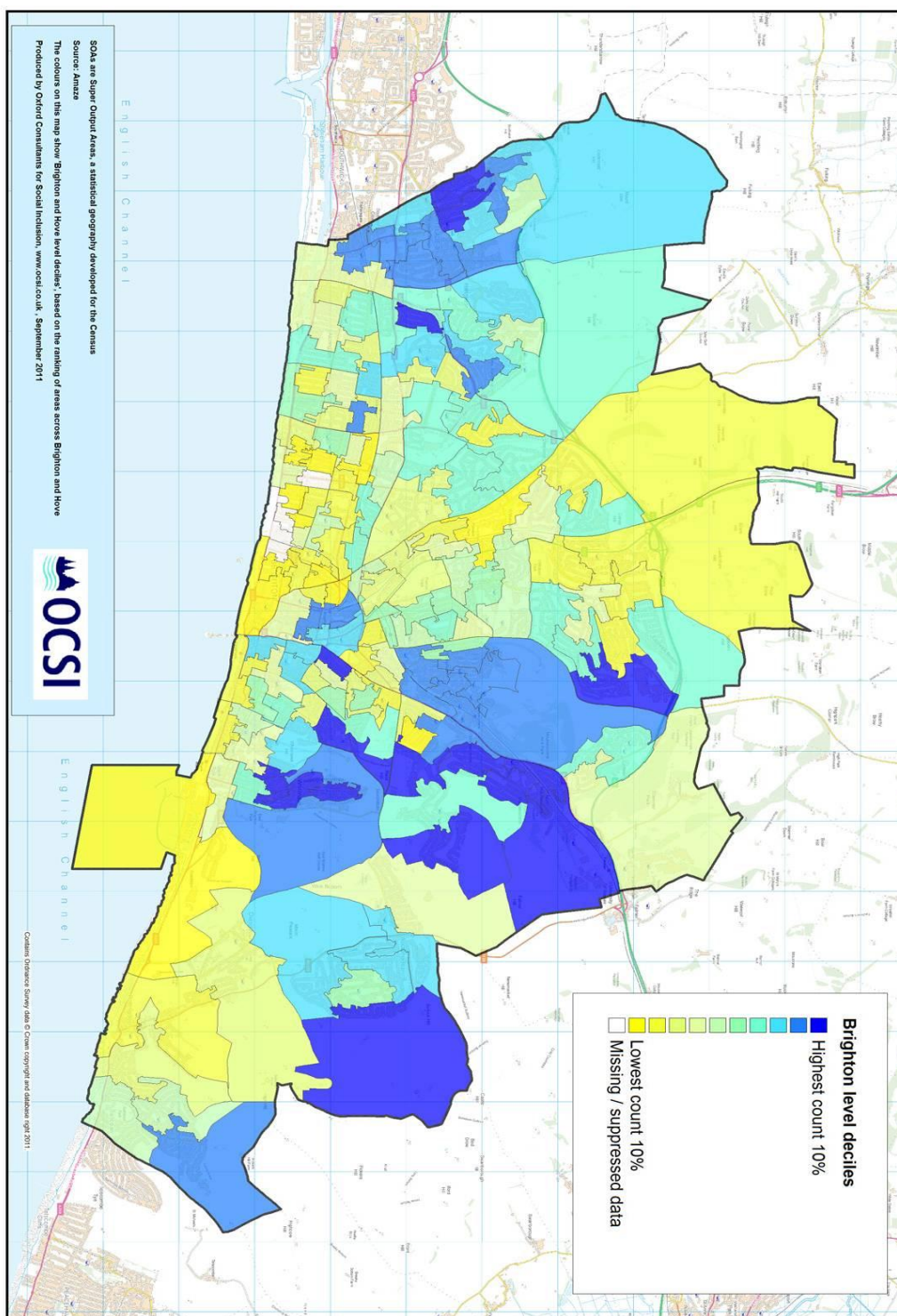
Thanks to the following staff and volunteers who have really pulled together to make this pilot project happen:

Amanda Mortensen
Claire Sillence
Kirsty Walker
Kalishia Le Coutre
Rhiannad Summerset
Angie Walker
Lyn Densley
Catherine How - Community Development Worker
Hangleton Holistics – Lizzie Beckett
Tracy Cox
Lucy Raynor - Moulsecoomb Primary School

We'd also like to thank the following for their financial contribution to date:

Brighton and Hove Link
NHS Brighton and Hove
Brighton and Hove City Council through Community Development Commission match funding.

Total number of children in the Compass Database
SOAs ranked across Brighton and Hove. Source: Amaze. Date: 2011.



Map 1. Neighbourhoods across the city with the highest *numbers* of children on the COMPASS register (areas shaded blue have the highest numbers, and those shaded yellow, the lowest)

The table below shows the SOAs in Brighton and Hove with the largest undercount in children with disabilities. In this case we have shown the *number* of children missing from COMPASS database, not the *percentage*, as Amaze are interested in targeting the areas where the greatest number of people are missing from their information. Other questions might need analysis by percentage.

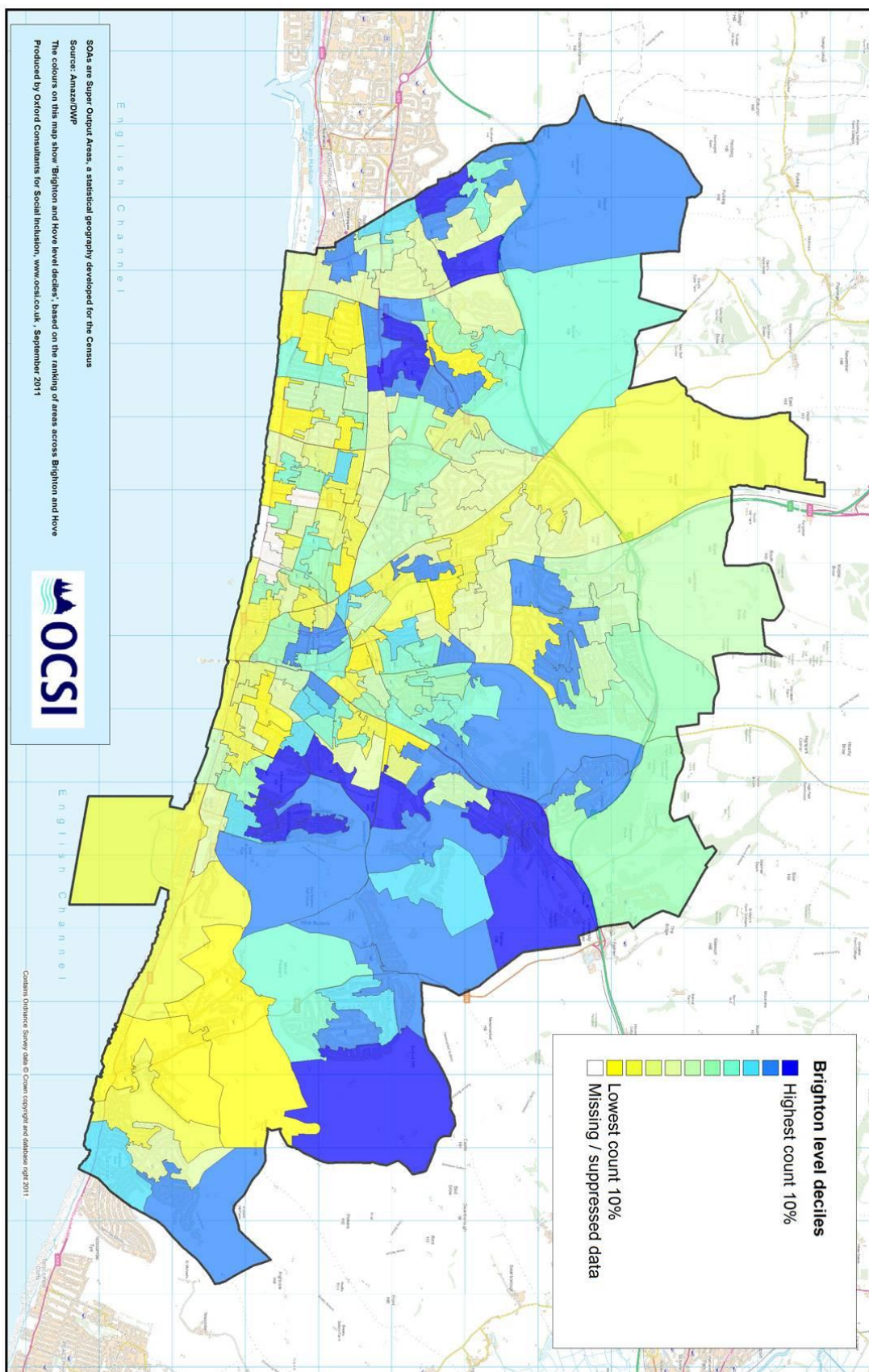
Area	COMPASS with DLA	Total with DLA	Undercount
Brighton and Hove total	793	1,450	657
East Brighton E01016866	15	40	25
Moulsecoomb and Bevendean E01016914	16	35	19
East Brighton E01016865	22	40	18
Moulsecoomb and Bevendean E01016910	7	25	18
East Brighton E01016868	15	30	15
Moulsecoomb and Bevendean E01016915	15	30	15
Hangleton and Knoll E01016879	16	30	14
Hanover and Elm Grove E01016895	6	20	14
East Brighton E01016867	2	15	13
Hangleton and Knoll E01016880	18	30	12
Moulsecoomb and Bevendean E01016908	13	25	12
North Portslade E01016919	18	30	12
North Portslade E01016921	13	25	12
Woodingdean E01017011	8	20	12

- 1.1.1 In 24 different SOAs across the city, the number of children with disabilities was undercounted by 10 or more (i.e. there were at least 10 more children with DLA than was recorded on the COMPASS database). Areas in Whitehawk and Moulsecoomb are the most underrepresented in absolute terms - In SOA E01016866 in East Brighton (Nuthurst area of Whitehawk) there were 40 children receiving DLA of whom only 15 are on the COMPASS database.
- 1.1.2 The map on the following page shows the areas with the largest undercounts across the city.

Map 3. Neighbourhoods across the city with the highest undercount on the COMPASS register (areas shaded blue have the highest number, and those shaded yellow, the lowest)

Undercount of children with disabilities in the Compass Database

SOAs ranked across Brighton and Hove. Source: Amaze/DWP. Date: 2010/2011.



Which ethnic groups are over/under represented in among groups with disabilities in Brighton and Hove?

1.1.3 The COMPASS database provides details on the ethnic breakdown of children on the system. This is based on broad ethnic groups which broadly correspond with the standard ethnic groups included in the 2001 Census and ONS population estimates⁵. We can therefore compare the numbers of children on the COMPASS database in each broad ethnic group with the number of children in the city as a whole⁶ in these groups to see if any ethnic groups are more likely to be in the COMPASS database (and consequently have a higher prevalence of disability). The age bands in census⁷ ethnic group figures differ from COMPASS database, with children covered under the 0-15 age range rather than the 0-19 in COMPASS. So we needed to filter this age band from the COMPASS groups.

Findings

1.1.4 People in Black Caribbean groups were more likely to be on the COMPASS database than other groups, with 13% of Black Caribbean children aged 0-15 on the amaze database⁸, compared with 2% of White British children. Other Asian were also significantly over-represented 9%. In absolute numbers terms, the highest number of children on the COMPASS database from a particular minority group was 'Other White' with 18 (which include children from EU countries such as Poland), followed by Bangladeshi with 16 children.

For further information on the Databridge project see www.databridge.org.uk.

OCSI, 21st October 2011

⁵ The COMPASS register includes an additional category for the large local Coptic community.

⁶ As Census data is available at small area level, it would in principle be possible to estimate the proportion of people with learning disabilities in each ward by ethnicity. However in practice, the numbers of children in each ethnic minority group is too small for robust analysis at neighbourhood level.

⁷ We used census data rather than ONS data for ethnicity because the ONS figures are based on applying the national birth rates of people from different ethnic groups to the ethnic profile of child bearing age cohorts in each Local Authority. These cohorts tend to be less reliable in university towns, where a large proportion of people in their late teens and early 20s are less likely to remain in the area to have children.

⁸ Albeit with low numbers.

Coffee Morning

Do you have a child with a disability, health problem or who is having difficulties at school?



All Sessions held at
Moulseccomb Primary School
in the Island Room

Dates & Time:

Mon 19th Nov 2012, 9am

Mon 3rd Dec 2012, 9am

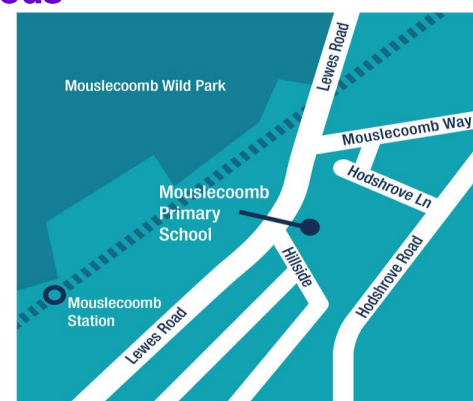
Mon 17th Dec 2012, 9am

Mon 21st Jan 2013, 9am

- Check you're getting all the benefits and services you have the right to
- Come and find out what's out there to help you
- Chat to other mums, dads, grandparents and carers
- Bring any friends who also have a child with special needs
- Under 5s welcome
- Free tea and coffee

Amaze is a local charity supporting parents who have children with special needs and disabilities. For a confidential chat about your child call the Amaze Helpline on 01273 772289. Or look at our website: www.amazebrighton.org.uk

Or for more information contact your local community development worker Kalishia Le Coutre on tel: 01273 676416, mob: 07411 251969 (call or text) or Kirsty Walker on 01273 262220



Island Community Room
Moulseccomb Primary School
The Highway
Moulseccomb
Brighton, BN2 4PA

Supported by the Trust for Developing Communities and Amaze

Amaze Brighton and Hove, UK Company Limited by Guarantee No: 3818021 Registered Charity No: 1078094



Coffee Morning

Do you have a child with a disability, health problem or who is having difficulties at school?



Come along to this support network and meet other parents and carers in a similar situation

All Sessions held at Moulsecocomb Primary School in the Island Room

Dates & Time:

Monday 12th November 2012, 9am

Monday 3rd December 2012, 9am

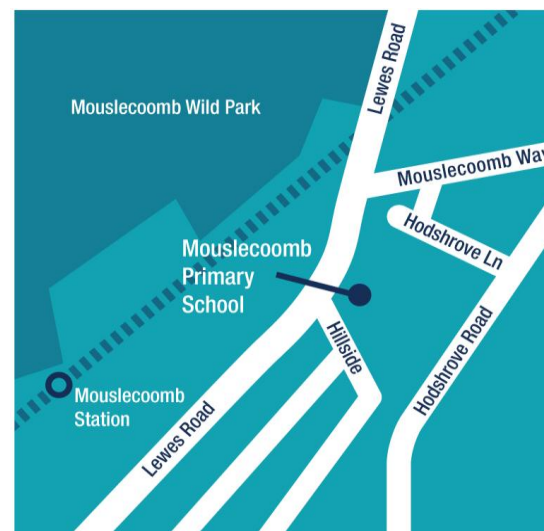
Monday 17th December 2012, 9am

Monday 7th January 2013, 9am

Monday 21st January 2013, 9am

Supported by the Trust for Developing Communities and Amaze

- Check you're getting all the benefits and services you have a right to
- Come and find out what's out there to help you
- Chat to other mums, dads, grandparents and carers
- Bring any friends who also have a child with special needs
- Under 5s welcome
- Free tea and coffee



Island Community Room
Moulsecocomb Primary School
The Highway
Moulsecocomb
Brighton, BN2 4PA

Amaze is a local charity supporting parents who have children with special needs and disabilities. For a confidential chat about your child call the Amaze Helpline on 01273 772289. Or look at our website www.amazebrighton.org.uk

Or for more information contact your local community development worker Kalishia Le Coutre on tel: 01273 676416, mob: 07411 251969 (call or text) or Kirsty Walker on 01273 262220



Hangleton and Knoll Family Coffee Morning

Do you have a child with a disability, health problem or who is having difficulties at school?



The Hangleton
& Knoll Project
Working for a better community

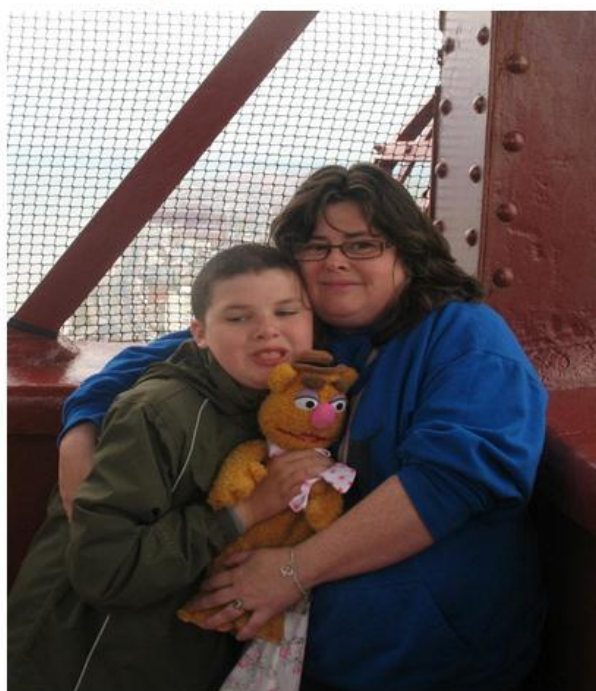
Is your child eligible for or receiving
Disability Living Allowance?

Tuesday 6th November

9.15 - 11.15 am

**At St Richards Church
and Community Centre**

Egmont Road Hove



Local Mum Rhianydd and her son Owen



**Come along and meet other parents
and carers in a similar situation.**

Be part of our Facebook group search Hangleton
and Knoll Family Coffee Morning and Join us!

**Enjoy a free Neck and Shoulder Massage or Manicure.
Tea, Coffee and Homemade Cupcakes provided**



The Hangleton and Knoll Project in partnership with Amaze.

For more information contact Claire Sillence at the Hangleton and Knoll Project
on 01273 383805 Catherine on 01273 410858 or email

claire.sillence@hkproject.org.uk

The Hangleton and Knoll Project is a registered charity no 1139971 and a company limited by guarantee no 7260539.
www.hkproject.org.uk. Amaze Brighton and Hove, UK company limited by guarantee no 3818021 and registered charity no

For more information about Amaze please visit www.amazebrighton.org.uk or call
01273 772289



