

Travellers and carers in Brighton & Hove – March 2018

Report Summary:

1. Introduction

This consultation was carried out by Amaze and Friend Families and Travellers (FFT) as part of the Third Sector investment Programme (TSIP). Amaze and FFT worked in partnership to design and run the consultation among Travellers who are in contact with FFT. This consultation explores the needs of the two communities from an intersectional approach. In particular we wanted to know any specific needs experienced by Travellers who are also carers of a child and/or young person.

To gather data, information and suggestions we ran an online questionnaire, a focus group and a table tennis session attended by young people. A total of 86 Travellers participated in this consultation and reported that:

Online questionnaire:

- Knowledge and awareness about disabilities and additional needs is widespread across the Travellers community
- 24% of respondents are parent carers; 45% have someone in their family and 60% know of someone who has a disability and/or additional needs
- 73% of respondents would like to receive more information and support through workshops and group sessions and also by face to face

Focus group:

- There is great level of support among the Travellers community
- Health care and education services in Brighton and Hove are good
- Travellers' status could have an adverse effect on their entitlements and have a detrimental effect on people's wellbeing
- Face to face home visit, support and advice provided by Amaze is highly valued among the Travellers community
- Easy to read information, both printed and online, should be provided to carers
- Traveller parent carers would like for one representative from their community to link up with Amaze and PaCC

As a result of this consultation we are recommending that:

- Amaze to carry on offering and providing face to face support in the community where capacity allows
- Amaze and FFT to work together on designing visual, accessible and easy read online information to upload on their Social Media

- Amaze and FFT to work together to design an easy read, basic flyer to be distributed among Travellers
- Amaze and FFT to run termly workshops or group sessions in the community if funding can be identified
- PaCC to invite a Traveller parent carer to sit on the Steering Group and be the link between the community and the forum

Report:

1.1 What Friend Families and Travellers (FFT) does

Friends, Families and Travellers is a lead organisation seeking to address the problems facing the Gypsy and Traveller communities providing advice and information along with a wide range of other services to Gypsies and Travellers nationwide.

FFT is the only national charity (registered charity no. 1112326) which works on behalf of all Gypsies and Travellers regardless of ethnicity, culture or background. FFT is also a non-profit making company limited by guarantee (no. 3597515).

FFT work nationally and for this project work solely with Travellers within Brighton and Hove City- whether they are resorting to or residing in Brighton.

1.2 What Amaze does

Amaze is Brighton and Hove's 'one stop shop' for families with children with disabilities and additional needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Amaze also manages the Compass Database and the Compass Card, a free leisure incentive card for 0 to 25 year olds with significant disabilities or special needs who live or go to school in Brighton and Hove.

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

1.3 What PaCC does

The PaCC, hosted by Amaze, is a city-wide engagement group with over 340 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs.

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

PaCC gives a voice to parent carers using different engagement methods as for example focus groups and forums to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve services for families.

2. Intersectionality

Brighton & Hove City Council (BHCC) and the local Clinical Commissioning Group (B&H CCG), through their Brighton & Hove Communities and Third Sector Investment Programme (TSIP), fund Amaze and FFT to engage with parent carers and Travellers. This consultation explores the needs of the two communities from an intersectional

approach. In particular we wanted to know any specific needs experienced by Travellers who are also carers of a child and/or young person. We want for this consultation to make clear recommendations on how Amaze, PaCC and FFT and also BHCCG and BHCC can work collaboratively to meet those needs.

3. Methodology

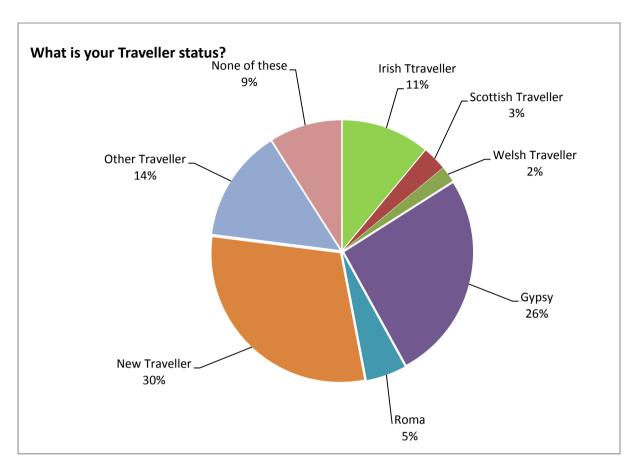
To gather data and information for this consultation we used two different methods:

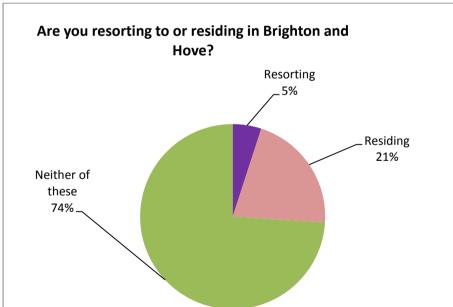
- An online questionnaire, easy to navigate and co-produced by Amaze and FFT and then
 designed with help from Amaze Database Manager. The online questionnaire had a few
 questions with 'please select' and 'tick boxes' options and boxes to provide extra
 information and feedback (See Annex 1: FFT, Amaze and PaCC surveymonkey survey).
 FFT posted the online questionnaire on their closed Facebook group. We received 67
 completed questionnaires which were collated into a summary (See Annex 2: Annex 2
 Travellers consultation survey 2018 Sharedexplore Public-view) and used to inform this
 report. Respondents to the online questionnaire weren't necessary parent carers.
- A focus group which we run in partnership at the Community Room at St Michael's Way Site. Nine carers took part to the focus group. Some of the participants were carers of children and/or young people and some carers of adults. Comments and suggestions from the focus group are included in section 5 of this report.

FFT Project Coordinator also organised for some photos to be taken at one of Tuesday table tennis sessions at Brighton Table Tennis Club. Young people from the Traveller community were coached by coaches with Down's syndrome.

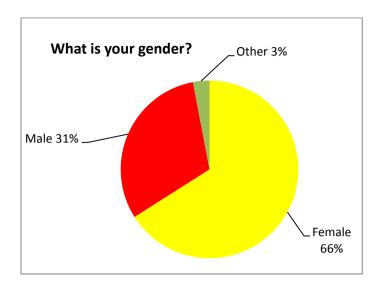
Parent carers' contributions to this consultation are reported in verbatim so to better reflect their experiences and comments.

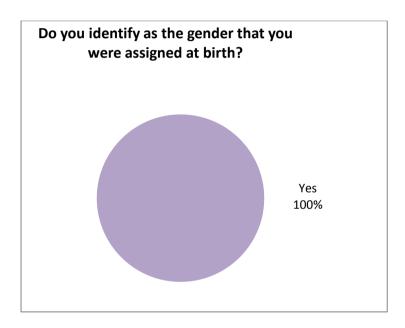
4. Demographics from the online questionnaire

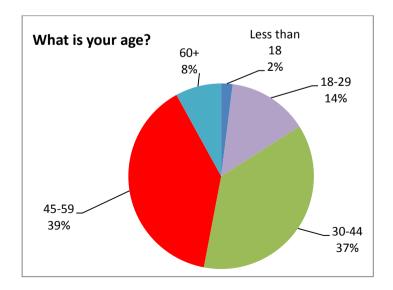


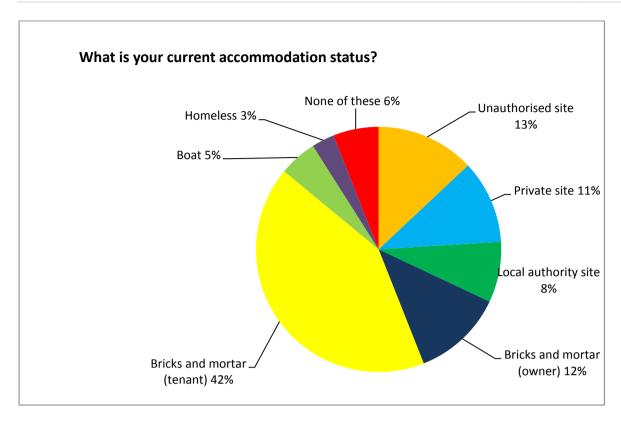


According to FFT's client database 45% of Travellers FFT work with have low or no literacy. The terms 'resorting' and 'residing' are not often used in the Traveller community therefore the high percentage of 'neither of these' suggest that participants of the survey didn't understand what the terms meant. In future surveys we will change the questions to 'living in Brighton permanently', 'staying in Brighton for a short time/ travelling', 'visiting Brighton', 'none of these'; this will provide more arcuate data.





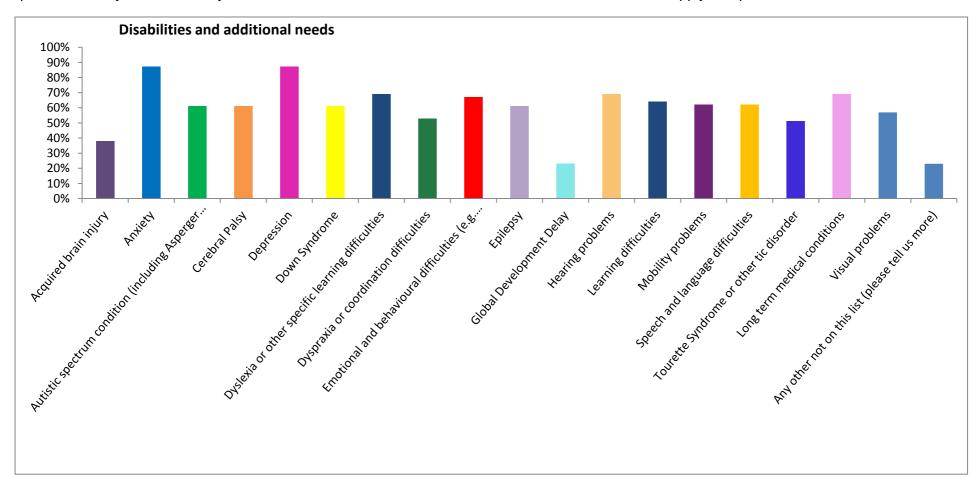




5. Findings from online questionnaire and focus group

5.1 Awareness of disabilities and additional needs

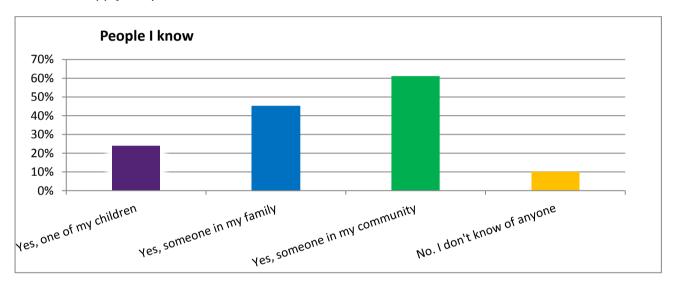
First of all we wanted to find out the level of knowledge of different disabilities and additional needs among the Traveller community. To the question 'Have you heard of any of the disabilities and/or additional needs below? Please tick all that apply:' respondents told us:



The findings clearly indicate that overall there is a widespread awareness about disabilities and additional needs among the Travellers community. Whilst anxiety and depression are known by approx. 87% of people who completed the online questionnaire many other disabilities and additional needs are equally recognised by an average of 50% of respondents. Among 'any other not on the list' people included asthma, angina and pathological demand avoidance or PDA. Full list of other disabilities and additional needs is available on the summary (See Annex 2: Annex 2 Travellers consultation survey 2018 - Sharedexplore - Public-view).

5.2 People you know

To the question 'Do you know of anyone with disabilities and/or additional needs? Please tick all that apply' respondent told us:



This online questionnaire was posted on FFT Social Media and not specifically targeted at carers. Findings point out that a quarter of people who completed the survey are parent carers, a high proportion of the respondents. 45% of people who completed the survey have someone in their family who has disabilities and/or additional needs. In addition to that over 60% of respondents reported to know someone in their community who has disabilities and/or additional needs. These percentages indicate that there are quite few families among the Traveller community who have children and young people with additional needs and disabilities.

Carers who participated on the focus group agreed that there is lots of support within the Traveller community. One parent commented that 'there is a lot of community support going on here, we help each other out. Everyone knows what's going in a family and people are ready to help out. Children are aware of a child who has additional needs or a disability and they respect that. I have never felt any barrier within our community'

Many carers also agreed that services in Brighton and Hove are really good. One parent commented that 'access to GP used to be difficult, they used to ask for our passport to prove our eligibility, but now that has changed. GPs are very supportive and welcoming'.

Interestingly, people commented on the fact that a diagnosis of disability or additional need makes the difference and once a diagnosis has been confirmed the services come together and so do benefits and support. This is true for all parent carers we heard from.

Similar satisfaction is expressed in relation to education. One parent has a child who attends a special school in the city, and she observed that 'special schools provide really good support; they inform and give flyers and other stuff, the same should happen with mainstream schools'. Another parent talked about the good support from a mainstream school where her child goes.

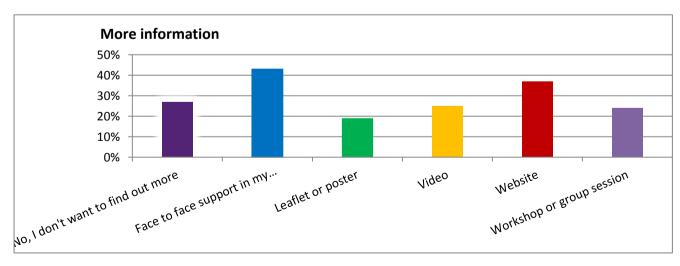
Travellers experience barriers to services in accordance with their traveller's status as for example problems faced by someone who lives in permanent accommodation or in transit accommodation. When in transit the situation can change all the time and of course parents want their children to get an education and get the best support available but the future is quite unpredictable.

One parent commented that she feels people in Brighton and Hove are listening to her and also keep her informed, and the support received from the Hospital has been great. The family lives in the transit section of the Site where they can stay only for three months at the time. They have been waiting for accommodation suitable for her son but none has been offered so far. And the Council is now threatening the family with eviction from the Site following refusal of accommodation. Amaze has been supporting the parent with claiming DLA for her son, she states 'My son is in the caravan all the time, unable to go anywhere. With higher rate of DLA mobility I could buy a car and could take my son to places'

The unpredictability of the Traveller's status does put extra pressure on the family and the stress levels are enormous. That amplifies anything that another parent experiences.

5.3 How and where to find out more

The main aim of this consultation was to find out from Travellers themselves which method of information and support would work best for them. To the question 'Would you like to find out more about disabilities and/or additional needs? If yes, how would you prefer to access that info? Please tick all that apply' respondents suggested:



73% of Travellers who completed the online questionnaire said they would like to get more information about disabilities and additional needs. The most popular method would be by

face to face support in the community followed by online information which could include a video. Some respondents would also like to have a workshop or group session which could be delivered, where possible, in the community, as for example using the Community Room at St Michael's Way Site.

Participants to the focus group confirmed that the best way to keep Travellers informed is through face to face, and while talking to people in a group is good for information a more confidential setting needs to be offered as some people prefer to talk in confidentiality. Amaze and The Carers Centre for Brighton & Hove could provide monthly information sessions and one to one in the community, if funding could be identified for this.

A parent suggested 'To have a person we can relate too, someone we can trust and understand us'. Ongoing support from one trusted person, a referral point' was also underlined by another participant 'for me it is very important to have one person as a referral point. We spent time and time again on repeating what we need; our children/young people conditions and needs. Having not to repeat that all the time will save so much time and make ourselves more relaxed and less stressed. For someone to record the situation, write everything on a letter..'

Everyone in the focus group agreed that more information would be very good but the format is very important because many Travellers are less able to read and write. Ideally people would like information which is less wordy and more visual. People also suggested that Amaze could have a very basic flyer with a recognisable photo or logo and a number that parents can call and get all the information they need about child and or a young person.

Two parents had already been supported by Amaze when the DLA Project Manager visited the Traveller Site and people reported a very high satisfaction with that because they can have the privacy to talk about personal stuff.

5.4 Other important issues and/or findings

Focus group participants talked about how Travellers are still experiencing abusive language and exclusion from other public places like shops, bars and restaurants. Having a child with additional needs can make these situations more complicated. One parent carer commented 'Sometimes we experience challenging situation in shops and supermarkets. People don't understand or don't see the 'disability' because my child looks neuro typical. What I do now when those situations happen is to tell the person in the shop that my child has an additional need and then they just relax and are not bothered by my child running along aisles. I feel that overall there is more awareness in Brighton about additional needs and disabilities. People and places are much more welcoming than other places. I used to live in London and people did react very negatively to situations similar to the one I just described'

One of the focus group participants has been supported by Amaze. She also has been supported and given advice to many parent carers in the Site. During the focus group it was suggested that she could become the link with Amaze, and perhaps get involved with PaCC, a sort of Travellers representative.

6. Table tennis engagement and outcomes

In a bid to raise awareness of learning disabilities in the Traveller community FFT arranged a meeting with Tim (director at Brighton Table Tennis Club) to discuss how table tennis could help break down potential barriers in the community. Tim arranged for 2 coaches (A and C) with Down's syndrome to have a one off session to train young Travellers in their weekly table tennis class. The session went incredibly well, the coaches introduced themselves and asked all the young people for their names and a brief introduction. The coaches then set up various table tennis exercises, offering the young people advice and showing them good techniques. The young people were constantly asking the coaches for advice and were also having general conversations; asking different questions like "how long they have been coaches for?", "when did you join the club?". The session ended with the young people paring up with coaches to play doubles, all the children were eager to pair up with both A and C.

On the minibus ride home I asked the young people if they knew what Down's syndrome was. None of the young people had ever heard of that condition before, however they did recognise that A and C had a learning disability.

Feedback from the sessions was really good from both the young people and the Table Tennis Club. A and C will now be coaching the young people every Tuesdays for the foreseeable future.



Young Traveller at Brighton Table Tennis club under the Roma flag (Traveller flag)

7. Recommendations

- Amaze to carry on offering and providing face to face support in the community where capacity allows
- Amaze and FFT to work together on designing visual, accessible and easy read online information to upload on their Social Media
- Amaze and FFT to work together to design an easy read, basic flyer to be distributed among Travellers
- Amaze and FFT to run termly workshops or group sessions in the community if funding can be identified
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7. Annexes

Annex 1: FFT, Amaze and PaCC SurveyGizo survey

Annex 2: Annex 2 Travellers consultation survey 2018 - Sharedexplore - Public-view

Annex 3: FFT Table Tennis Photos