



Parent Carers, Food Poverty and Active Living – April 2017

Report Summary:

With this engagement work Amaze and Parent Carers Council (PaCC) asked parent carers to talk about their experience of food poverty, defined as the inability for a person or a family to obtain and provide healthy food to their families. This report also looks at parent carers' and their families' ideas for healthy living, including taking part in activities.

We found out that **17% families are skipping meals** or don't have enough to eat as a result of economic hardship, changes in the benefits system and not enough time to prepare and cook healthy food due to their caring role. With the cost of living going up and stagnant income **33% of families with disabled children are experiencing food poverty**. Uncertainties around the new benefit system and its impact on parent carers and young people are having a negative impact on families' budget and on families' health and wellbeing.

In relation to active living our report reaffirms the importance of the provision of affordable and local activities but it also highlights the extra barriers that families with children with additional needs have to overcome. Among those are that some activities are not 'additional-needs' friendly' and sometimes incur higher costs. Amaze's Compass Card has resolved many of those barriers for local families, and more recently the City's Carers' Card, make some health and wellbeing activities more affordable but more can be done so that the whole family can enjoy an active life.

1. Introduction

1.1 What Amaze does

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

Since 1997 Amaze has been engaging parent carers at all levels of services provision for their child or young person, for themselves and for the whole family. Their aim is to increase parent carers' resilience and confidence which in turn has a direct effect on the

lives of their children. Since September 2014, in line with the new Children and Families Act, Amaze has been supporting families, and young people with SEND themselves, up to the age of 25.

1.2 What PaCC does

The PaCC, hosted by Amaze, is a city-wide engagement group with over 300 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs.

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

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

1.3 Parent Carers' engagement through B&H CCG

Brighton & Hove Clinical Commissioning Group (B&H CCG), through its Engagement Gateway Contract, funds Amaze and PaCC to gather information and present concerns and suggestions on health care services which they access as carers or for their disabled children (*See Annex 1: How Amaze and PaCC engage with parent carers*). As a result the local CCG is provided with clear intelligence about how children and young people with a variety of disabilities and their parent carers experience local NHS services.

In addition the local CCG's understanding of the needs of disabled children and their parent carers is improved, and health services are correspondingly made more responsive and are targeted to actual need. And finally parent carers feel that their views are valued and that they can influence decision making regarding local NHS services, and help effect change. PaCC and Amaze provide regular feedback and updates on the engagement work to parent carers through their termly newsletter and through social media.

2. Parent carers, active living and food poverty

At Amaze and PaCC we are fully aware of the extra demands that looking after a child with additional needs requires. That includes parent carers having less time to dedicate to other activities that perhaps some other people take for granted. There is also the economic factor to take in to account, the impact of caring for a child with additional needs on a family budget. Throughout the years reports have highlighted the difficulties facing families with children with additional needs.

With this consultation we wanted to look at how food poverty is experienced by parent carers and its effect on families with children with additional needs. For this consultation we understand food poverty as an individual or a family who for various reasons isn't able to obtain healthy, nutritious food, or can't access the food they would like to eat.

We also wanted to ask our parent carers what an active living meant to them and what barriers they experience when they try to participate in sport, leisure, dance and fitness activities, gardening and other physical work activities available in the city. As Amaze is

contracted by Brighton & Hove City Council to manage the Compass Card, a free discount card to access sport and/or leisure activities for young people 0-25 with significant disabilities, we thought useful to look into how parent carers also value this.

Suggestions and recommendations from this report will be passed on to Brighton & Hove Clinical Commissioning Group.

3. Methodology

Information and data for this consultation was gathered by three different methods:

- survey of Amaze services which answers date from within the past 2 years
- a short online questionnaire focusing on food poverty
- evaluation of Compass Card activities, managed by Amaze

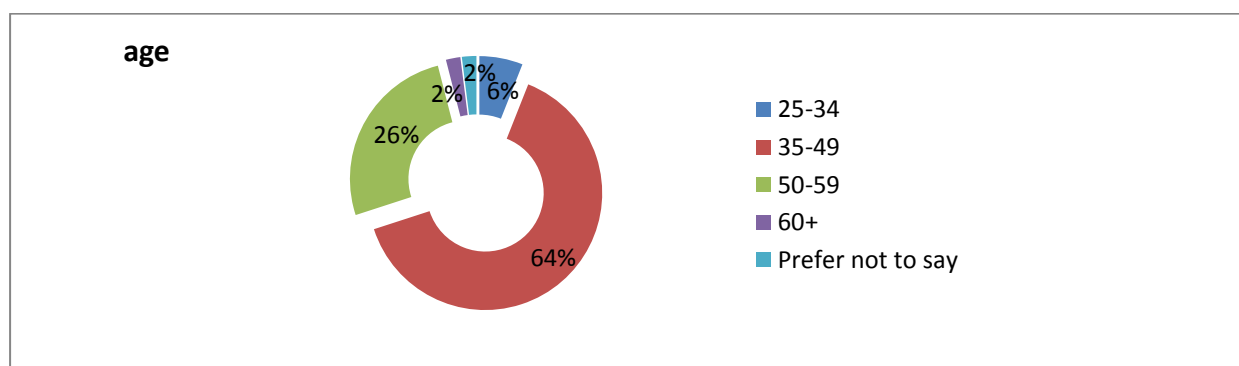
The survey of Amaze services (e.g. Compass, DLA, IAS) included a question about food poverty, 904 parent carers completed the survey.

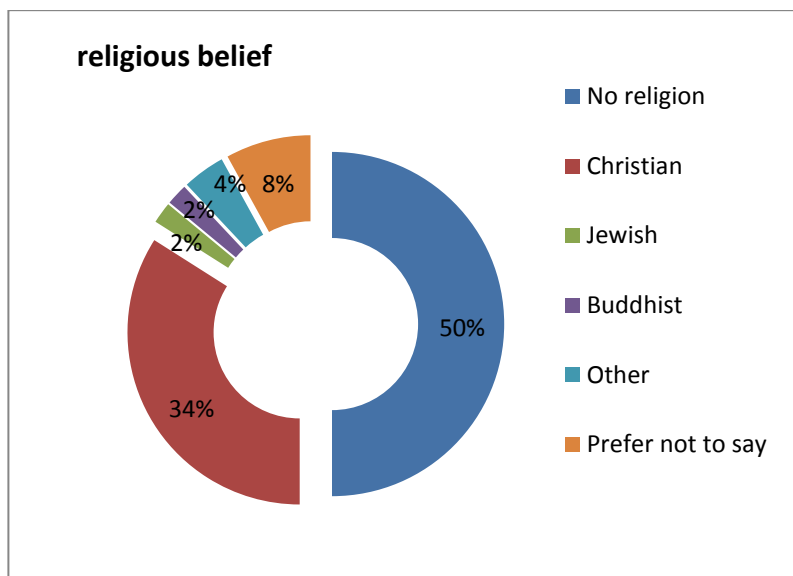
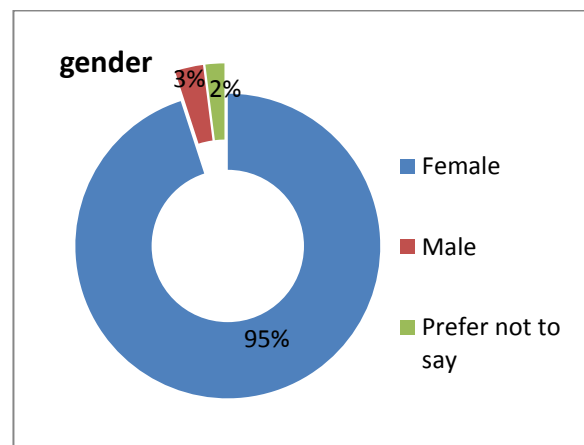
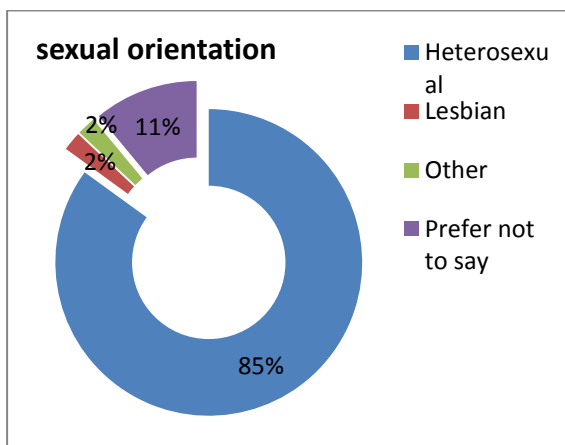
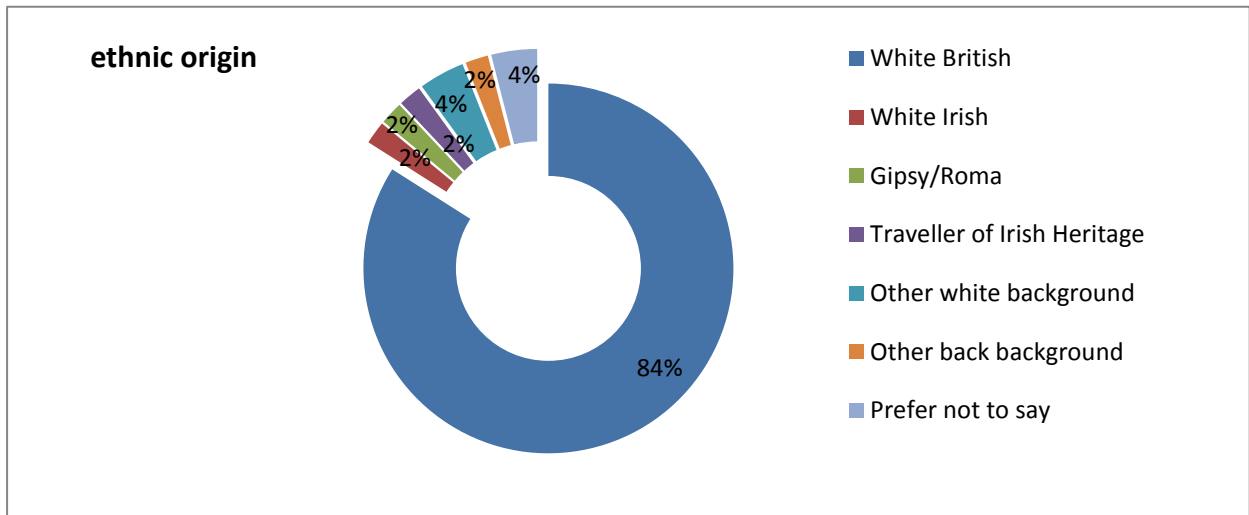
The online questionnaire was designed with help from Amaze Database Manager. The online questionnaire had a two questions with 'please select' and 'tick boxes' options and boxes to provide extra information and feedback. The questionnaire was sent to all parent carers who are on the Compass Register. We received 62 completed questionnaires which were collated into a summary ([Annex 2: PaCC_CCG Survey on Food and Health](#)).

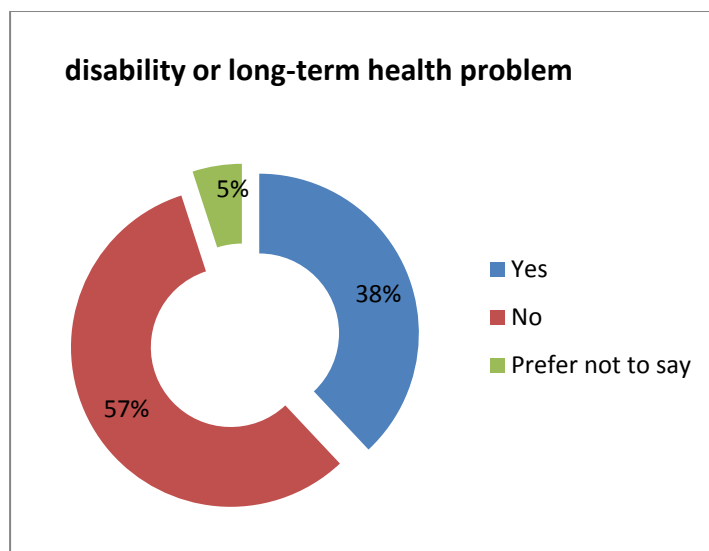
The evaluation of Compass Card activities included various questions about leisure activities and frequency and how they have helped with physical health, socialisation etc.

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

4. Demographics from the online questionnaire

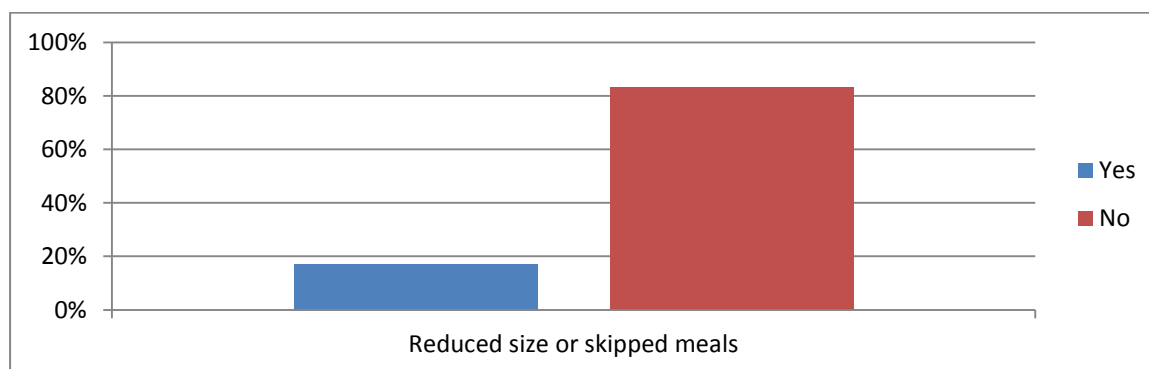






5.a Findings from survey of Amaze services

In order to provide services that reflect families' needs Amaze survey people who are on the Compass Database. The ongoing survey includes a question about food poverty.



To the question - *'Do you ever reduce the size of your meals or skip meals for the family because there isn't enough money for food?'* **17% of parent carers reported having skipped meals or reduced the size of them, as there wasn't enough money to feed the whole family.** Almost two thirds of the parent carers who reported this rely solely on benefits but one third report that they have at least one paid income coming into the household.

This is a very worrying finding, and not just because is happening in one of the richest countries in the world. It also speaks volumes about the complex circumstances many families are experiencing whereby an already difficult situation is worsened by the inability to put food onto the table.

5.b Findings from short online questionnaire on food poverty

To add to the data above we also run a short online questionnaire which explored a bit more in depth the findings on parent carers and food poverty. We received 62 completed questionnaires. Our first question looked in to family budget and basic living costs.



33% of respondents stated that they will not have enough money to pay for basic costs of living [tend to/strongly disagree].

A parent carer pointed out that the **cost of living is increasing while income doesn't**, one parent commented '*Cost of living increases. Wages stay the same and taxes increase. Also cost of gas and electric is becoming more expensive. Healthy foods cost more*' and another parent added '*All the prices are going up but not the income. It is getting more difficult to make the ends meet*'. Also living in an expensive city is becoming impossible for some parent carers '*With no rent caps rents are increasing so working class people can't afford to live in Brighton*'.

This issue has dominated the national news during the past weeks. According to some reports income in UK has not increased for long time while the cost of living has. The living wage, whilst an informal benchmark, and not legally enforceable like the national minimum wage, has received some news coverage and some companies have subscribed to it. **The living wage is based on the amount an individual needs to earn to cover the basic costs of living.**

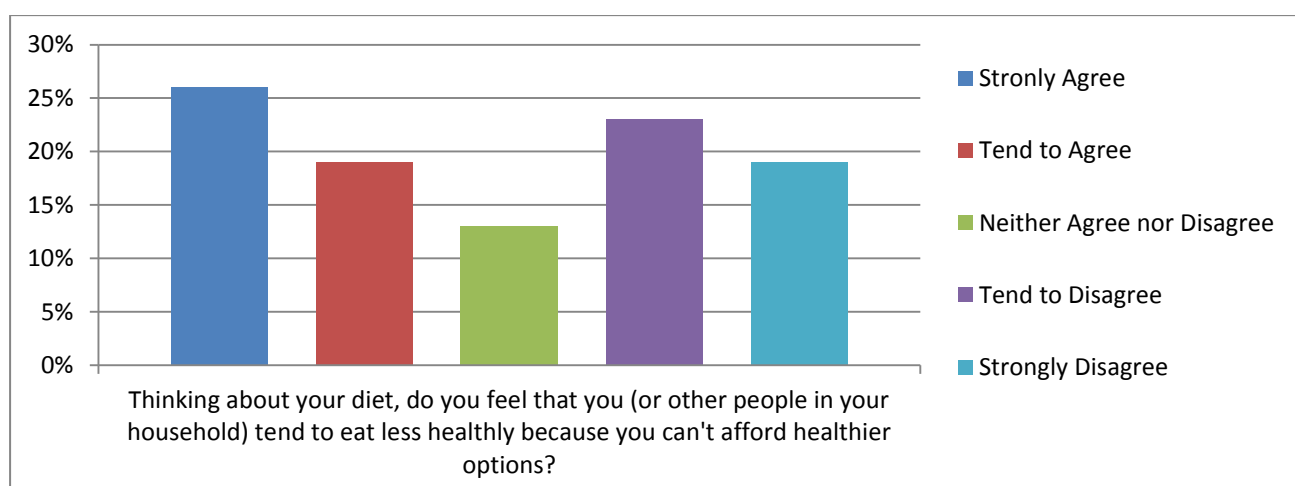
The increase on living costs and **changes on the benefits system are having a huge impact on many families who have one or more children with disabilities and additional needs.** A respondent commented '*It's not so much the usual household bills as the extra expense of having a special needs child*' whilst another pointed out '*If PIP is not renewed, or level goes down, we will be supporting our disabled son more financially and we will not receive careers allowance either*'.

Many reports highlighted the fact that supporting a child with additional need cost approx. three times more than providing support to a child without additional needs. And if we take into account that many parents with children with additional needs are single parents we can clearly see how detrimental this is on certain families. In addition some parent carers have a disability themselves '*We cannot afford to live a basic lifestyle currently. I have coeliac*

disease as well as my son having autism and we cannot afford for me to follow a gluten free diet. I used to buy all my food fresh and cook for scratch but now I find fruit, vegetables and meat too expensive for us to afford. **Things are so bad that I am anaemic to the point of possibly needing a blood transfusion and all my iron stores are depleted. This is totally diet related'**

Nearly 50% of respondents to our questionnaire could potentially experience food poverty as a result of real or perceived uncertainties in terms of costs of living. A respondent summarised the complex issue facing parent carers *'Yes we barley have enough money now sometimes to buy healthy food and I do occasional miss a few meals to make sure my family are eating healthy. The cost of food keeps going up, quantity goes down and bills go up, income stays the same. I do put some food shop on my credit card. My credit card balance is getting high'*

The second question from our online questionnaire then tapped in to families' diet and ability to buy healthy food.



Findings from the question above underline the fact that some parent carers try their best to have an healthy diet, as stated by one of the respondents *'We eat as healthily as we possibly can, knowing that it costs us more'* and another *'Cooking from scratch is cheaper than buying processed foods so not having much money encourages me to cook food and therefore be more healthy. Oh and not eating out either'*. But that is not always the case and **approx. 50% of respondents reported that they have to cut down on healthy food because they can't afford it.** One parent observed *'Having a big family ... would love to give everyone more fruit/veg and healthy choices but that comes with a more hefty price tag compared to junk food'*. Another parent highlighted the **demand on looking after a child with additional needs** *'Having SEN children it can make it a lot harder to cook from fresh, so whilst you may eat a variety of foods, some may be supermarket prepared meals'*.

Following a healthy diet can have additional challenges when looking after a child with additional needs. A respondent commented *'My son hasn't yet learned to feed orally (age 6) so we end up buying all sorts of unhealthy stuff to try and tempt him - which is potentially wasted or his sisters eat it which I would not normally choose for them'*.

Some children with additional needs follow a special diet which can put an extra demand on the family's budget *'My son is gluten and dairy free. There are good varieties of food, but they are expensive! The bread cost from 2-3 pounds'*

A parent condensed the complexity of the situation by commenting *'Sometimes the demands of crises occurring when caring for a child with additional needs, can mean **there's not time or energy to cook from scratch**, which is always our preference ...'*

5.c Active Living

From previous consultations **parent carers told us that they would like to be more active and exercise**, including going for a walk, playing a game or swimming, all activities that are very popular choice for people to also build their emotional strength. **Some parent carers wanted more activities to be provided and be advertised on a website**, for example hydrotherapy treatments and alternative therapies. Some respondents to our consultation were worried that **many activities that were once provided for free where been reviewed and perhaps closed down or limited in number or access** (*See Annex 3: Mental Health and Wellbeing - views from parent carers of disabled children*)

Overall many respondents to our previous consultations found the **carer role limiting the opportunities to get more active**. As much as 22% of parent carers who responded to our survey told us they hadn't had a single day or even an evening off from caring in over 6 months. The majority of respondents, **71%, felt that they don't look after themselves well enough or are in fact neglecting themselves**, and this increases to 85% if the parent has disabilities or additional needs. The main reason is because parent carers feel overwhelmed with the needs of their children, siblings, partner and/or household such that their own needs fall off the bottom of the list (*See Annex 4: Survey2013Analysis Report*).

The same survey pointed out that **20% or respondents felt socially isolated** and this increased to **35% if the parent carer had disabilities or additional needs**. A further **53% of parent carers said that they don't get enough social contact**.

A solution to that barrier would be to offer **more leisure activities or outings for the whole family**, and 99% of respondents agreed with that. Amaze is working hard to develop the Carers Card and Compass Card offers within the city. The budget for developing offers on the Compass Card has reduced drastically this year and the Sport England funding for developing inclusive activities ended in March'16.

Even with more options available some families can still face barriers to accessing them e.g. affordable and/or accessible transport, need for independent travel training and buddies/befrienders to accompany young people, cost etc.

A report evaluating the impact of Compass Card for families with children with additional needs highlighted the fact that **through the Compass, local families ended up doing things together in the same way as other families would take for granted**. As a result families became more active and physically fit and also more connected with other families with children with additional needs and overall an improved quality of life, happier and healthier (*See Annex 5: Opening Up Our World Through the Compass Card Gateway*).

The same report highlighted the financial barrier on joining activities and it underlined the importance of activities which are affordable. 99% of parent carers reported that the Compass Card has done exactly that. Parent carers spoke of how difficult it was sometimes to go to mainstream activities as a whole family. **Many parent carers especially those with children who have behaviour problems and/or who have hidden disabilities** such as ASC described situations where they felt judged as ‘bad’ parents because of the way their children might behave. Other issues such as their **children not understanding taking turns or queening can be significant barrier at leisure activities especially where this is not understood or recognised by the provider.**

Better and more provision of activities for the children would free time for parent carers to become themselves more active. And finally **travelling to an activity is also a barrier** and many parent carers would like *‘Something local’*.

8. Recommendations

- **For Brighton and Hove to create a safety net for families with children with additional needs who struggle financially**
- **This should include additional and ongoing funding for the Amaze DLA Project which brings in approximately £3million of (non means tested) additional benefits to families with disabled children**
- **Pressure on local supermarkets and independent stores to offer discounts on fruit and vegetables for families with a Compass Card so that families with children with additional needs are able to buy more affordable healthy food.**
- **For families to receive more information on how to eat healthy food even when dietary requirements limit diversity of food. For example Amaze and PaCC could encourage the parent carer community to share some links to very quick-to-make, child-friendly, healthy recipes on our Facebook groups.**
- **More affordable and inclusive activities organised across the city for the whole family.**
- **More activities for children with additional needs so their parents can use some of the time to take care of themselves (become more involved and more active) Consideration of more investment in the City’s Compass and Carers’ Card schemes.**

9. Annexes

Annex 1: How Amaze and PaCC engage with parent carers

Annex 2: PaCC_CCG Survey on Food and Health

Annex 3: Mental Health and Wellbeing - views from parent carers of disabled children

Annex 4: Survey2013Analysis Report

Annex 5: Opening Up Our World Through the Compass Card Gateway