



Opening Up Our World Through the Compass Card Gateway

The Stories and Experiences of Parent Carers and their Children with Additional Needs
Using the Brighton & Hove Compass Card

A leisure incentive card providing discounts and free access to leisure, sport and recreation for Compass Card holders



Summary of Key Findings

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Abbreviations and Definitions

Additional Needs We use the term additional needs throughout to describe the individuals registered on the Compass Database and relates to those with disabilities and special educational needs.

Child(ren) Many families who took part in the consultation for this evaluation have more than one child, sometimes with and without additional needs. We therefore use the generic term of child(ren) through out except where it is relevant to refer to children and young people.

JSNA Joint Strategic Needs Assessment. Joint Strategic Needs Assessment describes a process that identifies current and future health and wellbeing needs in light of existing services and informs future service planning taking into account evidence of effectiveness. Joint Strategic Needs Assessment identifies 'the big picture', in terms of the health and wellbeing needs and inequalities of a local population.

JHWS Joint Health and Wellbeing Strategy

SEND Special Education Needs and Disability

Parent carers Parent carers are people with parental responsibilities (parents, grandparents, foster parents, adoptive parents and others) who also provide additional care, assistance and support to children with learning or physical disabilities; complex health needs or illness or emotional behaviour difficulties.

PSSRU Personal Social Services Research Unit based at Kent University and London School of Economics.

Compass Card Database - Is Brighton & Hove's Disability Register, which Amaze is commissioned to run. It is sometimes referred to in Brighton & Hove as 'The Compass' throughout this report we refer to it as the Compass Database to be more understandable to a wider audience.

Compass Card Partners - refers to the businesses, charities and social enterprises that offer discounts to children and young people registered on the Compass Database.

Compass Card Activities - currently Amaze has funding to support 12 specific activities for children and young people with additional needs. These are endorsed by Amaze. Where relevant we refer to Compass Card Activities. Where we refer to 'activities' this is a generic term referring to activities that parent carers and their child(ren) access with the Compass Card.

Drawings - the drawings in the grey boxes used throughout represent the 'graphic notes' taken during the 2 Focus Groups held in September 2014 with parent carers, and are used to illustrate the points made and issues raised.

Through the Gateway Graphic - the graphic on the front page was designed pro-bono by Barry Gooch www.biggerfishdesign.com.

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The evaluators would like to thank the parent carers who attended the focus groups held in September 2014 and the families we were able to visit and undertake one-to-one interviews with. We would also like to thank the 127 families who took the time to complete our online survey. Thank you also to all the families who gave permission for us to tell their stories through the quotes and case studies which appear throughout this evaluation report.

We hope that we have represented your views fairly and accurately. Your voice is essential in telling the story of the difference the Compass Card has made to your lives.

We would also like to thank the staff at Amaze particularly Ann Blackburn for the information, help and support given throughout.

We would also like to thank our associate, Tim Childs, of Tim Childs Consulting (www.timchildsconsulting.com) who provided significant pro-bono time during August to October 2014, supporting the consultation with parent carers, Compass Card Partners and the writing up of the evaluation report. Thank you also for the laughter and the continuous questioning and challenging of assumptions - keeping us on our toes throughout.

Finally, thank you to Barry Gooch at Biggerfish Design who was inspired to create the graphic on the front page (pro-bono) after reading the case studies and stories contained in this evaluation.

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Opening Up Our World Through the Compass Card Gateway

Summary of Key Findings

The Compass Card is a project of Amaze, a Brighton and Hove charity, that supports parent carers who have children with additional needs. The Compass Card's primary aim is to provide financial discounts and incentives to children and young people with special educational needs and disabilities (SEND) who join Amaze's Compass Database – in order to increase their participation in leisure activities.

Parent carers describe the Compass Card as **'opening up their world'** being a **'lifeline'** and a **'gateway to new horizons'**. Through their voices and experiences we evaluate the social and economic impact of the Compass Card. They describe the difference the Compass Card makes to their lives and how it enables them to have more affordable choices so that they can go out as a family and engage in activities in the same way as families with non-disabled children would take for granted. They also tell stories of the stigma, barriers and challenges they face. Of being judged as parents because their children do not behave in the same way as others; the stress, anxiety and poor mental health of themselves and their child(ren) with additional needs; stories of self harm, depression, and withdrawal from the world before they had the Compass Card.

The profound effect on their lives is inspiring and humbling. Parent carers describe how their **'world opened up'** and how they feel the Compass Card **'has given them their life back'**.

On the next few pages we summarise our findings from the research undertaken during August and September 2014 with a sample of 127 parent carers who completed our survey; 5 - 1:1 interviews and 11 parent carers who attended two focus groups as well as 20 Compass Card Partners who responded to a short survey.

The methodology used, developed by JB Eventus Ltd, is Social Value – Made Real, which provides a coherent framework to establish impact as well as consider Value for Money, Added Value and Preventative Value – eg the potential savings to the public purse as a result of the difference made as reported by parent carers.

The full report provides details of the external and internal operating environment. This is followed by a Social Value – Made Real Outcome Map which provides the framework for the evaluation and evidence gathering. This is followed by a detailed analysis using Social Value – Made Real social and economic value indicators. Recommendations for development and future practice appear at the end of this Summary of Key Findings.

We have included 4 case studies which are a sample of the stories we gathered and appear in the full report. Zena and Ben's story on the next page demonstrates the profound life changing impact the Compass Card has for some families.



"A Gateway to normality, being the same as everyone else."

"A passport to being a fully blown member of the Brighton & Hove Community."

"Just to be able to go and experience things as a family with a little less stress and worry and to not worry about breaking the bank balance and to give the opportunities to my son that any other child can have is just amazing and I can't stress how much it has improved our quality of life. It's given us one."

Zena and Ben Case Study

Ben is nearly 16, he is Autistic and goes to mainstream school. Ben and his parents and younger sister moved to Brighton from the South Pennines 4 years ago. Zena, his mother said:

“Where we used to live no-one understood Autism, his school, teachers and people in the community. Ben was very withdrawn, hardly spoke and was self-harming and often spoke of suicide. People would keep away from us. He was labelled as naughty. He was bullied in school, often beaten up and called names. Our GP wrote to the school, but there was still no recognition of what was happening to him. They called it ‘character building’. We lived in a Pennine village, there was nothing to do there, no cinema, or other activities, we didn’t go swimming, as people could be judgemental of us. I used to go into Moss Side in Manchester to the park, where we would feel more accepted as a family and not judged. I was desperate and couldn’t see any way out. I had to give up work and was constantly worried about what would happen to Ben. I felt trapped and that I would be Ben’s full-time carer as his mental health was deteriorating. I sometimes felt the only way out was to kill him and myself.

The family decided that they needed to move away to somewhere where there were better opportunities for Ben, his sister and parents. Ben’s psychologist in the North West knew about Amaze and gave Zena print outs from the website before they moved. One of the first things Zena did was sign up for the Compass Card. She said that:

“it was extraordinary, a whole world opened up for us straight away. We could go out and be just like any other family. Compass Card Partners accept us they don’t condemn or judge Ben’s behaviour or us as parents.

It was amazing when we first came we would go to the Prince Regent swimming as a family and then to Pizza Express for a meal afterwards, they were Compass Card members at the time. We never did things like this before as a family. We were doing ordinary things that most families take for granted. We also started going to the cinema.

Ben now has the Compass Card in his wallet and uses it himself. He is no longer self-harming, he is growing in confidence and has a great deal of independence. He goes to his music lessons in taxis himself and will now catch buses on his own. The school acknowledge his musical abilities and he plays in every school concert – he plays classical guitar and piano. In his old school they just dismissed his music and were not interested. He is now thriving in school and feels valued. He communicates better, and like any other 15 year old. He still lives in his own world but it is a more content one.

As a family we are all less isolated. His sister benefits too, she is not told at school that her brother is weird and in trouble. She used to write stories about Ben about him not having friends and being different. Ben and Ruth now go to Fun-Fit Spiral together a Compass Card Activity for disabled children and their siblings. Not only are they more active and fitter, but also they are mixing with their peers, disabled children and young people and their siblings.

The whole family’s mental health, finances and wellbeing have improved. I have been able to go back to work part-time. Ben has a real sense of self-confidence, he can do things on his own. For the family it has given us back a sense of normality, we do what other families do, we have a normal life now, and I am not worried about Ben anymore. I don’t worry about what bruises and scratches he will come home with but has he done his homework.

We now feel part of the community, we feel like we belong somewhere and are accepted. The Compass Card is amazing and is so much more than the financial benefits, which are great, it has opened up our world. I can’t begin to imagine life without the Compass Card we would be lost.”

Ben’s father also commented on the transformation he has seen in his son since the family moved. When they lived in the South Pennines he worked away a lot but saw the distress of his wife and recognised their need to move away for the benefit of the whole family.

£1,022,571 total of Economic Impact

£677,000 of financial savings
(savings for 1000 families per annum)

+

£345,571 Preventative Value
(potential savings to the public purse)

£11.88 economic and social value for every £1 of investment

£52.63 investment per child/young person

Economic Impact

The total preventative value as described on the next pages is **£345,571** per annum. Together with the estimate of savings for families this equals **£1,022,571 per annum Economic Impact of the Compass Card**. Current (2013/2014) total funding is £86,000 per annum. That means that there is an estimated economic and social value of £11.88 for every £1 invested in the Compass Card, Compass Database and Compass Card Activities. Below we summarise how we have arrived at these figures. Full details of our methodology appear in Real Value pages 20-21.

Financial Savings

Amaze has estimated that the savings to each family per annum is around £677. In 2013/2014 there were 1634 children with additional needs registered on the Compass Database so if 1000 of their families were to experience this level of saving it would total **£677,000 per annum**. Given that it is well documented that families with disabled children are at higher risk of living in poverty than other families this saving is significant and makes an enormous difference as to whether they take part in sport and recreational activities or not. Increasing choice and being able to make decisions to go out are closely linked to affordability.

This represents excellent value for money currently costing Brighton & Hove City Council just £52.63 per child or young person registered on the Compass Database.

"My son's grandparents can take Tim to activities that might be beyond their means, were it not for the Compass Card. It means that he has richer experiences with them that build their relationship in a positive way. Instead of having to stay at their home, which would become same-y and boring (activities that require staying still and focussing can only be tolerated by Tim for short periods) he can get the stimulation he needs."

99% of parent carers said activities are more affordable

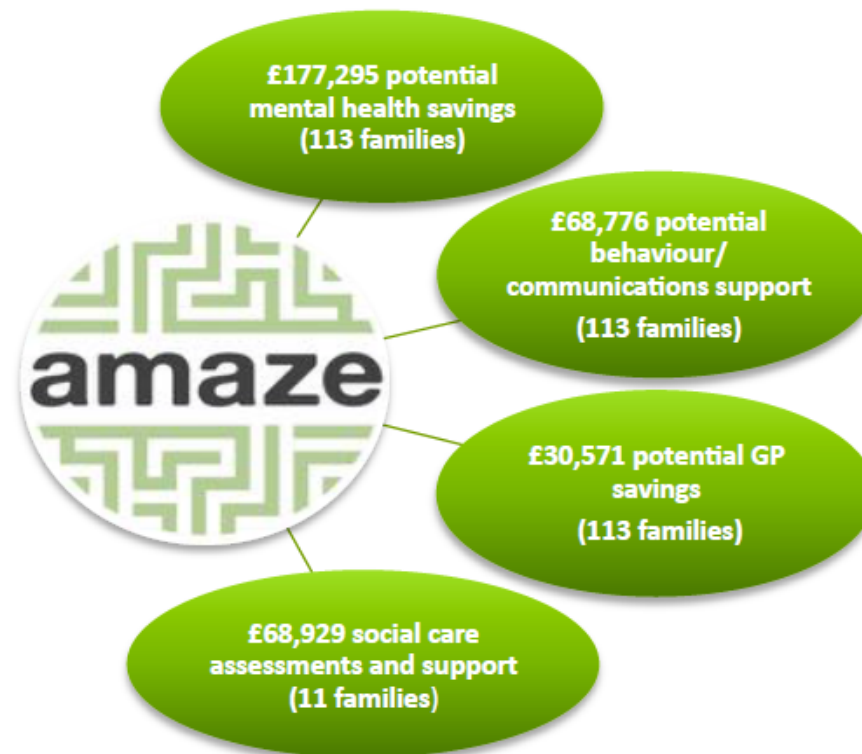
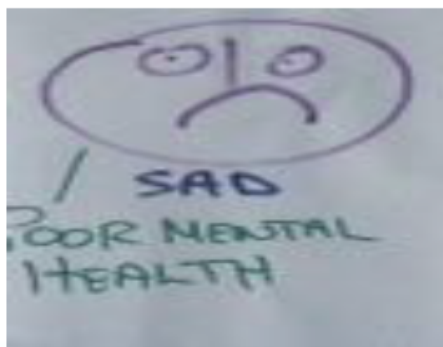
79% of parent carers said we go out more as a family

"The important consideration is that we do not waste money on activities that our daughter refuses to take part in or which have to be aborted due to disengagement / fear etc. Simple activities (swimming / cinema visit) can be enjoyed more frequently as the cost is reduced."

£345,571

potential preventative value savings to the public purse as a result of: reduced stress, improved mental health and crisis prevention for 350 (21%) Compass Card parent carers and their children with additional needs

"I think the main changes are in terms of mental wellbeing. Having a Compass Card has reduced feelings of isolation and increased our sense of pride in seeing our son achieve new things and gain confidence and new friends. On the whole I think the Compass Card has given the whole family much more confidence and a strong sense of feeling part of a community."



Preventative Values

Parent carers reported a wide range of impacts on their lives as a result of the Compass Card including the following which have the potential to reduce their reliance on public services. 28% of respondents to our survey said that the Compass Card had made 'a lot of difference' to their lives in the following areas:

- Reduced stress leading to improved mental health for both parent carers and their child(ren) with additional needs
- Improved resilience and coping strategies

- Improved behaviour, communications and life skills for their child(ren) with additional needs
- Crisis prevention and reduced need for social care assessments and ongoing support.

How we have calculated the preventative value and why we have used 113 or 11 families for the above figures are described on page 80 of the full report. Our methodology seeks to consider realistic levels of potential savings based on the evidence collected and linked to the wider external context of the service being evaluated. We use costs based on respected research often commissioned by Government from UK universities.

99% of parent carers think that the Compass Card has made leisure and sport activities more affordable

98% of parent carers feel that Amaze keeps them informed of Compass Card activities and special offers

80% of parent carers feel that Compass Card venues are more welcoming

Key Findings - Primary Outcomes

The following 3 Primary Outcomes directly relate to the primary aim of the Compass Card as described on page 5. Full details can also be seen in the Outcome Map which appears in Real Measures, pages 33-35 of the full report.

Social Value Outcome 1 The Compass Card increases access to, and choice of, affordable leisure activities for families with children with additional needs.

Social Value Outcome 2 Compass Card holders and their families are more informed about leisure activities that can meet their needs.

Social Value Outcome 3 Compass Card holders and their families take part in more sport and leisure activities.

For Compass Card families, affordability means that they are able to:

- Do more things together as a family in the same way as other families would take for granted
- Be more active and physically fit
- Be more connected with other families with children with additional needs
- Feel part of Brighton and Hove community and connected to the community
- Have improved quality of life, be happier and healthier.

99% of parent carers reported that the Compass Card has resulted in activities being more affordable which is extremely important when it is known that financial barriers are significant for families with disabled children.

Parent carers report that Compass Card Partners are more welcoming and are more able to meet their needs. However there is still a lot more that could be done to remove barriers and negative attitudes that some families reported that they had experienced.

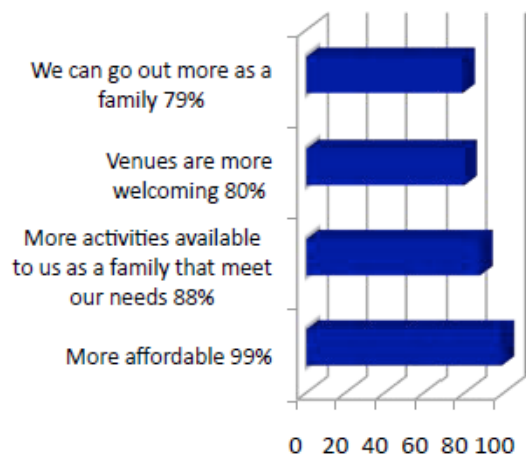
The range and frequency of information provided by Amaze also contributes significantly to enabling families to have increased choice and control. When lives are busy and planning is difficult due to their child(ren)'s disabilities families need regular, easy to access information. Many families referred to it as providing a 'lifeline'.

The title of our report aims to convey the strong message from Compass Card families that the Compass Card represents a '**Gateway to new horizons**', '**opening up a world of opportunities**' and contributes to '**removing barriers and the stigma**' often reported by families.

Being more affordable and increasing choice removes the stress and anxiety of trying something new or just going out not knowing if their son/daughter will be able to cope on any given day.



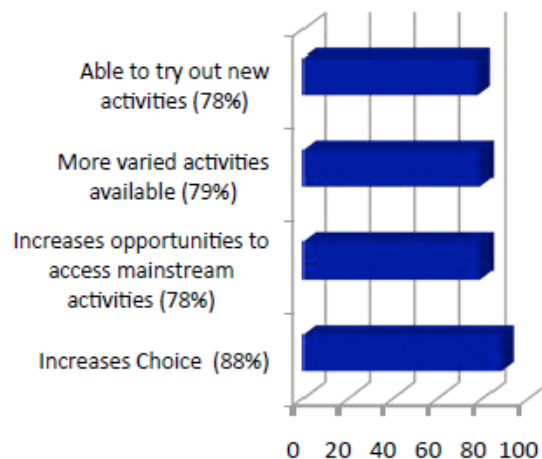
Some difference/a lot of difference



"The Compass Card is fantastic. We have to spend an awful lot of time going out to keep our son occupied (far more than the average family). This gets very expensive and the Compass Card has helped us to keep costs down... making a day out more affordable. This has been the most valuable aspect of the Compass Card for us."

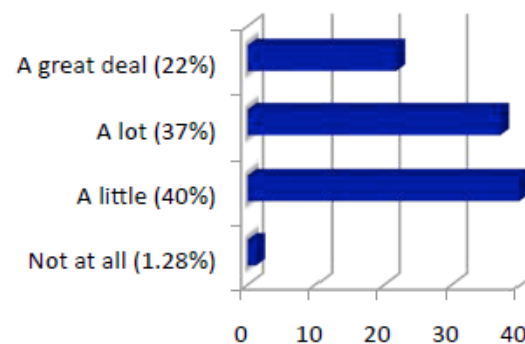
"Before the Compass Card Jazmine didn't want anything to do with the world, she would watch TV, didn't like going out and didn't sleep. She would have tantrums and did not like change. We were living on our nerves all the time. I felt that others judged me as an incompetent Mum, it was very isolating, we had no power over our own lives and it felt like we were lone voices in the world of specialists. I used to get very depressed, I had to sleep when Jazmine slept, we had no holidays or time out."

Choice for Children/Young People with Additional Needs



"Just being able to visit a variety of places that we may not have been able to afford before the Compass Card and we are able to give our son the stimulation and experiences that he needs."

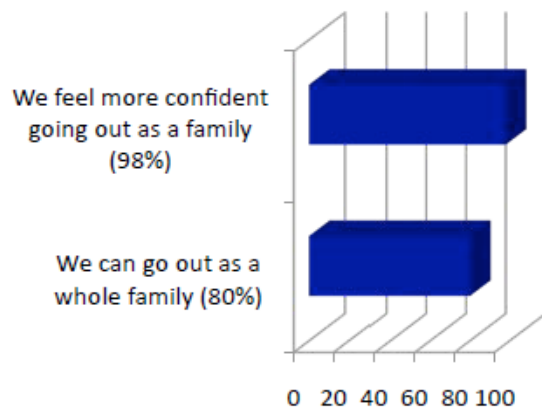
Compass Card Partners have improved their understanding of our children's needs



"The group activities have a range of children, some with learning needs and some without, therefore my son doesn't feel any different, and this has improved his confidence as there are a mix of abilities. Due to the different needs of the children, my son has learnt to be more patient and understanding of others with more complex needs than him, while enjoying mixing with other children who are much more able than him too."

"The attitude of staff seems to be more caring and understanding, also less judgmental."

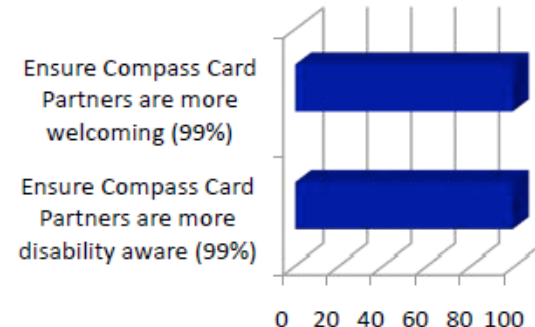
More able to do things as a family



"The Compass Card offers so much to families making them aware of places they can attend without feeling uncomfortable it gives them the same opportunities as other families have who have children without special needs."

"The Compass Card helps us do things as a normal family and we do a lot more together now than before."

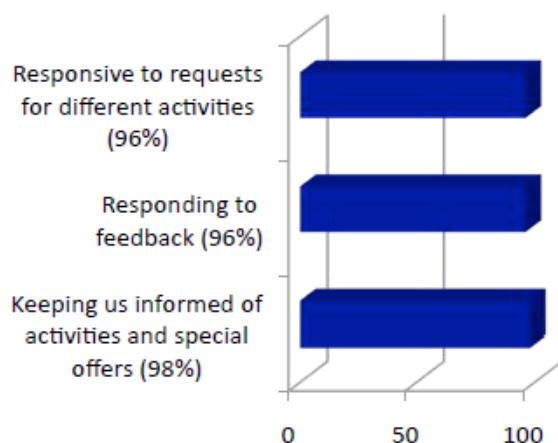
Amaze works hard to:



"Compass card is a useful tool in educating staff and the process has been much better than formal [disability] training."
Compass Card Partner

"As are family we are so thankful for the Compass Card, it has been a real game changer. Apart from the range of activities our son can now enjoy there are many knock-on benefits for the rest of the family, such as generally feeling more positive and integrated."

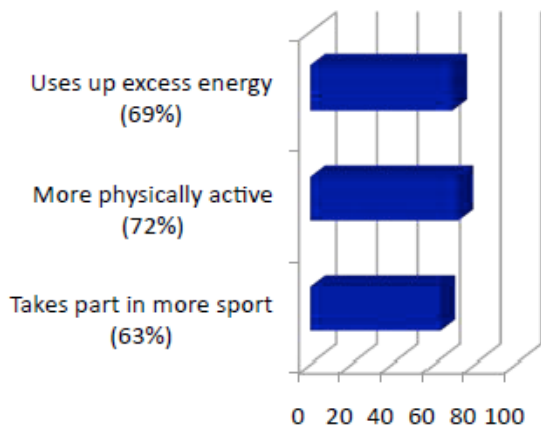
Amaze is good/excellent:



"I receive regular clearly written updates on all the new Compass Card activities, showing the ongoing hard work to ensure as many providers as possible in the city are welcoming and embracing children with special needs and their families."

"Most providers have realised not everyone is in a wheelchair!"

More Active - Children with Additional Needs

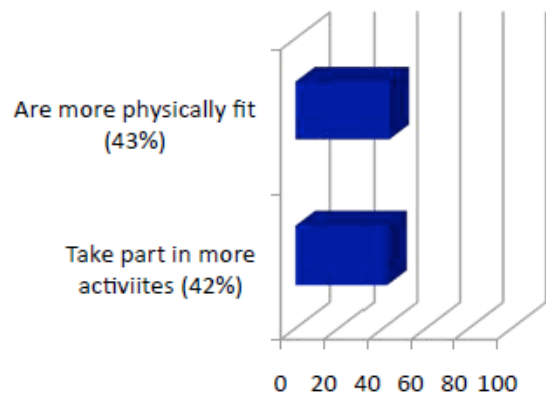


"My son needs to have physical activities where he can be supported and feel safe and understood. He has been delighted when we have been able to join clubs and activities and he doesn't feel misunderstood, which is very important to us."

"My daughter has mobility problems and through being able to swim everyday and carry out physio in water, it has been very beneficial to her health and reduced family stress."

"Circus skills and trampolining have helped a lot for my child to use excess energy and developing all the areas I have identified above."

Parent Carers More Active



"The Compass Card has allowed us to engage in frequent, common activities more often swimming or cinema, but has occasionally allowed us to try out new activities, hoping our daughter will engage and be involved (rock climbing/windsurfing etc). Our daughter is very reluctant to try new activities so the card is important that we do not waste money on trying something that has to be aborted. Our daughter needs constant supervision so we have not been able to benefit as much as we would like from activities which might mean an instructor taking over and giving us time to relax."

"It has made activities much more affordable which has helped enormously with my personal health and wellbeing."

"We have taken more exercise and got out of the house more as a result of the Compass Card. Meeting other families has been a great support to us."

"The benefits to us are participating in enjoyable activities alongside our daughter, as she is young too do these on her own. If the three of us go swimming together then husband and I might take it in turns to do a couple of lengths while the other is playing with daughter in the pool. It is really great for us to be able to get free swimming as a family, as it is good exercise for our daughter and will help her strength and balance, confidence and safety."

KATE AND IZZY CASE STUDY

Izzy is 17 and has Type 1 Diabetes with other complications. She has two brothers, 18 and 14 years old. One of her brothers has a sensory impairment but does not have a Compass Card.

Izzy said: "My Compass Card allows me to do things to help me look after myself. My family would not be able to afford these otherwise. I like it when some of the activities (such as swimming) allow me to take someone else along with me, for free, as I feel much more secure when I am with someone who understands my condition and what to do when things go wrong. It would be good if this applied to all the Compass Card activities."

Izzy's mother, Kate, explained: Having the Compass Card has made a lot of difference to our family. Compass Card offers are particularly useful as maintaining health is very important for my daughter with her health issues. They allow her to take an active role in maintaining her health and taking responsibility for the management of her condition. We would not be able to afford these without the Compass Card. The leisure activities are also useful as we live on a low income because I cannot work full-time because I need to be available to care for my daughter and my husband is on a relatively low wage. Leisure activities can lighten the stress of chronic illness and caring duties.

If I know my daughter is having a good time I can relax and switch off from worrying about her for a while. The Compass Card means we have a lot more time to relax, more time to spend with other family members or with friends. The quality of our life has improved a great deal and our perceptions of what our daughter can do has improved.

We still experience some barriers and find staff do not understand our needs or meet our needs. Often we have found a lack of understanding as to the specific needs of an individual at some venues. We have to limit the activities she participates in as there is still, generally, a cost. My daughter would rather attend leisure/sport activities with a friend or family member and in some cases this can be expensive. She doesn't like to do things designed specifically for people with disabilities.

The Compass Card gives her more opportunities, which help her cope with her chronic condition. Sometimes it makes it harder for her siblings who do not have a Compass Card and see her getting advantages over them. Siblings of disabled children have a lot to cope with as well.

Access to sport activities allows her to learn about controlling her blood glucose levels in a safe way. Exercise is particularly important for those with Type 1 Diabetes as they, inevitably have to eat a high sugar/carbohydrate diet to treat hypoglycaemia. Access to leisure activities is also very important for young people with a chronic condition such as Type 1 Diabetes as the burden of coping with the complicated day-to-day management is relentless and depressing. She also feels able to leave an activity if she feels unwell without worrying that she is wasting money.

She is more confident going to new places and using public transport, and it has made some difference to her confidence in the community, shops, cafes etc. The Compass Card has made some difference to how we feel part of the community. If the Compass Card were no longer available she would have less access to beneficial activities both for health and leisure and there would be a knock on effect on the whole family but particularly on the mental health and wellbeing of my daughter.

We would like to see the Compass Card extended to include non-disabled siblings and parents so we can do things as a family. We would also like a wider range of activities that are not directly linked to disability.

We would also like to propose that there is a Young People's steering group to suggest activities and improvements that young people want and to meet their needs.

83% of parent carers feel the Compass Card has improved their quality of life

72% of parent carers feel the Compass Card has helped reduce stress

79% of children and young people with additional needs have developed life-skills

Key Findings - Added Benefit Outcomes

The stories, quotes and statistics clearly demonstrate that, despite the variation in family make-up, their support mechanisms and the specific issues they may be facing at the time of undertaking our consultation, a significant number attribute the Compass Card to improving their quality of life, general health and wellbeing, and reducing feelings of isolation.

For many the value of the Compass Card is being able to do things together as a family but despite this 45% said that they have more respite from caring responsibilities. They also report being more resilient and have improved coping strategies (61% and 60% respectively).

Parent carers frequently refer to the Compass Card as being the catalyst that has **'given them their life back'**. For a number of parent carers this has included returning to work or taking up higher education.

They also tell stories about how their own and their child(ren) with additional needs have improved their aspirations about what is possible as a family as well as independently. Examples of the statistics and quotes from parent carers appear on the next few pages.

Social Value Added Benefit Outcomes:

Social Value Outcome 4 Some Compass Card holders and their families have reduced stress; increased respite; improved mental health; improved resilience, are happier and have a better quality of life.

Social Value Outcome 5 Some Compass Card holders have improved confidence and self-esteem, physical and mental health.

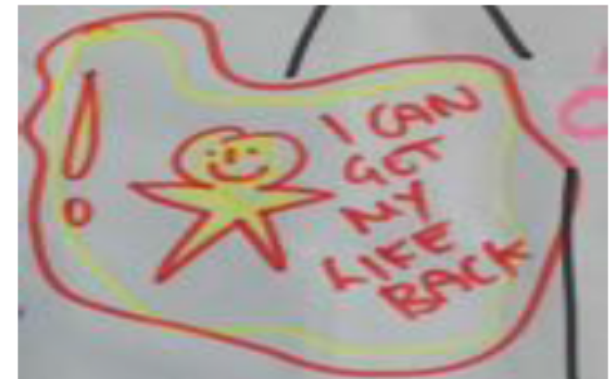
Social Value Outcome 6 Some parent carers have improved connections and relationships with other families who have children and young people with additional needs.

Social Value Outcome 7 Some Compass Card holders and their families are less isolated and feel more socially included and part of the Brighton and Hove community.

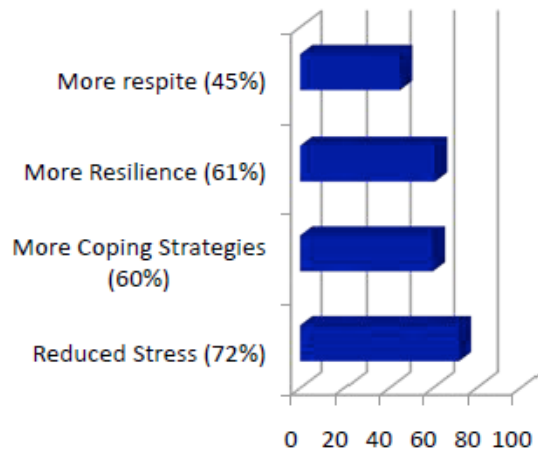
Social Value Outcome 8 Some Compass Card holders improve their life-skills as a result of engagement in more activities.

Social Value Outcome 9 Compass Card Partners are more aware of the needs of families with children and young people with additional needs.

Social Value Outcome 10 Some parent carers report that they are able to maintain employment.



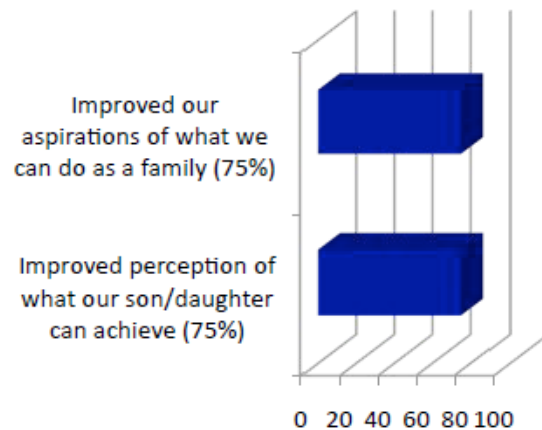
Improved Health and Wellbeing



"When my son is doing something with the Compass Card, he is happy so this means it's less stressful for us parents to care for him."

"It has made activities much more affordable which has helped enormously with my personal health and wellbeing."

Raised Aspirations

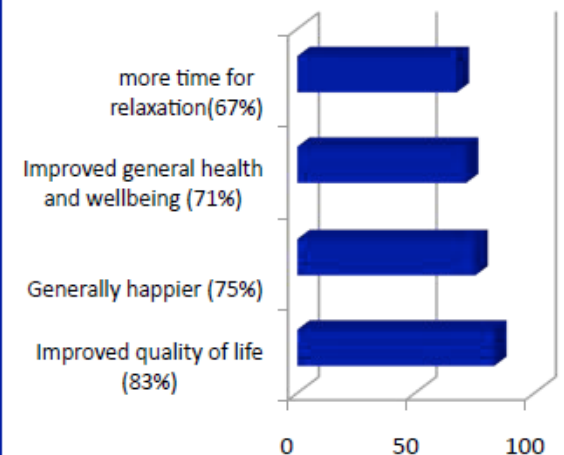


"The Compass Card offers so much to families making them aware of places they can attend without feeling uncomfortable it gives them the same opportunities as other families have who have children without special needs."

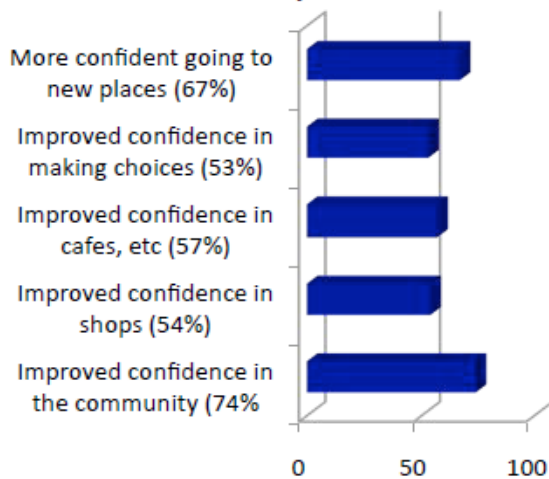
"I think the main changes are in terms of mental wellbeing. Having a Compass Card has reduced feelings of isolation and increased our sense of pride in seeing our son achieve new things and gain confidence and new friends. On the whole I think the Compass Card has given the whole family much more confidence and a strong sense of feeling part of a community."

"I used to get very depressed, I had to sleep when Jazmine slept, we had no holidays or time out."

Improved Quality of Life



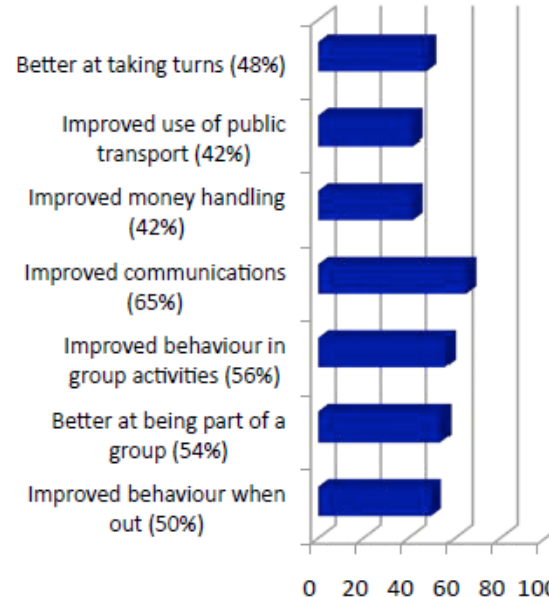
Improved Confidence Children/Young People



"Our son has dyspraxia and epilepsy, the medication he is on has made him gain weight, he has never been able to swim, having swimming available to us for no cost has enabled him to learn to swim, exercise that isn't strenuous and doesn't require great balance has enabled him to get fitter and gain confidence."

"Access to swimming for us has a profound effect. My son can now swim 8 lengths (400 metres) despite not being able to walk 25 metres. His school also uses the Compass Card to support him with swimming activities."

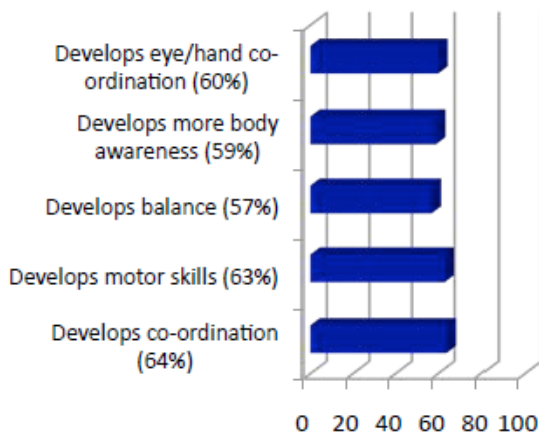
Developing Life-Skills Children/Young People



"Has really helped my son's confidence and imagination."

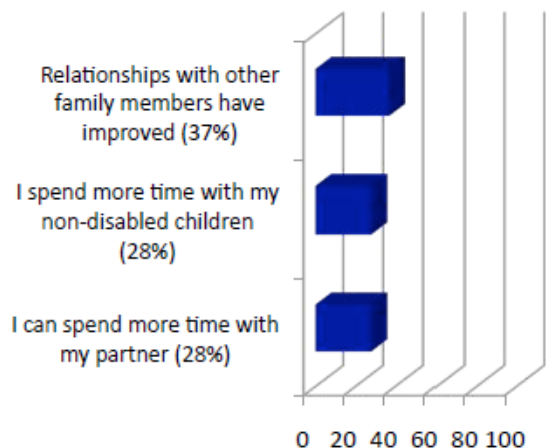
"He is happy and confident to ask library staff for help. He enjoys going out and it's good for his self-esteem, and his mental wellbeing. He feels very down if he cannot go out. He has no friends due to his disability but the Compass Card helps give him opportunities to go to group things if he wants to, and gives him activities that he can do on his own."

Improvements to Physical and Mental Health Children/Young People



"The group activities have a range of children, some with learning needs and some without, therefore my son doesn't feel any different, this has improved his confidence as there are a mix of abilities. Due to the different needs of the children, my son has learnt to be more patient and understanding of others with more complex needs than him, while enjoying mixing with other children who are much more able than him too."

Relationships with Family



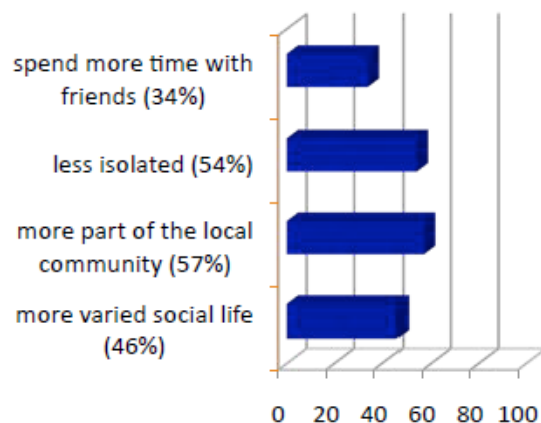
"When you have a disabled child it is easy to feel like you are in your own bubble and that the 'outside' world doesn't really understand the challenges you face on a daily basis. The Compass Card really breaks that feeling down as there are always activities that we feel really welcome to take our son to, and the 'outside' world really starts to feel much more welcoming and caring."

"It is much easier to cope when you know that within 10 minutes you can be at a welcoming, fun venue that caters to both your children. Being able to try and to subsequently regularly use new places psychologically lifts me, and I feel confident enough to approach other parents just to chat. Before, we were always counting our pennies and had to really decide where we could spend when it came to the children and going out. Now it feels like there is less pressure and everyone is more relaxed."

"One parent can spend quality time with the non-disabled child whilst other parent takes disabled child to take part in Compass Card Activity or use Compass Card. Non-disabled child finds it embarrassing to be seen out with disabled brother although we do try to do some things as a whole family, eg cinema, because we feel that is important, but we understand non-disabled child's embarrassment and like to meet his needs too."

"When my son tries something new his brother sometimes joins him and it gives my husband and I more time together. My son increases his self esteem when he tries new activities which makes us all happy."

Does the Compass Card make a Difference



"If we did not have the Compass Card we would feel much more isolated, and less part of the Brighton and Hove Community. We would no longer feel confident that local providers welcomed us. We would feel isolated, depressed and angry."

JAZMINE CASE STUDY

Jazmine is 7 years old and lives with her parents and younger brother. She is severely autistic and has speech, language and learning difficulties. She attends a special school. Her mother said that:

“Before the Compass Card Jazmine didn’t want anything to do with the world, she would watch TV, didn’t like going out and didn’t sleep. She would have tantrums and did not like change. We were living on our nerves all the time.

I felt that others judged me as an incompetent Mum, it was very isolating, we had no power over our own lives and it felt like we were lone voices in the world of specialists. She was not diagnosed until she was 3. We could not go anywhere like play groups she would wreck things including other children’s toys. We would be asked not to attend we felt rejected by society and I felt rejected by my own child who could not relate to me. The Brighton Unemployed Centre Crèche was the only place we could go and were welcomed.

We now have a PA for 10 hours a week but she won’t take Jazmine out on her own.

I used to get very depressed, I had to sleep when Jazmine slept, we had no holidays or time out.

The Compass Card enables us to try things out and gives us the confidence to go places, we feel welcomed and can relax knowing there are other parents with children with additional needs. We feel more connected and meet other parents, share information and learn from others’ experiences.

Jazmine loves the Sea Life Centre, Washbrook’s Farm, Spring Barn Farm. Free swimming is amazing and we have annual membership of Drusilas. Sometimes Jazmine loves an activity and others times she might refuse to go in. Because of the savings we worry less and this reduces stress and anxiety when going out. We can also try new things out.

It has given us all more confidence for example on a recent trip to London for an Autistic Friendly viewing of the Lion King when on the crowded train on the way home someone complained about the volume of Jazmine’s music I had the confidence to explain why she couldn’t turn the music down. We need to encourage people to accept and understand our children better.

As a result of the Compass Card we feel more part of the community; she has learnt to go into shops and behave appropriately and about taking turns. We are less isolated and more confident. It also helps others learn about our children and their needs.

The weekly newsletter is very important maintaining contact and keeping us informed. Its good to get something in return for the information we provide for the database. We spend too much time telling people the worst about our children.

The Compass Partners are good and have improved over the years we don’t need to explain about our children they are accepted. Some could do with more training though. Generally though we can relax and enjoy the experiences.

The Compass Card is a lifeline. I am also now able to work again.

Inclusive
Brilliant
Happy
Enabling
Affordable
Grateful
Useful
Freedom

"I think it would impact as it would signal that the community no longer considered children with special needs as a priority. What we all have to realise is that children/adults with special needs have an extremely special perspective on life and often combined with untapped talents that need to be brought out to the full."

This represents just a small extract of the voice of these families. The stories, quotes and statistics contained in this evaluation speak for themselves. The full report contains more details of our consultation, case studies and quotes describing the impact of the Compass Card and the difference it makes to people's lives.

The Word Cloud represents the most commonly used words by parent carers when we asked 'what 3 words best describe the Compass Card?' We also asked them to describe what life would be like without the Compass Card. The mostly commonly mentioned impact would be that **'it would reduce the amount of activities we would be able to take part in due to cost'** and phrases such as **'I think we would feel lost'**, we would be **'isolated, angry, depressed'**. In conclusion we summarise the recommendations and suggestions for future development parent carers have made as well as their comments regarding how life might be if the Compass Card were no longer available.

Recommendations

The following are recommendations based on the issues that arose during the consultation and writing up of the evaluation.

- 1 That Amaze should consider adopting the Outcome Map as the basis for future monitoring and evaluation.
- 2 That to develop Compass Card Partners and meet their needs for additional support will require additional funding and resources and that this could be explored going forward. Linked to this is additional funding to support siblings discounts and activities.
- 3 To seek additional funding to expand the range of Compass Card Activities.

4 To explore with other organisations such as the Federation of Disabled People how offers can expand to all people with disabilities/additional needs; and link to their access projects.

5 Future evaluations should expand consultation and feedback regarding the impact on employment for parent carers.

6 As the age limit increases to 25 improving confidence, independence and life-skills is even more important as young people make choices regarding education, employment and independent living. Future monitoring and evaluation should gather data regarding impact in these areas.

7 Future evaluations should include more in-depth consultation with Compass Card Partners and establish links to Corporate Social Responsibility good practice.

"Our family life would be greatly diminished if the scheme was stopped. My son's fitness and social development would be impacted and the whole family would feel more cut off from the wider community."

"It would make activities expensive and we wouldn't do them; it would mean we would feel isolated and misunderstood; it would mean my son would no longer benefit from all the offers and opportunities to socialise and develop healthy relationships with others. I would not be able to have time to myself in the knowledge my son is cared for and taught in a positive nurturing environment."

"I feel we are very lucky to live in Brighton and be able to benefit from the Compass Card. In an ideal world it should be a model that could be rolled out across the country to improve the lives of countless other families. I would say that Amaze really are getting this right and should be held up as a glowing example for others to follow."

"Please do not stop the Compass Card... it is such a massive help when we do use it, and the whole Compass Card service is run so well. Disabled children and young people need all the help they can to access services and do fun things that non-disabled people take for granted and the Compass Card really helps with that. Also we have used it for places like Legoland to prove he is disabled. It is worth its weight in gold."



Future Developments - Comments and Ideas from Parent Carers

1 That the Compass Card should have greater visibility. This relates to raising its profile to parent carers, partner organisations showing a Compass Card symbol or badge to advertise they are part of the scheme. Highly visible stickers on venue windows. Also consider introducing a grading scheme for Compass Card Partners to show the level of support, training and skills they have to in support families with children with additional needs.

2 Something on the card to show who and what Amaze is so that it is seen to be something that is given to children and young people with additional needs. This is a tricky one since some families also find their teenager children are reluctant to use it in case of stigma and being identified as having additional needs.

3 More activities for under 5's and under 11's.

4 More chances for children of similar levels and circumstances would be great as well as group outings, social activities, and clubs. Also more Compass Card Activities which can act as a gateway and a confidence builder to mainstream activities.

5 Brighton and Hove buses to offer discounts.

6 Age range extended to adults – all ages – affordability and inclusion are relevant across all ages.

7 More discounts to include siblings who can often feel left out and it can be expensive to do things together.

8 Expand beyond Brighton and Hove to East and West Sussex. Some parent carers would like to see a national scheme.

9 Discounts for music events.

10 More disability awareness training for Compass Card partners.

11 Networking for Compass Card partners.

12 Extend the Compass Card to practical discounts like shops for clothing, shoes, restaurants, and cafes etc.

13 A Young People's Forum to support the development of the Compass Card and Compass Card Activities.

The above are a sample of the most commonly mentioned ideas for development. Most frequently requested was expansion beyond Brighton and Hove; more activities for younger children and teenagers; and not stopping at 25 but being expanded for adults. More visibility was also mentioned especially with Compass Card Partners so that families are more aware of who offers discounts when they are out and about – this will be even more important if the scheme operates wider than Brighton and Hove. The final comment we will leave to one parent carer who summed up as follows:

"Great stuff, I think AMAZE is truly AMAZING and the Compass Card as well."

NAVOD CASE STUDY

Navod is 10 years old, he is Autistic and has little language, he lives with his parents. They moved to Brighton from Sri Lanka 4 years ago in order to ensure a better future for Navod. His mother explained that there were no services for children like Navod and his needs were often not understood. Although it was difficult for his parents to give up their jobs and leave all their family behind the move has been good for Navod and his development. He attends a special school where he is in a class of 7 children on the Autistic Spectrum. His father is working and his mother has just begun a University degree.

His mother said that after 4 months of moving to Brighton she found out about Amaze where she attended a course for parents with children with challenging behaviour. Through this she found out about the Compass Card. She said:

“The Compass Card has opened up a whole new world for Navod and for myself. I now have a social circle of other parents with children with additional needs. I have gained a best friend who I can share things with; we listen to each other; provide that shoulder to cry on when needed. As a family we are less isolated. We often attend activities with other parents, which puts your mind at ease, they do not judge us, and we don’t have to explain to them. When our children are not behaving there is often a knowing and friendly look of acknowledgement.

Navod is very active and needs lots of physical stimulation. I started taking him to trampolining at the YMCA, and Circus Skills. He still does the trampolining, which he loves. He has also learnt a lot from being able to socialise with other children, with and without additional needs, which is something he doesn’t get at school. The instructors are really great and accommodating.

Through the instructors at the trampolining Navod has learnt about taking turns. They were very patient. At first I would have to get onto the trampoline to get him off when his time was up; but over time they introduced a count-down and slowly Navod began to understand that this was when he needed to let others have their turn. We now use this method at home for example when he is in the bath; or when out in the park or at other venues. He now recognises the count-down as the time when something finishes.

He is also better at coping with other children with and without disabilities. He has more opportunities to interact with others and get to know other children. He doesn’t have friends to play with like other children his age would do. I also get a bit of free time to enjoy whilst he is taking part in activities.

He loves to go to soft play and Paradise Park in Newhaven, we go to farms, autistic friendly screenings and other activities. We like to encourage him to make choices and during half terms Navod will plan what he wants to do and the regular newsletter is a lifeline. Without the Compass Card we would not be able to do so much as we wouldn’t be able to afford it or we would worry that he wouldn’t want to stay somewhere so would be reluctant to try things out. It takes the stress out of visits to places.

Autism is hidden which can be difficult, but the Compass Card means we don’t have to explain- we are just accepted for who we are.

Because of our connections with other families we hear about activities and venues, we can get recommendations so have the confidence to try things out.

Coming here as a new family without friends was difficult. The Compass Card has enabled us to build a circle of friends that really understands what a family with a child with additional needs is going through. We can be open and ask for help which we couldn’t do back home in Sri Lanka.

The newsletter is amazing and I rely on it for information knowing what is going on and where we can go.

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