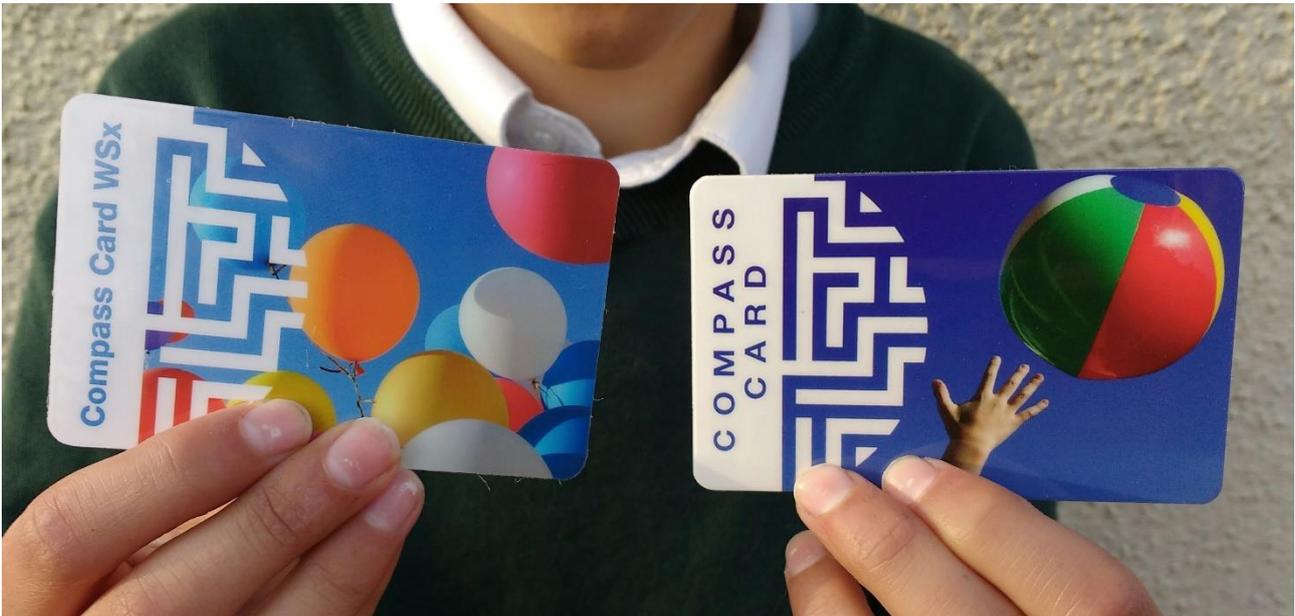


It Gets Me Out



**An independent study of the
West Sussex Compass Project
May 2020**



University of Brighton

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Throughout the report we use the word 'disabled children' to include children and young people aged 0-25 years with a range of additional or special educational needs. We also use the words 'parent' or 'parent carer' as a generic term to include anyone in a 'parenting' role with a child or young person. The quotes included are all from participants who took part in the research with the following colour coding to delineate their voices: **parent carers blue**, **young people red**, **leisure providers green**, and **service commissioners purple**.

Executive Summary

This report sets out the findings from mixed methodology research exploring the use and impact of the concessionary leisure Compass Card. Commissioned by Amaze Sussex, the findings provide insight into the West Sussex Compass Project and the way in which it tackles social exclusion.

Introduction

Amaze Sussex is a registered charity working with and for parent carers of children with special educational needs and disabilities, aged 0-25 years, across Sussex. Its West Sussex Compass Project includes both the *Compass Register* which is the children's disability register used to help identify local health and wellbeing issues to inform the delivery of local services; and the *Compass Card* which is a free concession card, that incentivises registrations by providing families with discounts and special offers at leisure venues.

There is a legal duty for every local authority to hold a children's disability register and West Sussex commission Amaze Sussex to operate the Compass Register on their behalf. Being managed by a parent friendly and trusted voluntary organisation, that innovatively introduced the Compass Card, has helped to ensure high numbers of sign-up and made leisure opportunities more accessible. The Compass Card contributes to the way West Sussex provides family support and is a meaningful part of the authority's Short Breaks Local Offer. The Compass Card is more universally available to children with special educational needs and disabilities (SEND) in the area, while Short Breaks are often restricted to moderate and severe needs and to 0 to 18s. So far, the Compass Project has successfully secured the involvement of 158 leisure providers with offers at 253 different venues in West Sussex. When combined with Brighton & Hove (B&H) offers, there are 205 leisure providers at around 330 venues, all available to West Sussex families to access. Since the introduction of the Compass Project in 2016, registrations have steadily increased with nearly 3,000 disabled children and young people now registered, which Amaze estimates to represent about 38% of those eligible to join.

Methods

The research comprised an online survey of 227 individuals using the Compass Card and qualitative research with 11 parent carers, leisure providers and service commissioners involved with the Project, using a combination of focus group discussions and in-depth telephone interviews. Desk research of the relevant literature and a secondary analysis of existing survey materials routinely gathered by Amaze, including the views of 5 young Compass Card holders, was also completed.

Key Findings

Fundamental to the Compass Project is the knowledge that disabled children and young people need and want welcoming places to go, enjoyable things to do, and people to have fun with, but they face barriers to being able to do so. The importance of access to leisure and the role leisure plays in tackling social exclusion and maintaining wellbeing was clearly identified.

1. **The West Sussex Compass Card is highly valued and appeals to thousands of parents, children and young people.** It is well used, satisfaction is very high, and the experience of using the card to access leisure opportunities is extremely positive. Nearly all participants (93%) said that fun and leisure was extremely or very important to their families and 82% said that they would access fewer leisure activities if they were without it.

2. **Families experience social exclusion and value the way the Compass Card promotes accessibility.** The inclusivity of the leisure providers involved, meant Card holders were able to gain simplified, non-stigmatised access to leisure opportunities, some of which they might not otherwise have used. Incentivising families to get-out-and-about helps stem the processes of social exclusion.
3. **The Compass Card improves the wellbeing and quality of family's lives.** As well as facilitating access to local leisure venues, almost two thirds of research participants said using the CC successfully helped to improve children and young people's physical fitness, mental health, and confidence. More than half (54%), perceived it to help promote their social skills and two fifths (38%), said it helped to promote independence. A large majority of parents (80%), said the CC had also built their own confidence to use leisure facilities. Being able to use the CC at the same places as everyone else, contributes to an increased sense of belonging and feeling part of the local community for CC holders (47%), and even more so for their families (64%).
4. **The Compass Project makes disability visible.** Both the literature and this research present evidence on the relationship between accessing leisure and the quality of life of disabled children, young people and families. The Project improves equality of access to leisure opportunities and helps to shape and develop services.
5. **Information about the Compass Card is vital to its success.** Parent carers and young people liked having information, knowing about the choice of leisure options available, and being made aware of new activities. The Card includes a vast number of leisure offers and the Project uses an extensive range of mechanisms to promote these. In order to improve communications extra funding would be required.
6. **Encouraging and promoting disability rights** is likely to be an ongoing task for all partners linked to the Project. Parents were very satisfied with the Compass Project, but there remains an underlying dissatisfaction with the lack of equality family's face, which makes the Card necessary to access leisure opportunities in the first place.
7. **Having leisure choices matters.** The commitment shown by leisure partners to welcome families and maximise accessibility, is impressive.
8. **Growing the Compass Project is reliant on a shared commitment from all stakeholders involved.** Ensuring the Card is easy to apply for, use and renew has been, and remains key to Amaze keeping existing registrations and encouraging new ones. Widening access and participation and ensuring that the necessary infrastructure is in place to maintain up to date and relevant data about families, plus deliver accessible leisure opportunities, is reliant on the continued partnership of all stakeholders.

1 Introduction

1.1 Background and Context

The Children's Act 1989 requires all local authorities to establish a register of children with disabilities in their area. The registers are confidential information databases designed to help local commissioners to plan and improve services, target resources more effectively, and share and promote information for children and families. Amaze is a local charity working with and for parent carers of children with special educational needs and disabilities, aged 0-25 years, across Sussex. Commissioned to manage the register in B&H since 2002, and then in West Sussex since 2015, the organisation runs a scheme that incentivises registrations by offering families a free Compass Card (CC), which provides discounts and special offers at 253 leisure venues across West Sussex (and a few beyond). While the overarching aim of the Compass Project is to build the Compass Disability Register so that it provides powerful, meaningful data to inform the delivery of supportive services in the county, this study sets out to examine whether or not using a concessionary card does more than provide a financial saving as an incentive for parent carers to register their details on the database.

In 2014, Amaze commissioned evaluators to assess the social and economic impact of the CC when it was operating solely in B&H, and which offered calculations about value for money and reductions in reliance on public services (Cousins et al 2014). For example, potential savings per family using the CC were estimated at £677 per annum, and probable savings to the public purse for the families registered on the database at that time, were estimated at £345,571 per annum. This research seeks to expand on those findings by drawing on the literature about leisure opportunities for disabled children and further exploring the use and impact of the CC on West Sussex disabled children and their family's lives.

We know that leisure matters. Taking part in recreational activities provides opportunities for social interaction and promotion of friendships, improved physical fitness and an increased perception of self-efficacy and social competence, learning and development, expressing yourself in different ways and challenging your existing identity (Franklin 2016, Allard et al 2014, Devine 2004). Not surprisingly, participation in leisure activities can lead to positive outcomes for disabled children and can enhance the quality of life of families too (Beresford and Clarke 2009; Badia et al 2013).

In 2004, the Government accepted that in families with disabled children "parents, child and siblings are at risk of social isolation from wider community and work networks because of being disproportionately home-based" (Preston 2005). Then in 2006, the United Nations acknowledged in the Convention of Rights of Persons with Disabilities, that persons with disabilities should be able to participate on the same terms as others in cultural life, recreation, leisure and sport (UN 2006). Yet it remains the case that disabled children and their families are blocked from fully participating in the social life of the communities they live in. The evidence clearly points to disabled children and young people participating less in leisure activities than their non-disabled peers (Shikako-Thomas et al 2014, ONS 2010) and highlights numerous barriers to their being able to take part in community activities such as arts and entertainment, outdoor recreation, sport and physical activities, visitor

attractions, volunteering and social networks (EHRC 2017). Making activities inclusive needs input like careful planning, adjusted environments, accessible transport, supportive staff, positive attitudes, affordable costs and determined parents, leisure providers and service commissioners to make it happen (Allcock 2018, Sense 2015, Beresford 2009, Stobbs 2008).

1.2 Aims and purpose of this study

The study set out to explore what the impact of providing the CC for local children, young people and families in West Sussex might be – does having the CC and improving access to leisure activities, improve parent and family well-being? To do this, we were keen to:

1. Capture the experience of parent carers supporting their children using the CC
2. Identify the impact for parent carers and their families using the CC
3. Understand the experience of leisure providers and commissioners involved in the scheme.

The research combines an evaluation and consultation with parent carers, young disabled people, leisure providers and service commissioners about their experience of the Compass Project. Most of what is captured in this study, is the perspective of parent carers, about their children and leisure.

1.3 Methods Used

We used a mixed methods approach including desk research, an online survey, a focus group and interviews with parent carers, interviews with key stakeholders involved in the development of the Compass, and a secondary analysis of existing survey materials routinely gathered by Amaze.

The quantitative data was collected and analysed using Qualtrics Data Collection and then Statistical Package for the Social Sciences software, while the qualitative data was thematically analysed (Braun & Clarke 2006) to answer the research question and offer an indicative overview of service experience and impact. The aim of the qualitative research was to complement the online survey and explore the views of participants in more depth. All desk research and data collection took place between December 2019 and February 2020.

The online survey was distributed to a total of 2,840 West Sussex CC holders via the Compass mailing list, Amaze, the CC website and social media and service partners. In total, 227 individuals completed the survey. The focus group, arranged by Amaze, was attended by 8 parent carers, and we conducted one individual telephone interview with a parent carer. Both the focus group and parent interview followed the same topic guide, were recorded and later transcribed. Parents received small thank you tokens and had their travel costs reimbursed. 2 interviews with leisure providers and service commissioners were completed and these were also recorded and later transcribed. All participants received a Participant Information Sheet and a Consent Form and agreed to the possibility of having their comments used in the final report. The West Sussex Parent Carer Forum helped to refine the design of the online survey and encouraged their members to join the focus group and complete the survey. In addition, a secondary analysis of existing survey materials routinely gathered by Amaze was completed, such as feedback from families about Compass communication methods, Leisure Providers about their involvement in the Project, and from young people about their experience of using the CC.

Of the 227 survey respondents, 96% were parent carers of CC holders and the remaining 4% included a special guardian and young disabled CC holders aged between 16-24 years. 95% of the respondents were women, 12% were living solely on benefits, 15% had experienced domestic abuse from a partner or family member and 28% were managing their own disability, learning difficulty or long-term health problem. Only 62% were in paid work, and more than half said this work had been negatively affected by their caring role. 92% identified as white British, 5% white other, 2% were from black and minority ethnic communities and 1% mixed backgrounds, and 3% spoke a non-English language at home. The majority (66%) of respondents were aged between 35-49 years, 15% were 50-59, 14% were 25-34, 3% were 16-24, and 2% were over 60 years.

2 Findings

This section explores the key themes that have emerged from the desk research and data collections, and our secondary analysis of existing survey materials routinely gathered by Amaze.

2.1 The experience of parent carers and young people using the Compass Card

We wanted to find out what works well or not so well for those using the CC. The 8% response rate (227 of 2,840) from the high numbers registered with the Compass compares well to other psychological research and is sufficiently large to have confidence in the findings. The first significant finding was that the CC is well used and valued. Of the 227 online survey respondents:

- 93% said that fun and leisure was either extremely or very important to their families
- 96% said they would recommend the CC to family or friends
- 53% said they used the CC at least monthly, and 20% used it at least weekly
- 82% said they would access fewer leisure activities if they were without it.

Typically, parents said:

“She loved it, it helped her to relax and she was so happy.”

“It’s free for both myself and my grandson...he loves it, it’s a real bonding thing for us as I’m so limited with my mobility as to what I can do with him. They are brilliant there, you just show the card and in you go.”

And young people attending the focus group said if they did NOT have the CC they would miss:

“Connecting with others”; “I won’t [be able to] go free, or skip the line, or pay cheaper”, “I can pop in somewhere and save the money. Having the option to do stuff”.

Another noteworthy finding was families’ common experience of social exclusion and the way in which the CC helps to tackle this primarily by improving accessibility. Social exclusion refers to the processes in which specific groups are systematically blocked from the rights, opportunities and resources that are entitled to all members of society. Accessibility is not just about physical or wheelchair access. In the research conducted by Copestake et al. (2014), disabled people reported

that the barriers to places and spaces they wished to visit, included a lack of reliable information, stigma and discrimination, insufficient choices, staff who had limited knowledge and awareness of accessibility, plus inaccessible buildings and a lack of clean and adequate disabled toilet and changing facilities. The research also highlighted how issues of inaccessibility contributed to feeling isolated, as it often seemed easier to stay at home rather than attempt a trip out.

“It’s nice to see them enjoying themselves and being independent and running around [laughs]...socialising with neurotypical children and not standing out.”

The CC aims to improve accessibility for disabled children, young people and their families in a range of ways. The following summarises what participants have said about how well or not, the CC helps to make leisure accessible, into three key areas:

- (i) Saving money, affording to try things out and take the whole family and friends
- (ii) Welcoming and inclusive attitudes helps to break down stigma
- (iii) Having information, knowing and choosing your options

(i) Saving money, affording to try things out, taking the whole family and friends

When survey respondents were asked to select the most important things about having a CC, the most frequently cited benefit was ‘saving money’ (85%), and the extra benefits, such as free tickets, theatre offers and free Compass Days (66%).

- 85% Saving money
- 72% Venues have a better understanding of SEN and disabilities
- 66% Extra benefits: e.g. free tickets, theatre offers, Compass Days
- 61% Feeling more welcome at venues
- 63% Not having to explain the CC holder’s additional needs
- 45% Getting news about leisure things to do
- 36% Being on the Compass database (to help shape services)
- 26% Using the Compass Card as a library card
- 4% Other (please tell us more)

The financial benefits were also reinforced by the conversations we had with the 9 parents we spoke with directly, and the 5 young disabled people who had taken part in the Amaze focus group.

“It enables me to go somewhere and not worry about leaving halfway through as I haven’t paid for all of it. Because it’s a bit cheaper it doesn’t make me feel bad, does that sound selfish?”

“It’s helpful, I get in for free swimming, I save money. I go all the time.”

The priority given to the financial benefits was expected, as the idea of ‘affordability’ links to the wider context of understanding the experience of families caring for disabled children. The research has long revealed how families are worse off financially and have noticeably poorer standards of living than those families who do not live with disability. For example, families have lower incomes than average, are disproportionately likely to live below the poverty threshold with benefits being part of their income, costs are higher, opportunities to work are limited and many are in debt and

live in unsuitable housing (Scope 2019, Melnychuk et al 2018, Buckner & Yeandle 2017, Papworth Trust 2018, Baldwin 2015, DWP 2013, Royston & Hounsell 2011, Gordon et al 2000).

This research found that having access to affordable options also meant that the whole family was included, or the disabled child or young person could take their Personal Assistant or friends along with them too.

- 87% of survey respondents said the CC enables the whole family to do more activities together
- 64% said it helped to give the family a better sense of belonging, or feeling part of the community.

“If you can all go as a family, like the fact that it’s cheaper does help, like we all have fun like any other normal family would.”

“You can get discounts...I wouldn’t have joined [the club] if I hadn’t had the CC.”

Whilst it might be obvious that parents (and young people) would identify financial savings as particularly important, having a CC can also lead to further benefits because not worrying about costs can help families afford to experiment with activities. Parents commented that they were more inclined to go to new places because they could leave earlier if their children were not coping knowing they had not paid a fortune to attend. 74% of respondents said that having a CC meant children and young people were able to try new activities, (with 65% saying they could do *more* of their usual ones). Taking risks and being brave to try things out, encourages children and young people to expand their horizons, giving them opportunities for personal growth and self-fulfilment.

(ii) Welcoming and inclusive attitudes help to break down stigma

A theme many parents (61%) mentioned time and again was how vital it was to feel welcomed and included at venues. Public attitudes can have a profound impact on our ability to make connections, and from the information parents shared, negative public attitudes and awkwardness about disability still exist, which Aiden and McCarthy report as a major barrier to leisure, access to public spaces, and social contact (2014). And stigma, as defined by Goffman (1963), is a social attribute that is discrediting for an individual or group, impacting on people’s confidence and willingness to ‘get out and about’.

Research conducted by Milner and Kelly helps to explain how for disabled people participating in the community, can mean moving away from comfortable or safe places of shared identity, to spaces where they can be in positions of inferior cultural knowledge, expertise or social capital (2009). A small number of studies of parents of disabled children have also shown how stigma by association (which is much like direct stigma) contributes to self-conscious, withdrawn and negative social interactions because parents can perceive judgment and blame regarding their child's disability or behaviour, or the way they parent their children (Green 2003, Norvilitis et al. 2002).

Parents seemed acutely aware of negative public attitudes and stigma, which undermined their confidence at times.

“Yeah, it's the look you get. It's not a nice experience...What's wrong with that child then, almost like everyone is judging you. It's the look you get, looked up and down, why have you got this?”

The CC is a small item that has the portability of a credit card. Visibly, it is almost indistinguishable from non-concessionary cards, and so it was interesting to hear the different views about using the card in public places.

“My eldest is 20 and striving to be normal, he says ‘I don't want them to see it’, he didn't want one with balloons on it, brightly coloured.”

“For my younger son he loves it, but my older son is like do I really have to have that?”

Related to this, was the significant importance parents and young people assigned to not having to explain their difficulties when they visited leisure facilities. More than half of the survey respondents (63%), identified this as a positive feature of the CC.

“For us it's an equalizer...for his own dignity I don't want to tell complete strangers...and I don't want him to think of himself as just what he can't do.”

“I just show it and they say yes you can come in”; “Asking questions is annoying. It's private.”

Unsurprisingly, we noticed in our conversations with parents, and in the Amaze young people's focus group too, that there was some variability and different experiences of the same venues. On further discussion, this often came down to the staff on duty at the time of the visit.

“Most people have to go and ask about the card as they don't know.”

“There's been a few instances where parents have rocked up with their CC and been refused, so it's always good to use the app because on the app it has the offer and they can't refuse it then.”

(iii) Having information, knowing and choosing your options

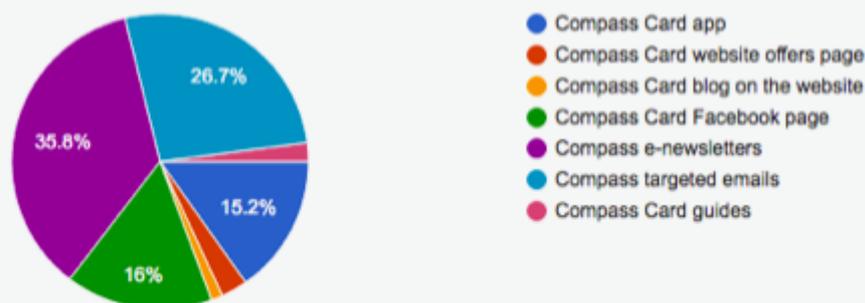
The CC seeks to overcome the obstacles that constrain children and family participation in society by providing better access to a wide range of leisure activities. One of these obstacles is not having enough information about what is available, which is why the Compass Project uses a range of mechanisms to promote what the CC offers. Late in 2018, Amaze conducted a survey (Compass Communication Survey) to ask how parents and CC holders find out about the CC options, in order to refresh its communication strategy. Even though this was a combined survey (Brighton & Hove and West Sussex), the majority of the respondents were West Sussex parents with the findings below highlighting the preferred communication methods, whilst also illustrating how hard it can be to provide information in a way that works for all.

Favourite way of hearing about CC offers and leisure news

Finding out about Compass offers and leisure-related news

What's your FAVOURITE way of hearing about Compass offers and leisure-related news?

243 responses



A very small number of parent carers responding to the survey (and young people at the focus group) shared their difficulties with the information available. For example, they mentioned that the app was sometimes unhelpful because it was either not working, or it did not include a distance function to help search for nearby options or did not have notifications that then linked to more information about the facility. They said there was not enough detailed information on the web about accessibility (other than Changing Places toilets), or quiet times, or allergy information. We were unable to investigate these comments further, however in contrast, the majority of parents we spoke with found the information available extremely helpful, although it was clear from their overall comments, that people have different energy levels to search for information, different thresholds for how frequently and how much information they want, and different preferences for ways to access it.

“It gives you a list of places to research and you can look at it on the website and plan a bit, where toilets are, what they serve in the cafeteria, do I need to take snacks or not take any at all, like coloured straws...information is key to a stress free trip, whether an hour or a day event.”

A further obstacle for families is not having access to a *choice* of leisure options. Numerous consultations with disabled children and young people have consistently reported that they want more and different things to do so that they can choose where and how they spend their free time (King et al 2014, EDCM 2007, Petrie et al 2007, Kelly 2005, Turner 2003). In this study, 45% of the online survey respondents identified getting news about leisure and things to do as one of the important things about having a CC. The Project has secured the involvement of over 158 leisure providers and offers at 253 venues across West Sussex and beyond. It includes different free and concessionary deals to leisure facilities, free special days out ('Compass Days') organised jointly by Amaze and leisure partners which are attended by large numbers of families each year, and annually giving away hundreds of free tickets to inclusive one-off events. But interestingly, some of the parents we spoke with (and the young people attending the Amaze focus group), expressed concern about the CC not including enough. They specifically mentioned there not being enough for older

young people and too few options available in specific areas such as Mid Sussex, Bognor Regis or Haywards Heath (and they offered suggestions). Although some of this information might not be exact, the perception was that there was a need for more. The Project has sought to respond to feedback from parent carers and young people regarding the offers, by ensuring targeted communications, providing information in a visual film format, conducting outreach activities to explain how to use the App, and producing and disseminating local guides, to break the offers down into a more digestible format for some areas. It is clear to us from the data collected in this study, that the CC is desirable, and leisure partners are both improving access and making activities fun because disabled children, young people and families return for more.

One young person's suggestions:

~~Wanted~~
App needs notifications.
Subboxes allow multiple ticks.

More
Gym's?
negotiate more
RESTAURANTS

Having a good experience at one place 'lifts the bar' and creates a standard for others to reach, which might disappoint when not met.

A total of 85% of survey respondents said the CC made them aware of activities they did not know about before having a card. Finding a balance and ensuring that the CC is available for use at a range of places that suit children and young people of different ages, locations, interests, abilities and comfort levels or preferences for mainstream or specialist provision, is a challenge. The C4EO Disability Review highlighted that while there may be a perception of a common understanding of 'inclusion', it can be interpreted in different ways and happen at different levels. Mainstream leisure activities may simply accept disabled children and young people at entry, or they might actively facilitate their participation with others, or they could provide disabled only sessions (Beresford and Clarke 2009). Parents really appreciated having options.

"My son wouldn't like to go to those sessions, he would rather go to a normal showing and sit at the back and just be quiet."

"It's almost uplifting, when you go to somewhere and there's someone like your children. We went to the panto one year, my son was sat in a booster seat, with his teddy, had his dummy in his mouth, ear defenders on, had his blanket and he was 9 at the time and I looked around and no one was judging me, no one was batting an eyelid, everyone was accepting of everything, it was amazing, it makes such a difference, no stigma."

We wondered if there might be an issue to communicate the limitations of the context within which the Project operates. In our conversations with parents at the focus group, we observed a tension.

On the one hand increasing access involves tackling social exclusion and promoting disability rights, while on the other hand, there is no duty nor inclusion targets that leisure providers must meet, and instead the Project is reliant on their goodwill and willingness to be involved. Understanding what the Project can achieve in its present form, might be key to managing people's expectations and

enable them to take full advantage of what is on offer. Like most of what Amaze does, if you know the system you can try to either get the most out of it, or to work to change it.

Other experiences of using the Compass Card

There were a few findings that while not significant in number, are worth a short mention here. For example, it was interesting to note that there was little mention of transport challenges to access places, which may of course be because it becomes a bigger issue later, as children move into adulthood or begin to develop travel independence. The literature identifies transport and venue access as barriers to taking part in sport and leisure opportunities, particularly in rural areas (Allcock 2018, Sense 2017). When we shared with the parent focus group that the last Compass evaluation (Cousins et al 2014) estimated that families in B&H were saving over £600 per year each, it opened a whole conversation about distances and nearby availability of leisure options. One parent commented and others agreed, that the savings would be more in West Sussex than in a city, because parents need to travel further and across the county to some leisure venues. A few parents then explained that public transport was unreliable and too infrequent to be able to use, and that it was particularly difficult for families without a car when the activities were not close to home. Comments recorded at the Amaze young people's focus group also point to a similar barrier. Of note is that neither CC holders nor parent carers appeared to hold any expectation that transport was a function or a failing of the Compass Project and it was heartening to learn from our interviews with the commissioner, that independent travel training had been funded so that disabled children and young people could learn the skills to use the local buses.

The CC acts as a library card in West Sussex and 26% of survey respondents using the CC as a library card was an important feature, while 36% of survey respondents also identified being on the Compass Disability Register as an important aspect of having a CC. And finally, we were struck by the frequency with which parents said they were using the CC while their children were out of school or not included in school trips. While these parents were very positive about and valued the CC, commenting how helpful it was to be able to include their children in other things to offset experiences and feelings of exclusion, it is disturbing to notice the reasons given.

2.2 The impact for parent carers and their families using the Compass Card

The previous section summarised how the CC has tried to make leisure activities accessible to disabled children and their families, but what effect does this then have on them? Below we look at the impact of the CC, through the eyes of the parent carers and young disabled people using it.

We have already discussed the significant benefits of being able to afford to access and try out leisure opportunities. Given that families with disabled children have lower incomes than average and the links between overarching health inequalities and income inequalities (Rowlingson 2011, Wilkinson & Pickett, 2010) is well-established, it is not unreasonable to consider the CC as an intervention that helps to address these inequalities. Survey respondents were also asked to comment on whether they thought the CC had helped to improve a range of wellbeing indicators, including mental health, physical fitness and health, confidence using leisure facilities, independence, social skills and a sense of belonging or feeling part of the community. Perhaps the

most palpable finding, was that close to two thirds of survey respondents thought that having the CC had made a significant difference to their children's wellbeing.

- 71% said it improved their child's mental health
- 66% said it helped to maintain or improve their physical fitness
- 63% said it improved their child's confidence

Research strongly links physical activity and fitness with good overall health and wellbeing. The benefits are numerous and universal for children, including those with disabilities. (Murphy et al 2008) and the mental and physical stimulation of taking part in leisure activities can just make you feel better.

"I like to be active. Doing the CC activity is fun, but it also gets me out to go there, so I get a walk to the activity and I get to do the activity".

We know that parents really appreciated the way in which the CC enabled their children to experiment with activities, knowing they could go for a short while because it wouldn't cost a lot. Risking trying things out appears to be allied to building resilience (Ungar 2015), as it helps children and young people to develop an internal locus of control. People with an internal locus of control tend to think of themselves as responsible for their own destiny and life and feel that they can make things happen, whereas people with an external locus of control tend towards seeing themselves as victims of other people or structures. A few parents said their children had had horrible experiences going to places in the past and were cautious about exposing them to more for fear of the same happening again. But children and young people, want and need ordinary experiences which can increase their confidence and self-esteem, especially as they achieve things that they never thought were possible. It can be very effective when parents encourage children to act as though they are confident when neither they nor their children feel that way, and the CC makes this doable.

"They loved it I was quite surprised as I was nervous."

"It's good not feeling guilty about not using the whole time, it allows me to go there for a bit."

It is not always straightforward for some disabled children to work out the rules for navigating their social worlds, and some need consistent and ongoing help over a longer time period to learn and acquire the skills that families of non-disabled children take for granted. For example, queueing and waiting your turn, sharing, following instructions, compromising, managing your anger, listening, communicating in ways to suit the situation, talking back and forth, reading the cues of others are all social skills that can be additionally difficult to learn or manage. Taking part in leisure activities can throw these skills into stark relief. However, 54% of survey respondents said that having the CC had helped their children to build their social skills.

"By taking them there they have become more confident socially with other children which has worked really well and so a great place to take them."

The opportunity for meaningful social interaction and the sense of belonging that going to local venues used by the general public, is not to be underestimated. Taking part in ordinary fun activities is a way to participate in community life, even if you simply attend. And it is a socially acceptable way of combating loneliness. It appears very likely that the CC enhances children's lives because it offers and makes additional outings possible - to visit or take part in an activity, to meet or take friends and relatives to an event, to interact with new people they meet at the venue, or to learn and experience something new.

"We tried swimming lessons, but she wouldn't go near them as she is sooo anxious...but I still kept trying because I got it free with the CC...I have taught her to swim!"

Having poor access to leisure creates barriers for disabled children and families, but perhaps even more importantly, it affects their chances to develop independence to use and enjoy those facilities.



In response to the survey question about whether the CC had helped to improve the CC holders' independence, a high number of respondents said 'no' (35%) or that the question was not relevant (19%). The survey did not ask for reasons, so it is difficult to know why this was the case. It may for example, reflect the CC holders age, preference or ability as some require significant additional support to access and use leisure facilities, or it may mirror research findings (Franklin 2016, Murray 2002) that young people have few or no friends to go with independently. Still, 38% said 'yes' the CC had helped with

independence (3% said they were not sure). We found that the CC was a key factor in providing the incentive or extra push to experience stimulating new activities and new places. Having some control and some autonomy to choose where and what to take part in, helps to build a sense of self-efficacy and independence (Quinn 2016, Stokes 2013). It was interesting to note that an aspiration shared by one of the commissioners, was that the CC would help young people to become as independent as possible by becoming more familiar and confident to use local services and be able to access them as they got older, so we think this is achieved for many.

"Mine are more confident doing different things now, I've tried that, I've done that, not as anxious trying something different now. I've always made the choices but now I've got one who is able to make the decision - never thought he would be able to do that."

"You can get discounts and you and a friend can go."

A total of 47% of survey respondents said having a CC improved the CC holder's sense of belonging or feeling part of the local community.

"The fact that its accepted in so many places where we live, it does make me feel generally that the community, that I live in a positive place, that's accepting of differences."

"I take my friend out everywhere, I am becoming a busier person, I volunteer in my park for five hours."

Has the CC had any impact on the use of services:	
Fewer GP appointments	3%
Fewer hospital visits	2%
Less input from mental health services	4%
Fewer overnight short breaks	.5%
Less social work support	5%
Other	4%
No impact	59%
Not sure	25%

As a follow up to their previous survey’s analysis, Amaze was keen to know if families felt their CC led to any reduction in their use of other services. The table illustrates how only a few parents were able to directly attribute the use of the CC to reductions in use of statutory services. Half of the survey respondents said there had been no impact, and a quarter said they weren’t sure.

Although of the parents who responded ‘other’, about half said they did not receive any services anyway, the remainder made specific comments such as: their children were a bit happier or more confident in social situations, they had fewer physiotherapy sessions, communication in the family had improved, they needed less respite in the daytime as there was more they could do together as a family, and they were less stressed so better able to enjoy the activities.

And finally, we wanted to note the important role parents play in improving leisure access for disabled children and families. While not a key part of the study, it was obvious that the CC had an impact on parents too. It is widely accepted that parent carers are frequently under considerable strain (Contact 2012, Broach and Clements 2020), and while they hardly mentioned their own need for leisure, the extra effort and planning required to get their disabled children to a leisure activity, and then help to make that activity work well, can go unnoticed and be under-valued. For example, working out what is difficult for children about going to leisure activities, acknowledging their fears or encouraging positive or experimental behaviours, explaining what they can expect, using visual supports, social stories, repeating information or instructions, finding real life examples, praising the effort they make and managing public disapproval or their children’s fall outs is ‘parenting plus’. The complex arrangements and contribution parent carers make to improving social inclusion for disabled children and their families ought to be better recognised. We included 2 questions in the online survey aimed at parents and it was heartening to note that 80% said having a CC improved their own confidence about using leisure facilities, and 64% said it had helped to improve their own sense of belonging, or feeling part of the local community.

A surprising finding for us, was that for some parents, the impact of the CC has manifest as increased confidence or determination to champion their disabled children’s rights.

“I try to use it at places not part of the Compass, and I use it to raise awareness, I know it’s cheeky, but you’ve got to have the balls, it’s about raising awareness in East and West Sussex.”

The literature clearly illustrates that disabled children and young people have the same preferences, wishes and benefits from the same types of leisure activities as their non-disabled peers (Coward et al 2004). However, one difference is that while many typically developing children will take part in leisure activities with their peers, disabled children participate more with their parents or other adults (Solish et al 2010, King et al. 2013). In 2018, the local parent support organisation, Reaching

Families, conducted its annual survey which was completed by 281 parent carers. Parents were asked to identify their challenges and 78% cited emotional stress, 62% said supporting their child's health and development, and 60% said accessing projects and services (Reaching Families 2018). Parent carers too face barriers to accessing leisure due to the demands of caring. It would be interesting to examine parent's need and access to leisure opportunities in the future. In the meantime, the following quotes illustrate an important aspect of the conversations had in the parent focus group:

"The CC do special days ...it's nice to meet other families who experience the same sort of thing, makes me feel like I'm part of something."

"We don't want to be special, we just need a bit of support."

2.3 The experience of Leisure Providers and Service Commissioners involved with the Compass Project

It is apparent from the data collected, that the CC is helping CC holders and their families to maintain or improve their sense of wellbeing. When asked to identify the most important things about having a CC, 72% of survey respondents said they really appreciated venues having a better understanding of special educational needs and disabilities. They mentioned how useful it was to show the CC and know that it would signal to staff that there is an additional need to consider, without them having to explain further.

"I don't look for the discount, I just want to know my strange son is welcome there."

Although a tiny number of parents (and young people) said it all rather depended on who you got on the day rather than the venue you visited, most parents were full of praise for the way in which staff welcomed and supported their children to take part, and were delighted to find that some larger venues have their own dedicated 'disability teams' tasked with making activities accessible for everyone.

"It's not just the savings, the fact that they are displaying we accept the CC here, it's like they accept disabilities. If they care enough to sign-up to the scheme, it makes me feel quite welcome."

"It makes me more likely to go there."

The success of the CC relies heavily on leisure providers willing to be involved. In 2018, Amaze conducted a survey which was completed by 17 West Sussex leisure providers, with the majority (91%) reporting feeling positive about their involvement. Almost half said the CC had a positive impact on their organisation and helped them to promote their inclusivity.

"An excellent scheme to help and encourage youngsters with special needs to engage in local activities".

"They were absolutely amazing. My little boy if he gets really anxious, he has to go into a wheelchair, the ladies who helped were so accommodating, he had a really great time, so did I!"

Once leisure providers join the Compass Card, there is very little drop-off of offers (unless companies close or lose funding), and some have even used Compass data to help with accessing funding to develop enhanced offers. The account below illustrates the way in which the Project and Leisure Partners work together.

Compass Leisure Partner: The Weald and Downland Living Museum

*We did a **big Compass Day** where we offered lots of activities on site and free entry for nearly **300 CC families**. We had people come all the way on public transport to get to the museum, and we were able to offer something specific. It's so important to show people that it's worth doing and we acknowledge that they have made a huge effort in coming. Compass suggested some autistic friendly activities, so we adapted things to the site and our purpose. We do realise that some activities aren't for everyone. It's stimulating here in terms of history and traditional skills and crafts and there's space and freedom to do things which is especially important for those with disabilities. Some people might have a meltdown after 38 seconds and there's space to go and do that and no one here is going to look at you as if to say 'what'?*

*Amaze are phenomenal with the support they give us. They keep the database with who is coming on the Day and they turn up with their banners and their smiling faces and the children in tow and things like that to help out. They are brilliant in terms of giving their weight behind it but hopefully it is a reciprocal and supportive relationship. The feedback was very positive with people saying things like: "best day of the summer." **It was real partnership working.***

*We take our commitment to enable people to access the museum seriously. By working with Amaze, it enables us to access a group of people we very much want to involve in the museum. We are trying to get a Changing Places toilet and they were fantastic about data on the need for provision for our fundraising team. Amaze is professional, and I have no doubt what they say they will do, they are reliable. **The Amaze staff are fantastic** and warm and sincere with the families. I feel that the partnership isn't just about getting our name in a book of places that offer discount or a day out, but about championing what families who sometimes remain hidden can access.*

While leisure is a discretionary service, offering a leisure scheme like the CC contributes to the way the local authority provides support for families, and is a meaningful part of West Sussex's Short Breaks Local Offer, because it is more universally offered to children with special educational needs and disabilities (SEND) in the area, whereas most short breaks have more limited eligibility.

There is also an important legal duty for each local authority to hold a register of children and young people with SEND, and so West Sussex commissioned Amaze to operate the Compass database on their behalf. Amaze estimates that 38% of West Sussex families eligible to join the Disability Register are now listed. Operational in West Sussex for just over 4 years, there is an eagerness to expand the scheme as quickly as possible. One way of estimating the rate of growth is to compare figures with the nearest comparison, which is the B&H Compass. Uptake increased in Brighton by 70% between 2008/09 and 2018/19, and so allows Amaze to calculate where the West Sussex Compass is likely to be in 10 years' time. There are undoubtedly differences between encouraging parents to register when they live in a small city like Brighton & Hove and a large rural county like West Sussex, which will impact take-up levels. Interestingly, parent support groups in the West Sussex area confirm that

reaching parents across different parts of the county is a significantly complex task that has taken them time to achieve.

The Compass Disability Register is an important data resource in West Sussex. Quarterly reports provided for commissioners, include various key performance indicators, such as statistics, demographics, the numbers needing various services, frequency of communications and data search enquiries. The Project receives numerous and varied requests for information each year, including for example, reporting on the numbers of CC holders in specific age groups or localities or the numbers with specific types of disability or needs. The information helps to assess need, design or develop services, compare information with other data sets, arrange targeted mailshots to families, or prepare reports for inspections and complete funding applications. For example, in 2019/20, 20 reports were generated for local planners and agencies and 8 targeted information emails were sent to parent carers.

“We have good links and tend to pick up intelligence from the [West Sussex] Parent Carer Forum and directly from parent/carers and organisations, and use the Compass to sort of back it up...it’s added data and when we drill down, we use it to confirm if what we are hearing is reflective in the data or not.”

When parents were asked to identify the most important things about having a CC, 36% of survey respondents said being on the Compass Disability Register. While some of the parents at the focus group were not so aware of the database, the discussions became quite animated when parents started talking about its function. They thought that if others better understood the purpose for registering their details, many more would sign up.

“If people think it might make a change to things, they might fill it in.”

“I was surprised how quick it was to do. A lot of us are so used to filling in massive forms.”

The Compass Project is well publicised, and while the focus is largely on making sure families have information about the CC offers, it is difficult to know how else it might ensure that parents understood the purpose of the Register. Amaze actively promotes the register to local West Sussex services and has information about it on its literature and the CC website. There have also been efforts to illustrate how the data is used, but this can be difficult when organisations don’t want to share this, or perhaps have asked for data but not used it. Staff consistently promote and refer parents to the CC, and encourage education, social care and health workers to endorse the Project, although it seems likely that this takes time to embed into practice, as the following commissioner’s comment illustrates:

“We promote the card to our providers...trying to encourage people like those accessing children and young people’s services to sign up to the register...constantly talking to social workers about it and we hope they will sell it to families and if need be support them to fill out the form.”

We suspect that the Compass Project is a win:win for all involved. The motivations in adopting a CC, seem intended to benefit both Amaze and disabled children, young people and their families, the local authorities, and the leisure providers involved. Our desk research and conversations with

these stakeholders suggest the benefits overlap or could be assigned to more than one, and while not an exhaustive list, their examples are summarised in the table below.

For Amaze and families	For local authorities	For leisure providers
Accessing leisure activities, increasing social inclusion	Meeting statutory obligations to provide a Disability Register and enhance the Local Offer	Direct marketing, promotion, endorsement of provision and new audiences
Increasing card usage to improve wellbeing	Increasing family access to, and use of their local communities Increasing favourability for young people to stay 'in county'	Increasing use, filled places at quiet times
Facilitating links to parent networks and range of Amaze and other services available	Centralised data collection to design or target services and information, access accurate data, assess demand	Contributing to the community and growing pride in increasing access
Increased knowledge and ability to represent families, backing up work of parent carer forums	Improving the authority's reputation	Creating new and used provision in response to needs

All of those involved in the Project, shared in various ways, their underlying interest in the Compass database and/or the CC promoting social inclusion and providing disabled children and young people easier access to leisure opportunities, to enrich and improve their lives. Ensuring local funding, commitment and enthusiasm for the Project appears to depend on their goodwill and vision. For example, the agendas for NHS Clinical Commissioning Groups are often chiefly concerned with hospitals, the elderly and frail, bed blocking and issues that have measurable clinical outcomes, rather than disabled children. For local authorities, managing severe budget cuts, growing social care demands and reducing inequalities presents funding and prioritising challenges. For leisure providers there is no obligation to take part. Having said that, external stakeholders in West Sussex appear highly supportive of the Project. In the interviews, commissioners and leisure providers shared their understanding of the wider benefits, commented on how accessing leisure contributes to improved outcomes, and held a vision about the CC helping to contribute to and build inclusive communities.

One commissioner said:

“Part of our thinking is that if you have been to the local gym or leisure centre with a CC and you feel welcome and it’s familiar, then you may feel more confident and more able to use these facilities when you are older”.

A leisure provider said:

“We love being part of the Compass Card and being able to offer a safe, fun environment to a wide range of people”.

And a parent carer said:

“We live in a world where disabilities aren’t included sometimes...the CC, it allows people to be accepted.”

When we asked what it might be like not to have a Compass Project, the service commissioner had this to say:

“We wouldn't meet our statutory obligation but also families would be less engaged in their local community...organisations would become less inclusive as they have training to be part of the CC scheme and there's a trust between the organisations and the families. We would lose opportunities for young people and families to engage with local services. Having a CC means that families are able to access the local community and benefit financially because of the discounts and become more confident in using services that they wouldn't have done otherwise.”



3 Conclusions

Our findings conclude that the Compass Project improves access to leisure activities for local disabled children and young people, and in so doing, enhances parent and family well-being. The following 8 points summarise the findings as follows:

3.1 The Compass Card is highly valued and appeals to thousands of parents, children and young people. It is well used, satisfaction is very high, and the experience of using the card to access leisure opportunities is extremely positive.

3.2 Families experience social exclusion and so value the way the Compass Card promotes accessibility. The inclusivity of the leisure providers involved, meant CC holders were able to gain simplified, non-stigmatised access to leisure opportunities, some of which they might not otherwise have used. Those using the CC loved the way the concessions and free events make leisure affordable, and more than that, they highly appreciated the way the CC enabled them to afford to experiment and try new things out. Parents and young people really appreciated the welcoming attitude they encountered at venues and noticed when this was not the case. They valued being able to take the whole family or friends to those venues where it was possible. These 'softer' outcomes should be shared as part of the marketing of the scheme to others.

3.3 The Compass Card improves the wellbeing and quality of family's lives. As well as facilitating access to local leisure venues, almost two thirds of research participants said using the CC successfully helped to improve children and young people's physical fitness, mental health, and confidence. More than half (54%), perceived it to help promote their social skills and two fifths (38%), said it helped to promote independence. A large majority of parents (80%), said the CC had also built their own confidence to use leisure facilities. Being able to use the CC at the same places as everyone else, contributes to an increased sense of belonging and feeling part of the local community for CC holders (47%), and even more so for their families (64%).

3.4 The Compass Project makes disability visible. The Project has a dual purpose - it improves equality of access to leisure opportunities, and it manages the children's Disability Register in order to help shape, change and develop services. Unlike some other concessionary cards, using the CC not only supports children and families to get out-and-about, but involves adding family details to the register, to ensure their needs are planned for.

3.5 Information about the Compass Card is vital to its success. Parent carers and young people liked having information, knowing about the choice of leisure options available, and being made aware of new activities. The CC includes a vast number of leisure offers and the Project uses an extensive range of mechanisms to promote these. Some difficulties using the apps, and wanting more links and detail included in notifications, suggest more could be done to improve communications, although the Project reports working at capacity and further funding may be needed to address technical developments such as this.

3.6 Encouraging and promoting disability rights is likely to be an ongoing task for all partners linked to the Project. Despite parent's satisfaction with the Compass Project, there remains an underlying dissatisfaction with the continued lack of equality family's face, which makes the CC necessary to access leisure opportunities in the first place.

3.7 Having leisure choices matters. A small number of parents and young people expressed eagerness to have more offers and more types of options available. While it is not clear if this would lead to an increase in take up or be sustainable, too limited a range or too few available activities contribute to children and families feeling marginalised and separate from their communities. It may not be a question of having the right number of leisure providers involved, but instead, providing the same access to the choices that are available to everyone else. The commitment shown by leisure partners to welcome families and maximise accessibility, is impressive. Inclusive leisure can include mainstream activities, actively facilitating participation with others, or providing disabled-only sessions and parents appreciated having the choice. Disabled children and families are not one homogenous group and there is a range of difference to cater for.

3.8 Growing the Compass Project is reliant on a shared commitment from all stakeholders involved. Ensuring the CC is easy to apply for, use and renew has been, and remains key to keeping existing registrations and encouraging new ones. There is some pressure to increase the size of the Disability Register quickly, and whilst this is clearly desirable, growth needs to be sustainable and appropriately resourced. It might help to compare the potential rate of growth with the nearest comparison (the B&H register) or research other schemes if they exist across the country. Parents thought more awareness of the way in which the Disability Register has helped to positively change, shape or improve services would encourage new registrations. Monitoring and evaluating the impact of marketing efforts to achieve further CC take-up and registrations, will be reliant on having the resources and staff time to do so.

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