

It Gets Me Out



An independent study of the 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 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 Compass Project includes both the *Compass Register* (B&H and WSx) 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.

Interestingly, leisure is a discretionary service with no statutory requirement to provide activities, or to offer a concessionary scheme like the Compass Card. However, there is a legal duty for every local authority to hold a children's disability register and Brighton & Hove 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 Project has successfully secured the involvement of over 200 leisure providers with offers at over 300 venues. It has over 2,100 disabled children and young people signed up to the Brighton & Hove Register (which started in 2002 and Amaze estimates is about 70% of families eligible to join). And in West Sussex, where the Compass Card was only introduced in 2016, registrations have progressively increased to close to 3,000 disabled children and young people (which represents about 38% of those eligible to join).

Methods

The research comprised an online survey of 469 individuals using the Compass Card and qualitative research with 24 parent carers, plus 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 young Compass Card holders, were 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 has to play in tackling social exclusion and maintaining wellbeing was clearly identified.

1. **The Compass Card (B&H and WSx) 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.
2. **Families experience social exclusion and 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. 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.** The CC helps to improve children and young people's physical fitness, mental health, and confidence as well as promoting their social skills and independence. It also builds parent's 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 and their families.
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 CC 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 CC 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 CC 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 Brighton and Hove (B&H) since 2002, and in West Sussex (WSx) 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 over 300 leisure venues across B&H and WSx (and a few beyond). While the overarching aim of the Compass Project is to build the Compass Disability Register (B&H and WSx) so that it provides powerful, meaningful data to inform the delivery of supportive services in the two areas, 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 Compass Card 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 adding WSx CC data to the mix and drawing on the literature about leisure opportunities for disabled children, to further explore the use and impact of the CC (B&H and WSx) on 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 B&H and WSx 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, focus groups 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 4,977 CC holders (2,137 B&H, 2,840 WSx) via Compass mailing lists, Amaze and CC social media and websites and service partners. In total, 469 individuals completed the survey. The 2 focus groups, arranged by Amaze, were attended by 18 parent carers (10 in B&H and 8 in WSx), and we conducted 2 individual telephone interviews with parent carers from each of the two areas. Both the focus groups and parent interviews followed the same topic guide, were recorded and later transcribed. Parents received small thank you tokens and had their travel costs reimbursed. A total of 4 interviews with leisure providers and service commissioners in B&H and WSx 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. Both the Brighton & Hove Parent Carers' Council and the West Sussex Parent Carer Forum helped to refine the design of the online survey and encouraged their members to join the focus groups and complete the surveys. In addition, a secondary analysis of existing survey materials routinely gathered by Amaze was completed, such as feedback from

families on Compass communication methods and from Leisure Providers on their involvement in the Project.

Of the 469 survey respondents, 96% were parent carers of CC holders and the remaining 4% included 2 foster carers, 1 grandmother, 1 special guardian and 11 young disabled CC holders aged between 16-24 years. There was an almost equal number from each of the two areas, with 46% B&H, 48% WSx, and 6% holders of both cards. 93% of the respondents were women, 16% were living solely on benefits, 18% had experienced domestic abuse from a partner or family member and 30% were managing their own disability, learning difficulty or long-term health problem. Only 61% were in paid work, and just over half said this work had been negatively affected by their caring role. 89% identified as white British, 6% white other, 3% were from black and minority ethnic communities and 2% mixed backgrounds, and 4% spoke a non-English language at home. The majority (60%) of respondents were aged between 35-49 years, 21% were 50-59, 12% were 25-34, 4% were 16-24, and 3% 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 10% response rate from the high numbers registered with the Compass compares well to other psychological research and is sufficiently large to have confidence in the findings. Overall, there was no substantial difference between the responses from survey respondents in B&H and in WSx.

The first significant finding was that the CC is well used and valued. Of the 469 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
- 50% said they used the CC at least monthly, and 20% used it at least weekly
- 81% said they would access fewer leisure activities if they were without it.

Typically, parents said:

“The CC gives my child the opportunity to enjoy outings and activities I’d never even think of trying and really significantly improves their quality of life.”

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

And young people attending the focus groups said if they did not have the CC they would miss:

“Connecting with others”; “I won’t go free, or skip the line, or pay cheaper”, “Freedom of choice”, “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 particular 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 (B&H and WSx) 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' (77%), and the extra benefits, such as free tickets, theatre offers and free Compass Days (58%).

- 77% Saving money
- 63% Venues have a better understanding of SEN and disabilities
- 58% Extra benefits: e.g. free tickets, theatre offers, Compass Days
- 57% Feeling more welcome at venues
- 54% Not having to explain the CC holder's additional needs
- 40% Getting news about leisure things to do
- 37% Being on the Compass database (to help shape services)
- 14% Using the Compass Card as a library card (WSx only)
- 4% Other (please tell us more)

The financial benefits were also reinforced by the conversations we had with the 20 parents who attended the interviews and focus groups, and the 10 young disabled people who had taken part in the Amaze focus groups.

"The CC saves us money and an acknowledgement that my children are cared about and makes their life a bit better."

"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 not unexpected, 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
- 71% said it helped to give the family a better sense of belonging, or feeling part of the community.

“To just get one person free to us makes a big difference.”

“You can get discounts and you and a friend can get a membership to a snooker club...I wouldn’t have joined the snooker 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. 64% of respondents said that having a CC meant children and young people were able to try new activities, (with 58% 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 (57%) mentioned in the survey, interviews and focus groups 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). Stigma, is defined by Goffman (1963) as a social attribute that is discrediting for an individual or group, impacts 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.

“Initially it [CC] is a bit hard to use...it’s an emotional thing...but once you have used it and seen the benefit of it, it’s straightforward.”

“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.”

“My youngest one sometimes feels a bit left out as he doesn’t have a CC... bit of sibling rivalry.”

Related to this, was the significant importance parents and young people assigned to not having to explain their difficulties when they visited leisure facilities. Just over half of the survey respondents (54%), 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 groups 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.

“The staff don’t always know what a CC is, so I just say to Google it up, or ask the manager.”

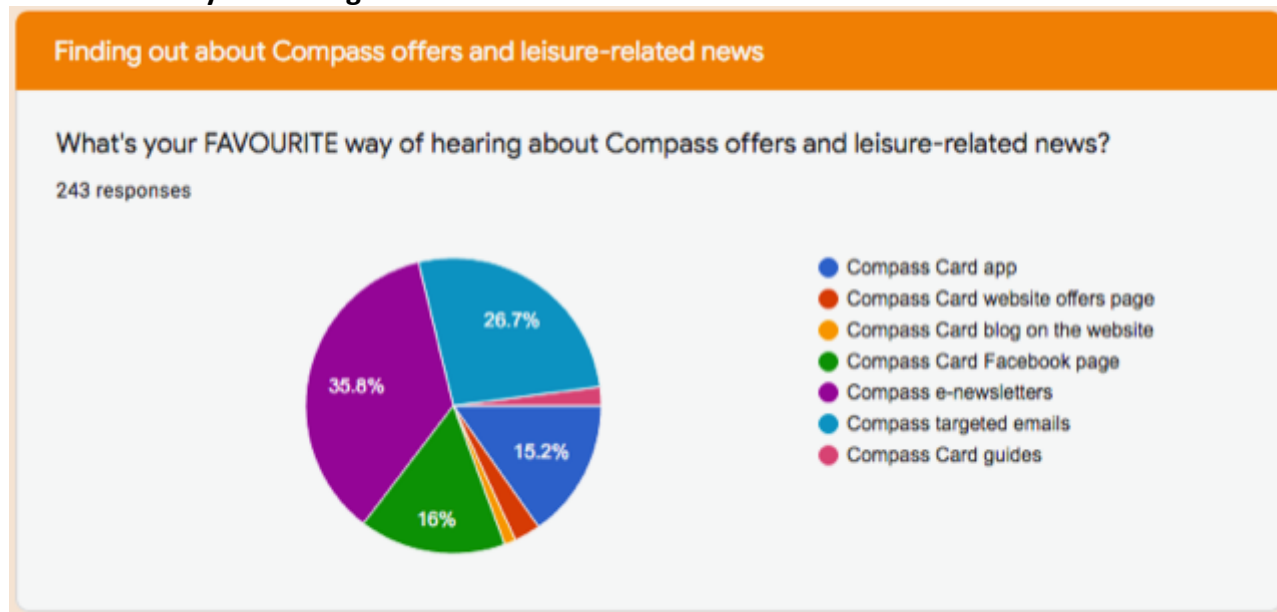
“There’s been a few instances where parents have rocked up with their CC and been refused, so it’s always good to use the app because on the app it has the offer and they can’t refuse it then.”

(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 (Amaze Compass Communication Survey) to ask how parents and CC holders find out about the CC options, in order to refresh its communication strategy. The findings highlight the preferred communication methods, but also illustrate 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



A very small number of parent carers (and young people at one of the Amaze focus groups) shared their difficulties with the information available. For example, they mentioned that the app was unhelpful because it was either not working, or they did not know there were two apps one for B&H and one for WSx or it did not include a distance function to help search for nearby options, or it 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. All these comments were made in the survey by parents or young people from WSx, which we were unable to investigate further. In contrast, the majority of parents we spoke with (and young people attending the Amaze focus groups) 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, 40% 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 200 leisure providers and offers at well over 300 venues across 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 at the WSx focus group (and the views of young people attending the Amaze WSx focus group), expressed concern about the CC not including enough. They specifically mentioned there not being enough options for older young people and too few options available in specific areas such as Mid Sussex, Bognor Regis or Haywards Heath and 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. Having a good experience at one place 'lifts the bar' and creates a standard for others to reach, which might disappoint when not met.

One young person's suggestions:

~~was asked~~
APP needs notifications.
Subboxes allow multiple ticks.

more
Gym's?
negotiate more
RESTAURANTS

A total of 87% 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."

"I love going to places where it's a designated SEN morning, I just think phew, my shoulders unloose. No explanation, and you can open your eyes to everybody."

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 groups, 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 WSx 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 WSx because the difference was that everything is closer in Brighton whereas in WSx, parents have to travel further to 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 WSx 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 commissioners, that independent travel training had been funded so that disabled children and young people could learn the skills to use the local buses.

There was no significant difference between the survey responses provided by parent carers or young CC holders, nor was there much difference between the WSx and B&H responses, except for two areas. Firstly, the CC acts as a library card in WSx and so the 14% of survey respondents who said using the CC as a library card was an important feature, only relate to WSx parents completing the survey (approximately half of the total returns). Secondly, more WSx than B&H survey respondents identified being on the Compass Disability Register as important although the difference was marginal.

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
- 64% 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 and of 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. Even when parents encourage children to act as though they are confident, when neither they nor their children feel that way, can be very effective 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, and young people commented on the link between going out and making friends.

“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.”

“You can be more socialised and be more interactive”; “You get to hang out with your friends”; “If you go out you get more friends”; “If you are stuck inside you won’t get any friends.”

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’ (34%) or that the question was not relevant (23%). 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 (5% 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.

“I’ve always made the choices...never thought he would be able to do that.”

“It’s amazing, I don’t think she would be going as much, it’s giving her a bit of independence.”

“You get freedom and do all the things you want to do.”

A total of 45% of survey respondents said having a CC improved the CC holder’s sense of belonging or feeling part of the local community. When we analysed the responses from just the 11 young CC holders who answered the survey, 8 said the same (2 said there had been no improvement and 1 was not sure).

“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.”

Has the CC had any impact on the use of services:	
Fewer GP appointments	5%
Fewer hospital visits	3%
Less input from mental health services	6%
Fewer overnight short breaks	1%
Less social work support	6%
Other	6%
No impact	49%
Not sure	24%

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 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 70% 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.

“At first, I thought am I cheating the system? Really, I feel a bit awkward about jumping the queue. Now I think my son’s life is hard enough and if it makes it a tiny bit easier.”

“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). As families register for a Compass Card in Brighton and Hove, they are also asked to complete a parent carer survey too. Latest data from March 2020 shows 52% have not had a break from their caring role in the past year (which was even higher than the Carers UK survey in 2017, which reported 40%). Parent carers too face barriers to accessing leisure due to the demands of caring. The Amaze survey shows 68% of parent carers do not have any or as much social contact with people as they would like, but it would be interesting to further examine their 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 two parent focus groups:

“The connections with the other services, knowing all of this stuff as a package helps me feel not as alone...makes me feel like I’m part of something.”

“Some offers are for carers and this is important.”

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, 63% 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.”

“It’s a safety thing...you feel you’re in society and deserve to be in society.”

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 gives the staff an idea of something hidden in the child. They don’t question or ask, you don’t have to go through that process.”

“Most of the staff know who I am. One guy is really nice and makes everything a bit better.”

The success of the CC relies heavily on leisure providers willing to be involved. In 2018, Amaze conducted a survey which was completed by 38 leisure providers, with the majority reporting being very positive about their involvement, just over half saying it helped them to promote their inclusivity, and more disabled children with a CC were attending. It also appeared that they would like to do more as nearly half said they would welcome more Compass information leaflets and knowing more about how the Project could promote their involvement.

“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 following account 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.*

Leisure is a discretionary service and there is no statutory requirement to provide activities or to offer a concessionary scheme like the CC. However, there is a legal duty for each local authority to hold a register of children and young people with special educational needs and disabilities, and so B&H and WSx commission Amaze to operate the Compass database on their behalf.

“When I was in Yorkshire, we used the CC to get into places and the response was ‘we could do with one of these in our area, this is amazing’.”

Amaze estimates that 38% of WSx and 70% of B&H families eligible to join the Disability Register are now listed. The WSx Compass has been operational for just over 4 years, and the B&H Compass, for almost 18 years. There is an eagerness to expand WSx Compass as quickly as possible and one way of estimating the rate of growth is to compare figures with the nearest comparison, which is of course the B&H Compass. This shows that the uptake increased in Brighton by 70% between 2008/09 and 2018/19, and so allows Amaze to calculate where WSx 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 WSx, which impact take-up levels. Interestingly, parent support groups in the WSx 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 B&H and in WSx. Quarterly reports provided for B&H and WSX commissioners, include various key performance indicators, such as numbers, 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 particular 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, prepare reports for inspections and complete funding applications. For example, in WSx, in 2019/20, 20 reports were generated for local planners and agencies and 8 targeted information emails were sent to parent carers.

“They give me so much I get a breakdown by age, ward, sex, condition so I have enough.”

“We were able to draw on some of the data from the Compass, as part of building a business case for extra investment in neurodevelopmental services (there is no good needs assessments or national data that helps us build a case of need and prevalence).”

“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, 37% of survey respondents said being on the Compass Disability Register (B&H and WSx). While there were some parents attending the focus groups and interviews who were not so aware of the database, the discussions became quite animated when groups started talking about its function. Parents thought that if others better understood the purpose for registering their details, many more would sign up.

“Our children should become identified and we would be forgotten otherwise.”

“A lot of parents might want to feel they are doing something for the greater good, feeding something into the community and not wanting others to go through it.”

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 services and has information about it on its literature and the Compass Card website. There have also been efforts to illustrate how 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. The Amaze staff team consistently promote and refer parents to the CC, and encouraging education, social care and health workers to endorse the Project further helps, although it seems likely that it 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 in B&H and in WSx, 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	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 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 B&H and in WSx 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:

“If you think of health holistically, the ability of those families to access leisure facilities has got to have some contribution to their overall wellbeing and functioning.”

A leisure provider said:

“We see it as being able to give back to the community...Amaze has paved the way; we use the Amaze model as a template for doing other things.”

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, one of the service commissioners 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 (B&H and WSx) 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 families lives. As well as facilitating access to local leisure venues, two thirds (70%) 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 (45%), and even more so for their families (71%).

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 (B&H and WSx) 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, particularly in WSx. 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 Amaze keeping existing registrations and encouraging new ones. There is some pressure to increase the size of the WSx 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. WSx 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.

References

- Aiden, H. and McCarthy, A. (2014) Current attitudes towards disabled people, Scope.
- Allard, A., Fellowes, A., Shilling, V. (2014) Key health outcomes for children and young people with neurodisability: Qualitative research with young people and parents. *BMJ Open* 4(4)
- Allcock, A. (2018) *Disability and access to leisure*, The Institute for Research and Innovation in Social Services: Scotland.
- Amaze Compass Communications Survey 2018
- Anaby, D., Hand, C., Bradley, L., Direzze, B., Forhan, M., Digiacomio, A. (2013) The effect of the environment on participation of children and youth with disabilities: a scoping review. *Disabil Rehabil.*, 35:1589–98.
- Badia, M., Orgaz, M. B., Verdugo, M.A., Ullán, A., Martinez. M. (2013) Relationships Between Leisure Participation and Quality of Life of People with Developmental Disabilities, *Journal of Applied Research in Intellectual Disabilities* 26 (6):533–545.
- Baldwin, S. (2015) *The costs of caring: Families with disabled children*, Routledge: London.
- Beresford, B. and Clarke, S. (2009) Improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities, Disability Research Review, Centre for Excellence and Outcomes in Children and Young People's Services (C4EO), London.
- Broach, S. and Clements, L. (2020) *Disabled Children: a legal handbook*, 3rd ed LAG: London
- Buckner, L. and Yeandle, S. (2017) *Caring More than Most: A profile of UK families caring for disabled children*, Report. Contact: London.
- Carers UK (2017) State of Caring 2017, Carers UK: London.
- Contact (2012) *Caring more than most: A profile of UK families caring for disabled children*, Contact with the University of Leeds: London
- Copestake et al. (2014) Removing barriers, raising disabled people's living standards . OPM & MORI.
- Cousins, J., Childs, T., and Giddings, B. (2014) *Opening Up Our World: Through the Compass Card Gateway*, J B Eventus Ltd.
- Cowart, B., Saylor, L. C. F., Dingle, A. and Mainor. M. (2004) Social Skills and Recreational Preferences of Children with and Without Disabilities, *North American Journal of Psychology* 6 (1): 27–42).
- Devine, M. (2004) Being A 'Doer' Instead of A 'Viewer': The Role of Inclusive Leisure Contexts in Determining Social Acceptance for People with Disabilities. *Journal of Leisure Research* 36 (2): 137–159.
- DWP (2013) Fulfilling potential. Building a deeper understanding of disability, *UK Today*.
- EDCM (2007) *If I could change one thing: What disabled children and young people have told us would make the biggest difference in their lives*, London: Every Disabled Child Matters.
- Eime, R. M., Young, J. A., Harvey, J. T., Charity, M. J., & Payne, W. R. (2013). A systematic review of the psychological and social benefits of participation in sport for children and adolescents: Informing development of a conceptual model of health through sport. *The International Journal of Behavioral Nutrition and Physical Activity*, 10(1).
- Equality and Human Right Commission (2017) *Being Disabled in Britain: A journey less equal*, Equality and Human Rights Commission.
- Franklin, A. (2016) *Friendship Opportunities for Disabled Children and Young People*, Briefing Paper, The Children's Society: University of Coventry.
- Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. New Jersey: Prentice-Hall.
- Gordon, D., Parker, R., Loughran, F. and Heslop, P. (2000) *Disabled Children in Britain: A Reanalysis of the OPCS Disability Survey*, London: The Stationery Office.
- Green, S.E. (2003) What Do You Mean 'What's Wrong with Her: Stigma and the Lives of Families of Children with Disabilities, *Social Science and Medicine*, 57:1361–74.
- Kelly, D. (2005) *Inclusive leisure opportunities for children and young people aged 8–16 with special educational needs and/or disabilities in south east England*, Stoke on Trent: English Federation of Disability Sports.

- King, G., Petrenchik, T., Law, M., Hurley, P. (2009) The enjoyment of formal and informal recreation and leisure activities: a comparison of school-aged children with and without physical disabilities. *Intl J Disabil Dev Educ*, 56: 109–30.
- King, G., Gibson, B., Mistry, B., et al. (2014) An integrated methods study of the experiences of youth with severe disabilities in leisure activity settings: the importance of belonging, fun, and control and choice. *Disabil Rehabil*, 36: 1626–35.
- Melnychuk, M., Solmi, F., Morris, S. (2018) Using compensating variation to measure the costs of child disability in the UK. *The European Journal of Health Economics*, 2018, 19(3), pp419–433.
- Milner, P. and Kelly, B. (2009) Community participation and inclusion: people with disabilities defining their place, *Disability and Society*, 24(1), pp.47–62.
- Murphy, N. A., and Carbone, P. S. (2008) Promoting the Participation of Children with Disabilities in Sports, Recreation, and Physical Activities, *American Academy of Pediatrics*, 121: 5, 1057-1061
- Murray, P. (2002) *Hello! Are you listening? Disabled teenagers' experiences of access to inclusive leisure*. Joseph Rowntree Foundation. York.
- Norvilitis, J.M., Scime, M., Lee, J. S. (2002) Courtesy Stigma in Mothers of Children with Attention-Deficit/Hyperactivity Disorder: A Preliminary Investigation, *Journal of Attention Disorders*, 6(2):61–68.
- ONS (2010) Office for National Statistics, *Life Opportunities Survey*. Interim Results 2009/2010 Office for Disability Issues: London.
- Papworth Trust (2018) *Facts and Figures 2018: Disability in the United Kingdom* .
- Petrie, P., Knight, A., Zuurmond, M. and Potts, P. (2007) *On holiday! Policy and provision for disabled children and their families: final report*, London: University of London, Institute of Education, Thomas Coram Research Unit.
- Powrie, B., Kolehmainen, N., Turpin, M., Ziviani, J. and Copley, J. (2015) The meaning of leisure for children and young people with physical disabilities: A systematic evidence synthesis. *Dev. Med. Child Neurol*. 57, 993–1010.
- Preston, G. (2006) *Helter Skelter: Families, disabled children and the benefits system*, Centre for Analysis of Social Exclusion (CASE) Report 92, LSE: London
- Quinn, M. (2016) Promoting Independence among Children with Disabilities at the Milwaukee Center for Independence (MCFI). *J Child Dev Disord*. 2:3.
- Rowlingson, K. (2011) *Does income inequality cause health and social problems?* London: Joseph Rowntree Foundation
- Royston, S. and Hounsell, D. (2011) *4 in 10: Disabled children living in poverty*, The Children's Society: London.
- Scope (2019) *The Disability Price Tag*, Policy Report, Scope.
- Sense (2015) *Making Play Inclusive*, London: Sense.
- Sense (2017) *Someone cares if I'm not there: addressing loneliness in disabled people*. London.
- Shikako-Thomas, K., Kolehmainen, N., Ketelaar M, Bult, M., Law, M. (2014) Promoting leisure participation as part of health and well-being in children and youth with cerebral palsy. *J Child Neurol*. 29:1125–33.
- Stobbs, P. (2008) *Extending inclusion: access for disabled children and young people to extended schools and children's centres: a developmental manual*, London: Council for Disabled Children.
- Stokes, H., Turnbull, M., Wyn, J. (2013) *Young people with a disability: independence and opportunity*. The University of Melbourne, Australia: Youth Research Centre.
- Turner, C. (2003) *Are you listening?* What disabled children and young people in Wales think about the services they use: a consultation to inform the children and young people's national service framework, Cardiff: Welsh Assembly Government.
- Ungar, M. (2015) *Working with Children and Youth with Complex Needs*, Routledge: New York.
- United Nations General Assembly (2006) Convention on the Rights of Persons with Disabilities
- Wilkinson, R. & Pickett, K. (2010) *Spirit level* (2nd ed.). London: Allen Lane.