

Holiday, What Holiday? Vacation Experiences of Children with Autism and Their Families

Lorene Amet*

Mulberry House, 21 Manor Place, Edinburgh, EH3 7DX, UK

Abstract

This work aims at identifying the types of holiday experienced by families of children with autism spectrum disorder (ASD). 35 families of ASD children and 25 control families of children with Down's Syndrome (DS) living in Scotland took part in a small scale semi-qualitative study to explore their experiences on holiday. In both groups, a significant proportion of the families had not taken any holiday away from home more than once in the last 3 years and there was limited use of children holiday centers. Families of ASD children who had been on holiday expressed overall less positive impressions of their experiences and showed limited use of public places such as restaurants, cafes, cinemas and hotels normally accessed by typical families whilst on vacation. Five areas were identified as influencing the quality of their experiences: 1-child's disability, particularly with regard to behavior, 2-lack of suitable holiday structures, 3-financial limitation of the family, 4-lack of empathy from surrounding communities towards the disabled child and his or her family, 5- general state of exhaustion of the parents. The paper further describes two pilot holiday community experiences organised with 10 families with ASD children in an attempt to address some of the issues hereby identified. A retrospective analysis of these experiences and surveys suggests that amongst all five identified barriers, the issue of the child's behavior is the most significant difficulty encountered by these families. Supporting families in understanding and improving their child's behavior is needed to enable families to maximise their experience on holiday. Increasing the understanding of the condition, improving access to leisure activities and some financial aid would equally be beneficial.

Keywords: Autism; Down syndrome; Family; Holiday; Sibling; Vacation

Introduction

Autism Spectrum Disorders (ASD) are developmental disorders characterized by impairments in language, communication and social functioning accompanied by a restricted range of interests and behaviours [1]. Although the exact pathology of these disorders is unknown it is believed that a combination of genetic vulnerability and environmental factors (in utero, peri-natally and in infancy) cause a failure in the normal development of the central nervous system. ASD is now officially recognized to affect 1% of children aged 5-16 in the UK; these conditions are more often associated with physical and health complaints than any other mental disorder [2]. Affected children can suffer from acute sensory sensitivity (sound, light) [3], anxiety [4] and sleep disorders [5]. Autism varies in degree of impairment, ranging from mild to severe [1].

It has been reported that psychological difficulties and stress are much more prevalent in parents of children with autism than in parents either of non-disabled children [6,7] or of children with mental retardation or Down Syndrome [8,9]. A large proportion of parents (81.9%) were reported to be stretched beyond their limits [10]. Increased divorce rates are reported, with 1 in 3 families with ASD children breaking up in the UK [11] compared to a national average of 1 in 10 [12] and a per annum annual divorce rate in 2005 in England and Wales of only 1.3% [13].

The level of psychological distress was found to relate to the paucity of welfare support provided to the family as well as to the level of behavioral impairment of the ASD child. A National Health Interview Survey conducted in the United States in the years 2003-2004 on a sample of parents of 102 children with autism indicated that 43% of children had emotional problems, 34% had conduct problems, 65% had hyperactivity issues, 82% had difficulties interacting with peers [14]. The 5 main categories of conduct problems were violence and aggression to others, self-injurious behavior, destructive behavior,

repetitive and stereotyped behavior, and disruptive and antisocial behavior.

A child with ASD places additional pressures on the family. Difficult and challenging behaviors can prevent families from attending events together; couples often cannot spend time alone due to extreme parenting demands and the lack of qualified staff to supervise the disabled child in their absence. In addition, the responses of fathers and mothers to the disability of a child with autism reveal different levels of perceived stress and impaired health [15-17], potentially contributing to conflict. A further significant stress factor relates to the increased cost of living, most particularly for parents who are unable to work due to their duty of care [18,19]. Additional factors impacting on the family relate to the lack of adequate support services, the lack of acceptance of autistic behavior by society and sometimes by family members, and a low level of social support [10,17,20]. A National Survey of Children's Health conducted in the United States further has confirmed a range of problems including diminished family functioning, more school absences, less participation in community activities, and difficulties with child care and employment [21].

According to the American Academy of Paediatrics, "Families are the most central and enduring influence in children's lives... the health and well-being of children is inextricably linked to their

***Corresponding author:** Lorene Amet, Autism Treatment Plus, Mulberry House, 21 Manor Place, Edinburgh, EH3 7DX, UK, Tel: 0131 558 7444; E-mail: L.Amet@autismtreatment.org.uk

Received November 25, 2013; **Accepted** December 06, 2013; **Published** December 10, 2013

Citation: Amet L (2013) Holiday, What Holiday? Vacation Experiences of Children with Autism and Their Families. Autism 3: 123. doi:10.4172/2165-7890.1000123

Copyright: © 2013 Amet L. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

parent's physical, emotional and social health, social experience and child rearing practices" [22]. It is therefore possible that dysfunction of families with an ASD child can impact negatively on the development of the ASD child and of his or her siblings.

For the siblings of ASD children there are many potential sources of stress: feelings of anger, guilt, embarrassment, jealousy, being the target of aggressive behaviors, loneliness, concern regarding their parents' stress and grief, and concern over their role in care-giving [23,24].

Against this background the need for periods of vacation would appear to be more acutely necessary for families with one or more ASD children. For most people leisure, traveling and recreation are important aspects of life as they allow horizons to be expanded and they foster the development of new interests. Periods of vacation also allow relaxation and make a significant contribution to overall emotional and psychological well-being. Ghates and Hazel [25] reported on the benefits of family holidays; these included parents and children being able to "recharge their batteries" by relief from everyday stress, vacations provided opportunities to strengthen family relationships, and families reported that spending quality time together away from everyday problems was of particular importance.

Although there are no reliable figures that specifically address parents and children, the percentage of UK families in 1996 able to take a week's annual holiday away from home was 66% (European Communities, 2002). This is consistent with the UK government statistics estimating that 69% of all UK children in 2005/2006 took at least one week's holiday away from home with the family, while in families with an income below 60% of the median only 44% of children took at least one such holiday [26]. Indeed, lower socio-economic and higher age groups have the lowest vacation rates [27]. Non-vacationers also include those with poor health or with career or work commitments [28]. A lack of vacationing has been considered as a failure to participate properly in the life of the community [29,30]. The significance of holidaying away from home each year has been recognized by the UK Government in its measures to assess child poverty [31]. One of three indicators used in their calculation of childhood poverty was the inability of children to holiday with their family away from home for at least a week per year.

Despite their undoubted benefits, vacations can present a major challenge for ASD individuals and notably for their families. It is generally accepted that individuals with autism present with some degree of inflexibility of learning and often lack "common sense" in day to day situations [32]. Difficulties in generalization are commonly encountered and there is a tendency to show maladaptive responses to novel environments and situations. For these reasons ASD individuals tend to prefer, or are constrained to, simplified environments with reduced exposure to novelty. In consequence, whereas the notion of being away from home seems appealing and pleasurable to most people, this is not necessarily the case for individuals with autism because holidays constitute a change of routine and environment. In addition, many parents of ASD individuals feel they do not receive the help they need during vacations [33]. Furthermore, going out in public with a disabled child can elicit intolerant responses from by passers [34,35], these potentially act as a further deterrent to taking vacations.

Little has been published with regards to holiday trends in families of children with autism, although many anecdotal accounts suggest that the holiday period can be distressing both for the child with autism and his or her family [36]. Charitable national groups in the UK such as the National Autistic Society (NAS), Contact a

Family (Joseph Rowntree Foundation), and Barnardo's are clearly aware that accessing and experiencing vacations can be difficult for such families particularly because of the limited and geographically uneven availability of supported holiday schemes during the lengthy periods of school recess. These organizations have therefore focused on listing possible leisure opportunities for disabled children or other forms of vacation support [37,38]. The NAS has published a Holiday Help Guide which lists a range of respite holiday centers and different funds that can be made available to families with financial difficulties. Barnardo's has also published "Postcards from home" that recounts the experiences of disabled children during the school holidays [39]. However, in the studies by Shelley (2002) and Murray (2002) it was not clear whether children with autism were included in the leisure experiences described.

The critical issue of respite and need for short breaks for families of children with autism was raised in the UK by the All-Party Parliamentary Group on Autism in a published manifesto [18]. This stated: "the framework also recognises the need for short breaks, which is particularly acute for the families of children with autism. It recognises that weekends and school holidays are crucial times for short-break services to be delivered". Lord Astor of Haver reported in the House of Lords that 93% of parents did not receive help during the holidays, although 87% request a break from caring [33]. Audit of local authorities and a variety of stakeholders commissioned by the UK Department for Education and Skills also emphasized respite services as a priority area with a gap in provision for children with ASD [33].

The available reports suggest that families with ASD children have increased difficulties in vacationing, and may in fact be under increased stress during school recess periods. However, little if any research to date has addressed the rates and qualities of vacationing in families with ASD children. A pilot survey was therefore performed to assess vacationing in families with ASD children. For comparison, a similar number of families with Down Syndrome children was also surveyed. The present paper reports that vacationing rates in both groups are substantially reduced and presents a pilot study aimed at remedying this situation.

Methods

Vacation frequency and quality

A semi-qualitative methodology was used to explore the vacation experiences of families with ASD children compared to families with Down Syndrome (DS) children. A questionnaire was developed that focuses on diverse aspects of vacationing in both family types; specific topics covered were as follows. 1. Family profiles, including (a) diagnosis and other disabilities, (b) age of the disabled child, time of diagnosis, welfare support, place of education (c) level of support from family and disability groups (d) training in providing assistance regarding the child's disability. 2. Holiday trends, including (a) how often the family has taken a vacation in the previous 3 years, (b) vacations with or without the disabled child (c) vacation locations, what type of accommodation and travel were used, and with whom did they spend their vacation time, and (d) what types of public facilities did the family visit while on vacation. 3. Vacation quality, including (a) the family's rating of the quality and benefits of the period of vacation (g) what factors impacted positively and negatively on vacation quality (c) factors needing to be addressed in order to improve vacation quality. The questionnaire encouraged families to give personal accounts of their experiences and perceived positive and negative outcomes. The

questionnaire for DS families was identical but with ASD/autism replaced by Down syndrome.

Following initial contacts the questionnaire was sent by post, phone, e-mail or through their child's school to 150 families with ASD children resident in the vicinity of Edinburgh, UK. For questionnaires sent by mail, pre-paid return envelopes were provided. Parents of DS children also resident in the vicinity were contacted via Down Syndrome Scotland; 50 questionnaires were sent to these families. This investigation was conducted between March and November 2006 and covered the 3 yr period prior to completion of the questionnaire by respondents.

Assessment of the co-vacationing pilot study

Perceived benefits were evaluated through semi-structured interviews with participating families 2 mo after the periods of vacation. Interviews focused on evaluating semi-quantitatively the benefits to the ASD child and siblings, as perceived by the parents, whether the parents felt the overall experience was positive, with regard to the organisation, location, choice of activities, group dynamics, opportunities to socialise amongst adults, children and as a group. The evaluation also took account of the most likable and dislikable aspects of the holiday and asked for suggestions on how to improve future holiday experiences.

Results

Response rates

The response rate for the ASD families was low, with only 34 questionnaires being completed and returned from 150 enquiries (overall 23% response rate). For DS families the response rate was substantially higher with 20 responses being obtained from 50 enquiries (40%).

ASD family profile

Within the ASD family sample children were aged between 3 and 18 with a mean age of 6.5 yr. Eleven families had only a single child (32%) and the average number of children per family was 1.8. One of the families had 2 children with autism and one had a sibling with dyslexia. The age of diagnosis of autism ranged between 19 mo and 6 yr of age with a mean age of 2.6 yr. Additional diagnoses were: colitis in 2 children, inflammatory bowel disorder in 2 children, epilepsy in 3 (8.5%), IgE multiple allergies, 1 child, dyspraxia in 1; 1 child had an additional diagnosis of developmental delay, 1 had moderate learning disability, 2 had severe learning disabilities.

Twenty three of the disabled children (66%) received government welfare support (Disability Living Allowance, DLA); 15 (43%) of these received the DLA higher rate for personal care while 10 (28%) received the higher rate for mobility care. Twelve children (34%) received no DLA.

The largest subgroup of the ASD children (43%) were educated in Special Needs schools, 23% were in an ASD unit attached to a mainstream school, 11% were in a mainstream setting and 20% were educated at home. The profiles of these families are presented in Figure 1.

A proportion of these families (38%) lived in proximity to close relatives while 47% had no regular contact with their immediate families. Approximately half of the families (47%) described themselves as having no friends while 44% described themselves as having regular contacts with friends (Figure 2). Half (41%) of the families were regularly connected via the internet to similar families or to an ASD

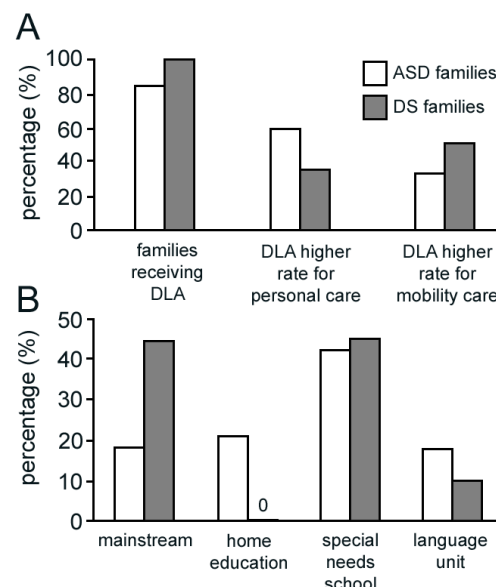


Figure 1: Welfare support and child's place of education of families with ASD or DS children. A. Government welfare support: receipt of Disability Living Allowance (DLA) at standard or higher rates. Not all families with ASD received DLA, whereas all DS families received this support. Families with ASD children tended to receive the higher rate component for personal care, whereas more DS families received the higher rate for mobility care. B. Place of education. Children with DS are more often educated in a mainstream setting compared to children with autism. No children with DS were home-educated compared to 21% of ASD children.

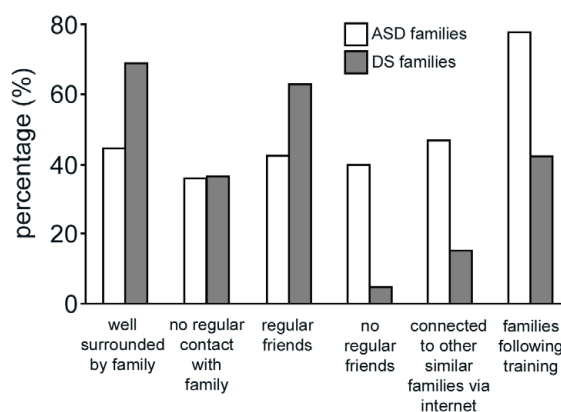


Figure 2: Community contacts of ASD and DS families. ASD families reported having fewer regular contacts than families with DS children but had more connections to other similar families. A higher percentage of ASD families had followed some training with regard to their children's disabilities than families with DS.

support group. A high percentage of families (77%) had followed some form of training with regards to their child's disability. The most popular forms of training were Hanen (speech and communication) (22%), Applied Behavior Analysis (19%), Son-Rise (16%), PECS (13%), or training provided by the Scottish Society for Autism (8%). Other forms of training included verbal behavior (5.5%), TEACCH (2.7%), Makaton (2.7%), Signalong (2.7%) and training from the National Autistic Society (2.7%). The majority of respondents (53%) had attended relevant conferences or lectures regarding their child's disability.

Down's Syndrome (DS) family profile

Children in the DS group were aged between 2 and 19 yr with a mean age of 11.0 yr. Five of 20 families (25%) had a single child; the average number of children per family was of 2.5. One family had 2 DS children, 2 families had another child with autism (these families were not included in the ASD group), and 1 family had 3 disabled children (other disabilities were not specified). The age of DS diagnosis ranged between 32 wks of pregnancy and 2 wks after birth; in one case an additional diagnosis of severe hearing impairment was made at age 4 yr. In this group of families, children with DS often had additional diagnoses; 2 had an additional diagnosis of autism while 1 required feeding by gastrostomy, presented with almost no speech and had severe behavioral problems. One had underactive thyroid and a heart condition. Two were visually impaired, 1 of whom had severe communication difficulties. One had severe hearing loss, 1 had an additional diagnosis of moderate learning disability and 1 a diagnosis of Hirschsprung's disease.

All families surveyed (100%) received DLA; 28% received the higher DLA rate for personal care, and 57% received the higher DLA rate for mobility care (Figure 1A). A proportion of these children were educated in mainstream settings (59%), while 32% attended a Special Needs School. A further 5% were educated in a special education unit attached to a mainstream setting, while 1 child was at college (5%). None of these children was home educated (Figure 1B).

Most families (45%) lived in close proximity to immediate family members while 40% had no regular contact with their immediate families. The majority of the families (95%) described themselves as having regular friends, only one family (5%) reported no regular friends. Half of the families (50%) were not connected to other similar families or groups via the internet (Figure 2). A minority of families (45%) had followed some training with regard to their child's disability, with Singalong and Makaton being the most popular. A proportion (15%) had attended relevant lectures and conferences.

Holiday trends in the ASD and DS family groups

Analysis of questionnaire responses revealed that 12 (35%) of the

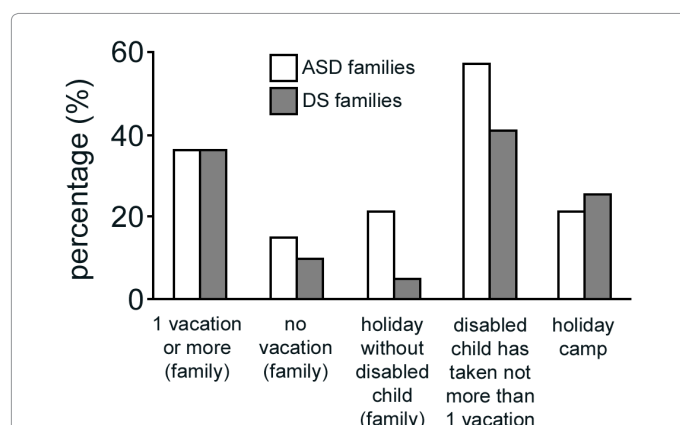


Figure 3: Vacation rates in ASD and DS families over the 3 yr study period. The same proportion of families in the ASD and DS samples were not going on holiday more than once over the last 3 years, but a higher proportion of ASD families had not gone on holiday at all over the last 3 years. Equally more ASD families had gone on holiday without their disabled child compared to the DS families sampled. Consequently a higher percentage still of ASD children have not been able to go on holiday more than once in the last 3 years compared to families with DS children. Very few families have used a holiday camp for their disabled children in both groups.

ASD families had not taken a vacation more than once in the 3 yr study period, a finding reiterated with the DS families (40%) (Figure 3). Some of these ASD families (6, 18% of the total families) had not taken any vacation at all, which was also the case for a proportion of the DS families (15%). A proportion of the ASD families (18%) had vacationed without their disabled child, a larger proportion than seen in the DS families (6%). Of the ASD children sampled 35% had vacationed once or less in the 3 yr study period as did 40% of the DS children.

For those families taking vacations with their disabled child the preferred place of stay for both ASD and DS families was in self-catering accommodation (19 ASD families, 68%; 10 DS families, 59%) (Figure 4). Of the ASD and DS families, 29% and 18% respectively stayed usually at a relative or friend's house. Both groups showed similar profiles for camping and caravanning (Figure 4A). However a greater proportion of DS families stayed at hotels; with 47% using this type of accommodation (8 families) versus 18% for the ASD group (5 families).

Within the group of vacationing ASD families, the majority commonly vacationed alone as a family (79%), as did the vacationing DS families (77%), or often stayed with relatives (75% of ASD families versus 41% of DS families) (Figure 4B). Of the ASD families, the majority (24 families, 86%) vacationed in their home country (UK) as did the DS families (77%) (Figure 4C).

While on vacation, and over the 3 yr study period, the public places most often accessed were swimming pools for both ASD and DS families; 79% and 94% of the families respectively used these facilities on a regular basis. However, for the other public places listed there were significant differences between the 2 groups: a higher proportion of vacationing DS families visited cafes (94%) and restaurants (94%) than did the ASD families (64% and 46% respectively) (Figure 5).

Perceived vacation quality of families with ASD and DS children

Families taking vacations were asked to rate their overall vacation experience(s) in one of 3 categories: "very good", "average", or "not so good/poor". For those families taking at least 1 vacation over the 3 yr study period, 32% of ASD families rated their vacation as very good (9 of 30 vacationing families), 53% rated their vacations as average (13 families), and 14% were held to be of poor quality (7 families) (Figure 6). In contrast, the majority of the 19 DS families who had taken a vacation rated their vacation experience as very good (82%), 12% reported average quality, and only 6% reported their holiday to be of poor quality (Figure 6). There is thus a major difference in the perception of positive and negative family vacation experiences between the DS and ASD families sampled.

ASD and DS Families who rated their vacations as very good:

For families rating their vacations as very good (9 ASD, 32% and 14 DS families, 82%) the most common factors reported as being relevant to the quality of their vacation were (1) choice of location, (2) the people they vacationed with, and (3) their financial situation (Figure 7). The factors rated as being the least relevant to vacation quality were the disability of the child (only 5 families, felt it related to their holiday quality) and travel arrangements (only 5 families rated this as a relevant factor for the quality of their vacation) (Figure 8).

There were 2 main differences between these ASD and DS families. First, the DS families felt more inclined to state their family type was linked to their successful holiday, illustrated by comments of the type "son's disability does not stop us doing things we want"; "child has

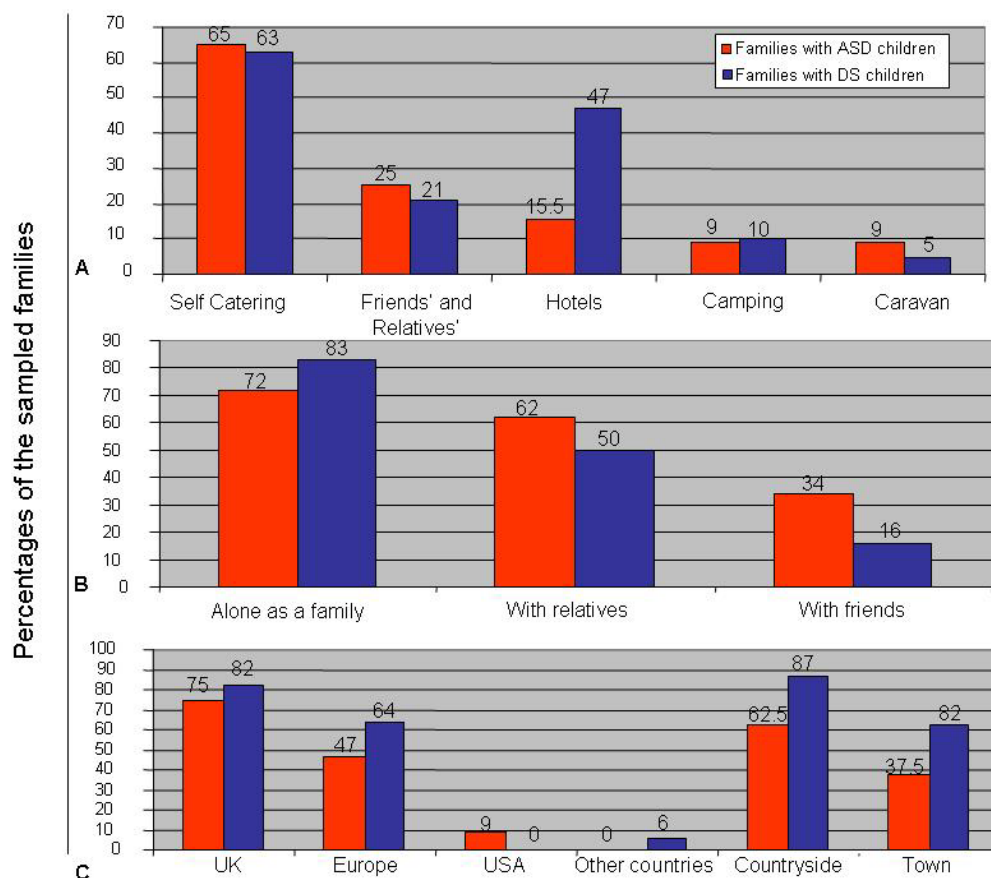


Figure 4: Locations of vacations taken by ASD and DS families. A. type of accommodation. ASD families visited hotels much more rarely than DS families. B. Type of vacation. Profiles were similar for the ASD and DS families although ASD families stayed with friends a little more often. C. location of vacation. There were no major differences in choice of location between the two types of family.

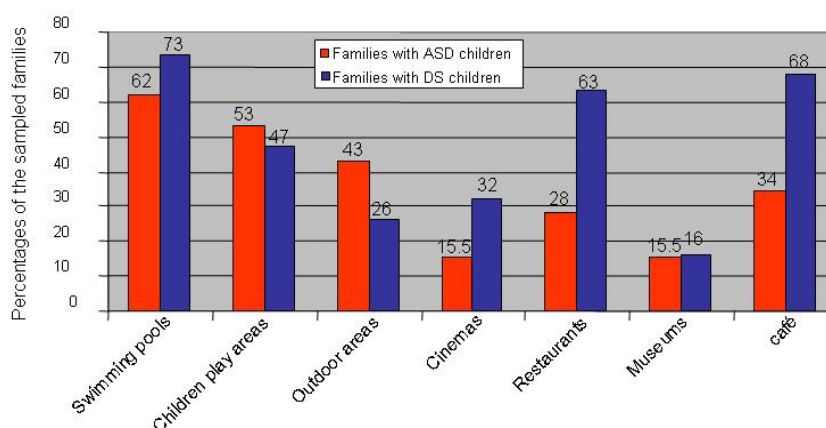


Figure 5: Locations and public places accessed by families on vacation. There was a trend that ASD families tended to visit cinemas/movie-houses, restaurants and cafes less frequently than families with DS children, and to use children's outdoor play areas more often.

always been encouraged to fit in with our life style and has well adapted to this", or "we are a family who love family holidays, we just happen to have 2 boys with DS". Second, for the DS families, the quality was less often rated as being related to the type of people they holiday with. This suggests that DS families were more independent as a unit than the ASD families in their ability to achieve a successful vacation experience.

Families who rated their vacations as average or not so good: For the ASD families who rated their holidays as either average or not so good (a total of 19; 15 average, 4 not so good), the most commonly reported factors impacting on the quality of their vacation were as follows. First, the disability of the child (74%). Second, the energy levels of the parents (74%); third, the choice of location (63%); fourth,

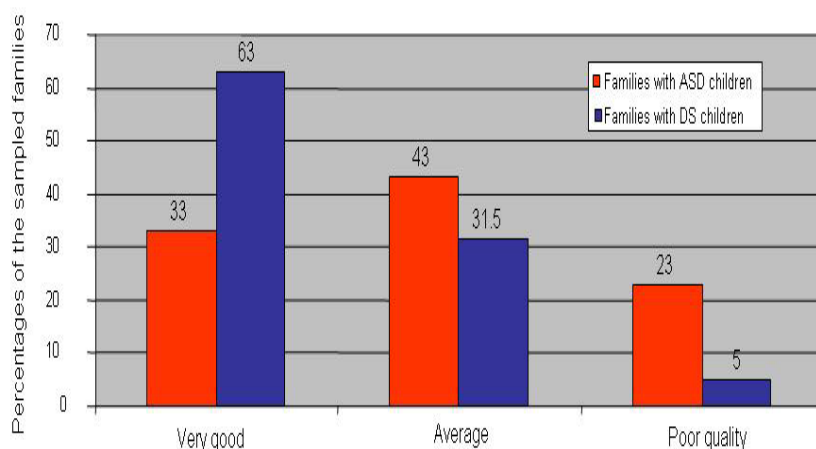


Figure 6: Perceived vacation quality of families with ASD or DS children. Families were asked to rate their vacation experiences as either “very good”, “average”, or “poor”.

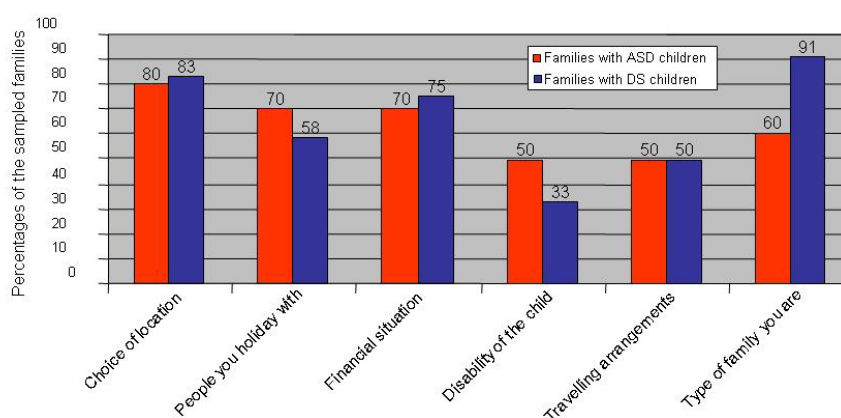


Figure 7: Factors reported to contribute to or constrain vacation quality. Both types of families identified the choice of location, the people they holiday with and the financial situation having positively impacted on the quality of their holiday. ASD families more commonly reported that the disability of their child impacted on the quality of the holiday and were more likely to report that the holiday quality was linked to the people they holiday with. A large proportion of DS families felt that the quality of their holiday was linked to the type of family they are. The percentages indicated are for the “very true” and “some true” answers combined.

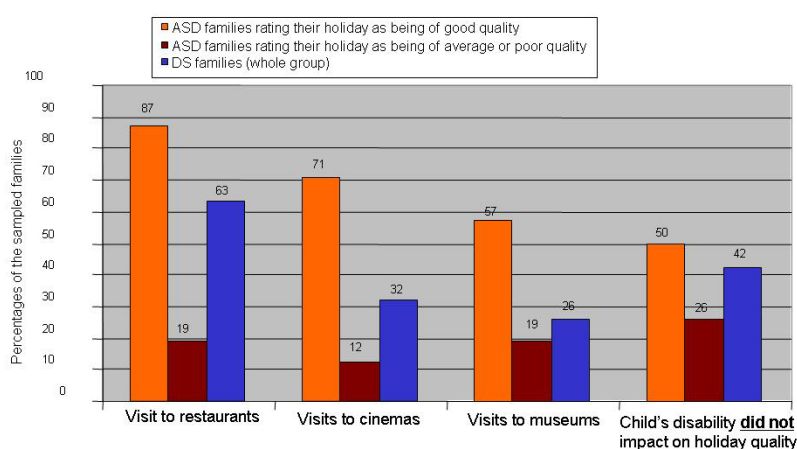


Figure 8: Incidence of use of 3 most common public places (restaurants, cinemas and museums) whilst on holiday in the groups of ASD families rating their holiday as very good, ASD families rating their holidays as average or poor and whole DS families. ASD families who rated their holiday as being very good did experience restaurants, cinemas and museums with a much greater incidence than ASD families reporting an average or poor quality of holidays and DS families. The impact of the child's disability seems lesser in the families who have reported good quality of holiday than in the other 2 groups.

difficulties in accessing public facilities (63%). Finally, level of finance (58%).

For the DS families who rated their holidays as either average or not so good (a total of 3; 2 average, 1 not so good), the only factors identified as significant were the child's disability and lack of support from others.

Additional information volunteered by 13 ASD families were for the most part linked to the child's behavioral difficulties, anti-social behavior, sleep, anxiety, need for routine, safety, and the child's sensory and food sensitivities. Attention was also drawn to the lack of availability of supported holiday schemes, notably with regard to access to appropriate professional support and environments accommodating issues of sensory overload. Some of the comments received illustrate these points well: "no autistic-friendly holiday structure", "lack of integration with normal children", "not worth the effort", "more support is needed", "additional person is needed to be with the child with autism", "behavior is difficult particularly because of phobias", "change of surroundings is difficult", "child's sleep is affected when on holiday", "too many children around, personal space is too restricted and overall the experience is overwhelming to an ASD child", "lack of suitable safe-play area for the ASD child", "inability to adjust the degree of sensory load of the holiday environments to be compatible with child's sensitivities", "child behavior forces parents into isolation during meal times", "rigidity of behavior and lack of suitable activities are difficult", "safety issues are not met", "lack of acceptance from other people", "holidays are for the children but the parents cannot rest". In addition to these factors, several families identified the following needs: access to changing rooms for older children with incontinence issues, more restaurants catering for special diets (e.g. gluten-free casein free). The issue of waiting for airplane boarding and access services was also commonly stated.

Reported factors to be addressed to improve vacation quality

Families were asked to identify from a list of possible negative factors whether improvement would improve vacation quality; in each case potential amelioration was rated as "very true", "somewhat true", or "not relevant".

Major factors identified by the ASD families that need to be addressed in order to improve their vacation frequency and quality were first, other people welcoming and interacting with the ASD child as they would with any other child (68% of the parents rated this as being very true); second, more understanding from others regarding their child's behavior and disability (68% rated this as being very true); third, better access to support structures and professional assistance to help their ASD child take part in the activities (65% of the parents rated this as being very true). Less essential factors were lack of funding (53% of parents stated this was an issue), difficulties in accessing public places (47% of parents reported this was an issue) and lack of support with traveling (32% of parents said this was a problem) (Figure 9).

The responses given by the DS families differed substantially in as much as the families mostly identified the listed factors as being irrelevant or only partly relevant. For example, DS families generally did not feel that more understanding from others would improve their vacation experience; only 25% of the families felt this was relevant. By comparison, the figure for the ASD families was 68%. The same trend was seen with "other people welcoming their DS child as any other child" and regarding the need for professional assistance. More funding was thought to be required for only 5 of the 14 DS families (25%) compared to 53% of the ASD families. Furthermore, the DS families generally reported there was no need for improvement regarding accessing suitable accommodation or support for traveling. Though these were still perceived as desired changes, the extent to which these issues were prioritized was far less than for the families with ASD children. This represents another major difference in perceived needs between the DS and ASD families sampled.

Pilot project: co-vacationing as a means to resolve barriers to inclusion

In the above it has emerged that families with ASD children often have difficulties organizing vacations where the child and the family can participate fully in typical holiday activities. This was partly due to the child's behavioral difficulties and to limited support for the family. Notably, a lack of understanding and acceptance from the surrounding community was felt to be a significant issue. Potential therapeutic

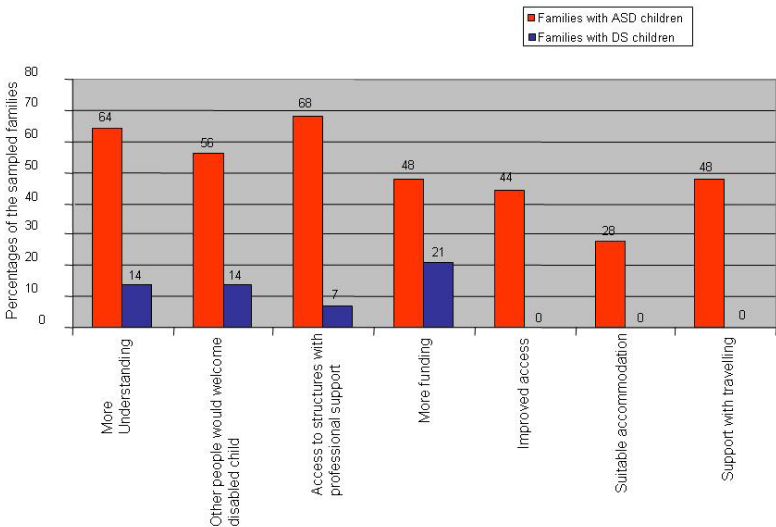


Figure 9: Factors identified by ASD and DS families as being needed to improve the quality of their vacation.

benefits of a vacation to the ASD child and his or her family were not explored in the survey, but because many families reported negative experiences it is likely that for many families there was no significant benefit at the emotional, physical or psychological levels.

Some factors cannot be addressed easily, for instance the child's behavior. However, co-vacationing with other families of ASD children, whose level of acceptance and understanding of ASD and its ramifications would be expected to be high, could potentially alleviate problems associated with non-acceptance. In addition, by vacationing together, it is possible that parents of ASD children could reduce the burden of care provision by assisting each other in the supervision of their children. A pilot project was therefore initiated to explore the possibility that co-vacationing might offer a route to improving the vacation experiences of families with ASD children.

Two vacations were therefore organized in conjunction with a total of 10 families of children with autism. The chosen location was rented self-catering accommodation in the South-West region of France. In year 1 five families of French nationality took part and in year 2 five families of UK nationality took part. The accommodation was in 3 cottages, the largest of which accommodated most children (with the exception of the younger ones and more sensitive ASD children) and was used as a central area for cooking and dining. In year 2, a total of 5 families (4 French and 1 British) took part in up to 2 consecutive weeks of vacation. All families were hosted in a single large accommodation. In year 2, 4 of the families had known each other from the previous summer experience.

Logistic constraints prevented random selection of participating families. Instead, a decision was taken by the organizers to invite families via established autism groups (mostly contacted by e-mails) because these families had already demonstrated active involvement in intervention strategies. This approach was felt to increase the likelihood of selecting families with pro-active attitudes towards their child's disability. Because such a group experience could not afford higher levels of challenges for some ASD children, those requiring constant 1:1 supervision at home or in highly secure settings were not included. No other selection criteria were applied to the ASD children.

Group activities aimed to include all children (examples including

ball games, treasure hunts, singing, farm activities including milking goats and feeding pigs and hens); typical leisure activities (horse-riding, canoeing, swimming, and sightseeing) were also proposed. In year 1, days were highly structured with 2 h of on-site group activities each morning, off-site activities each afternoon, and further communal activities each evening. Breakfast, lunch and dinner were additional opportunities for socialization. In year 2, a looser structure was adopted: each morning the ASD child was with his parents and left free to choose activities of his/her choice. Afternoons were used for group activities. In the evenings there were further social activities.

Evaluation of benefits

Perceived benefits were evaluated through semi-structured interviews with participating families 2 mo after the periods of vacation (Methods). Overall, co-vacationing with other families with ASD children was reported to be particularly valuable for the siblings and also for the children with ASD and their parents (see below). However because this type of vacation is of potential therapeutic benefit to the ASD child the positive and negative outcomes are reported in more detail.

Children with autism: The vacations comprised a total of 10 ASD children, ages ranging from 3 to 14 yr; with 8 boys and 2 girls. The children were divergent in their presentation of ASD and covered the full spectrum, from non-verbal and mostly non-compliant with significant behavioral issues, to very verbal, social, and with good play skills. One child had a diagnosis of Asperger while all others were ASD. One ASD child had an additional diagnosis of epilepsy. Seven of the children followed a gluten-free casein free diet. Three of the 10 families were with single parents; all the ASD children had siblings that accompanied them (in total 13 siblings).

Benefits for the ASD children were evaluated from the following interview questions put to parents: (1) ASD child was generally happy and relaxed during his stay, (2) the ASD child was able to cope well with the proposed group activities and experiences, with limited behavioral issues, (3) in the parent's view, the ASD child showed growing awareness of the other group members, both adults and children, and (4) the ASD child displayed increasing levels of interaction with others by any means of expression or communication (verbal or non-verbal).

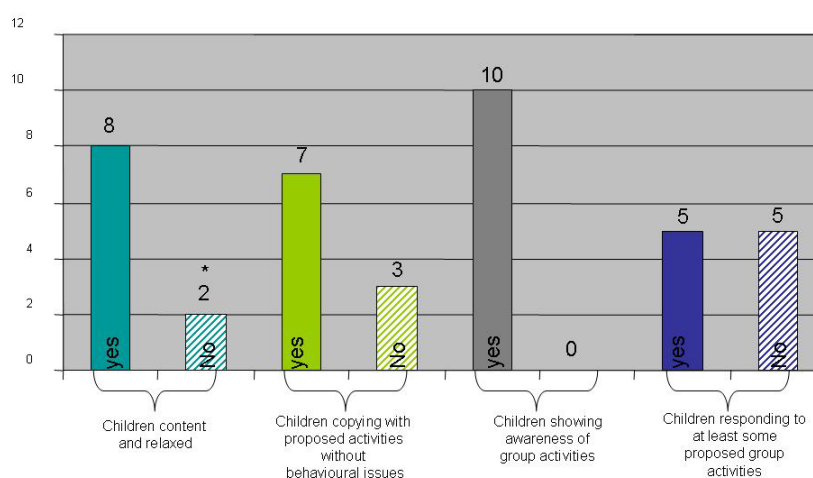


Figure 10: Community holiday experiences: benefits seen in children with autism. All children showed some degree of awareness towards the proposed group activities, 7 out of 10 children were able to cope without major behavioral issues, 5 out of 5 could respond with expression and in context to some activities. *2 children did not appear to be fully content and relaxed during their stay because of health matters.

The benefits reported varied according to the child's level of autism and health (Figure 10). Seven out of the 10 ASD children were generally happy and content, however one child was significantly agitated, unable to sleep, and was unsettled throughout the week. Another child was very affected for part of the week due to an ear infection causing acute pain, behavioral deterioration and necessitating emergency medical treatment. A further child was unsettled for half of his stay with increased seizure frequency linked to an infection. Two children were able to cope without much assistance in the proposed activities but the majority of the children needed assistance to focus on the activities and to respond when required. Some activities were more challenging and socially complex than others. Significantly, ASD children were generally reported to have shown improvement in their ability to engage in the activities with decreased need for support and increased interest in the proceedings.

Interestingly, some children clearly appeared to benefit from the highly-structured routines in year 1, and within a day or 2 appeared to increase their understanding and involvement in group activities. In year 2, with increased opportunities for spontaneous and unstructured play, the children initially progressed more slowly in their interaction with other members of the group. Nevertheless, after about 10 days their involvement was reported to improve in diverse ways, possibly reflecting more fundamental changes taking place. For example, towards the end of the vacation period one particular child started to show considerable interest in interacting with the other children and became spontaneously involved in play activities. The same child after watching a pantomime play spontaneously cut out paper shapes to add on to the story. Another child, again after 10 days of the vacation experience, started to interact more with all the adults, although this was essentially to meet his needs. The same child initially found it difficult to enjoy particular activities (e.g. dancing) but eventually came to enjoy this pastime. He also spontaneously participated in singing with other children.

Other children were reported to benefit from being supervised by other adults during the temporary absence of their parents. For some children, at both ends of the spectrum, it was less clear how much they benefited from this experience. The children that were more affected by health and sensory issues may have benefited but assessment is problematic. Equally, mildly-affected children may have benefited more from vacationing with children without behavioral issues.

Two children with autism presented serious behavioral issues. This was felt to be principally due to a lack of behavioral management strategies. For example, one non-verbal ASD child was unable to gain his mother's attention without using inappropriate behaviors (i.e. when he was well-behaved his mother gave him less attention). He appeared to develop a strategy of poor behavior in order to gain his mother's attention (e.g. he would break light bulbs with a broom handle). Each time it appeared that he was successful in gaining his mother's attention. Another ASD child was very solitary, dwelt on repetitive activities, and rejected most attempts at communication (this included avoidance of shared meals by overt antisocial behaviors in this context). Again the organizers suspected that this behavior had been acquired and reinforced.

Siblings: A total of 13 siblings took part in these vacations with up to 8 siblings at one time. At first the siblings got to know each other and appeared to be eager to share their experiences. It was reported that central issues debated between themselves included inappropriate behaviors in their ASD sibling, producing embarrassment in public places, and loneliness and frustration. Whereas all children made

considerable efforts to offer compassion and support, it was apparent that they would have preferred to have dealt with other issues and activities. Short periods of freedom to play amongst themselves were reported to be very valuable to the siblings of ASD children. These children played and laughed from morning to evening (and at night time). Nevertheless, the siblings were reported to have been exposed to new and valuable experiences and were able to interact profitably with their parent(s) because joint supervision of the ASD sibling had alleviated the burden of care-giving.

Parents: The experience was generally reported to have been enriching in view of the opportunity to exchange views amongst parents and to receive some emotional support and understanding from others. A context of implicit acceptance of behavioral issues in ASD was felt to be particularly positive. In addition, parents reported that they benefited by seeing the evident enjoyment in the ASD child's sibling(s). Furthermore, many parents were pleased with the improvements in social interactions demonstrated by their ASD child. Revealingly, on several occasions some parents became very emotional in expressing the severity of their daily life and receiving informed and genuine support from other parents was considered to be particularly valuable.

However, the experience was generally onerous for the organizers and for the parents overseeing community activities and tasks. In both vacations there were problems with one particular family (a different family each year) principally because of ineffective behavioral management strategies for their ASD child. This increased the burden on the rest of group. Diverging views on how to address such issues led to conflicts between families and parents, reminiscent of the problem of family breakdown as discussed earlier (Introduction).

Discussion

The aims of the current study were two-fold. First, to assess the vacation experiences of families of children with autism spectrum disorders (ASD) in comparison with families of children with Down Syndrome (DS). This study employed semi-quantitative surveys focusing on their needs and difficulties. Second, to perform a pilot study of co-vacationing as a means to resolve some of the issues identified in the survey.

The small sample sizes of the two family groups surveyed (34 ASD and 21 DS families) restricts interpretation of the results to the identification of major trends and differences between groups. In addition, because there were many non-responders it is unclear how representative the views expressed by the responders are of the wider population of families with ASD or DS children.

It is furthermore possible that the methods used to contact families biased the results by unintentionally selecting particular types of families. It was intended to contact all families within a defined geographical area but this was not feasible. Even contacting families via autism charities and Special Education schools yielded a low response rate. Therefore, additional sampling was conducted by telephone interview instead of by mail. The low response rate may reflect the daily difficulties encountered by families with ASD children. In contrast, families with DS children were easier to reach and had a higher response rate.

In both groups only a small proportion of families had taken vacations in the study period (the previous 3 years). The proportion of ASD families taking vacations was lower than for the DS families. In addition, a larger proportion of families in the ASD group took

vacations without their disabled child. Given the importance of holidays for the mental, emotional and socio-cultural well-being of the individual the current situation for both ASD and DS families would appear to be sub-optimal.

The challenge afforded by their child's disability was similar in the 2 groups, based on both the level of government welfare support received and the complex additional diagnoses present in both groups. However, it appears that ASD families face more challenges linked to the behavior of their child than do DS families. Thus, the disability of children with ASD was more often rated as being directly linked to the low frequency/quality of their vacation experience than for DS children. The level of difficulties encountered by ASD families is reflected by the high percentage undergoing some form of training to assist with their disabled child. Family income was not directly evaluated, but a greater proportion of ASD than DS families felt that additional income was required to improve the quality of their vacations. In both groups, families who rated their holiday as "good quality" reported that finance was important for holiday quality.

Overall, the frequency of rating vacation quality as "very good" was markedly reduced in the ASD families compared to DS families, and the perception of poor vacation quality was increased in the ASD group. It is notable that there is an inherent bias in the question as most families might be expected to rate even average vacations as "very good"; the trend towards "average" or "poor" suggests that vacation quality was generally lower than for the general population. In support, 82% of DS families, a tentative proxy for the wider population, stated that their vacation was "very good" while, conversely, 70% of ASD families rated their vacation quality as "average" or "poor".

There was no clear trend of an expressed desire for vacation improvements in families with DS children other than additional financial support. For families with ASD children there were needs across the whole range of listed parameters: for accessing leisure structures with professional assistance for the disabled child, for more understanding and supportive attitudes from others, for other people to welcome the disabled child as any other child, and for financial assistance to access vacations.

A potential conclusion from the above is that the level of family conflict with regard to vacations is more pronounced in families with ASD rather than with DS children. The main reason for this difference appears to be related to lack of support in dealing with the behavior of the disabled child. There may also be a greater public lack of understanding and empathy for children with autism versus DS children, not only regarding the management of their behavior but also regarding the nature of their disability.

Both groups cited financial constraints as a factor constraining vacations. However, the DS group received more governmental support through the DLA scheme than the ASD group. Unlike ASD, both the diagnosis of DS and perception of the disability are uncomplicated and this may facilitate the identification of support needs. All DS families received government welfare support (Disability Living Allowance, DLA), in contrast to the families with ASD children where only a proportion received similar support. In those families receiving benefits, the level of financial support differed between the ASD and DS families. More DS families than ASD families received the higher DLA component for mobility care. This finding is of some interest because most DS families interviewed did not report significant physical disability; it is assumed that decisions concerning attribution of the higher rate of mobility care support take into consideration other

behavioral aspects of mobility such as the need for safety. For families with ASD children there is a need for constant supervision with regard to mobility, and even verbal individuals can have little appreciation of danger and are likely to wander and get lost if not fully supervised. The discrepancy between the family groups in financial support regarding mobility care may reflect lack of recognition and knowledge of autism by the relevant authorities.

There was also a striking difference between the ASD and DS families with regard to place of education. DS children were more frequently educated in a mainstream setting than ASD children. Because of the lack of suitable educational settings for ASD children, it would appear that many families resort to home education. Effective educational and behavioral approaches in autism have been identified, and the lack of availability of suitable educational settings as well as mainstream placements may also reflect lack of recognition and understanding by the authorities of the needs and issues faced by children with autism and their families.

Consistently, ASD families on vacation were much less likely than DS families to access public places including restaurants, cafes, hotels, and cinemas. The absence of professional assistance for the disabled child was identified as contributing factor. The major factor restricting access to public places appeared to be related to the challenging behavior of the ASD child and the lack of understanding of the condition.

Given the potential benefits of periods of vacation for both the ASD children and their families, and the fact that a lack of understanding and acceptance from the surrounding community was felt to be a significant issue in constraining vacations, a pilot study was performed to address this issue. Co-vacationing with other families of ASD children, whose level of acceptance and understanding of ASD would be expected to be high, could potentially alleviate problems associated with non-acceptance. In addition, by vacationing together, parents of ASD children potentially could assist each other in the supervision of their children, improving the quality of the vacation experience. The 2 group vacations reported here were generally rated as highly beneficial by the families taking part. Important aspects were: (1) benefits for the ASD child: many children were reported to have increased their level of social interaction within the group and awareness during the vacation period, and being supervised by other adults in the temporary absence of their parents was seen as a contributory beneficial factor; (2) co-vacationing gave parents opportunities to meet with other parents sharing similar life experiences and to discuss relevant issues to autism; in addition, co-vacationing allowed sharing the burden of child supervision; (3) the siblings of the ASD children were able to express their individual needs and report on their own experiences, and contributed positively to activities that included some ASD children; (4) participating ASD families were able to access leisure facilities and experiences that they would otherwise have been unable to access. Overall the pilot study indicated that co-vacationing with other families of ASD children is a practicable route for improving the vacation quality of these families.

Despite the significant benefits reported by the families some difficulties were encountered due to ongoing behavioral issues in a minority of ASD children. These behaviors caused tensions across the whole group and were not easily resolved. This may suggest that expert assistance from a trained counselor could be advantageous in future studies of co-vacationing in ASD families.

Behaviors in autism are held to be amenable to biomedical and/or educational intervention [40-49]. Addressing medical needs can reduce chronic pain, distress, confusion and sensory overload that are

common in ASD children, and can ameliorate the behavior and social integration of the child. Equally, providing guidance to parents as to how avoid reinforcing inappropriate behaviors can improve the overall functioning of the child and hence of his or her family.

The provision of additional support to families regarding both behavioral management and biomedical/educational intervention could potentially improve the vacation experience of the ASD child and his/her family. Local and national holiday schemes have started to be developed in order to address the issues identified in the current study. Simple solutions, such as reducing time spent queuing at airports or waiting to access to children attraction (e.g. Disney World) should continued to be promoted across leisure settings and facilities. Parents need to be made aware of these possibilities and encourage asking for them. Equally, indoors and outdoors centers could be assisted with “Autism Friendly” staff, who could on request assist a child to access and be included in the activities as any other children would. Governmental funding could be made available to train and pay for such staff to be included as required assistance. Some cafes and restaurants could also take part of an “Autism Friendly” scheme, welcoming families with autistic people. Reduction in sensory overload (for example, showing films with reduced sound volume, or changing lighting and organization in shops) could also be of great benefit, not only to autistic individuals but to the wider population. Finally, a holiday financial package should be made available to families of ASD children to enable them to buy in the specific support they would benefit from in order to make their holiday more successful. In addition, because financial constraints were often cited as a factor impacting negatively on the vacation experiences of ASD families, greater recognition by government agencies of the pervasiveness of the disability in ASD would also be beneficial.

In conclusion, this study suggests that taking a vacation for families with ASD children affords a major psychological and logistic challenge. In addition, when the families did go on holiday the reported vacation quality was low. In consequence, families with ASD children tend to go on vacation infrequently compared to the general population. Given the importance of vacations for the emotional and psychological well-being of the ASD child and his or her family, steps should be taken to facilitate vacationing by such families. Financial constraints and non-acceptance of the ASD child were major constraining factors. To address the latter, a pilot study of co-vacationing with other ASD families was carried out, with major benefits being reported both for the family and the ASD child.

Acknowledgements

This project was completed in partial fulfillment of the requirements of a Master's program in Special Education for Children with Autism Children at the University of Birmingham. The author would like to thank Dr. Tommy MacKay and Dr. Glenys Jones for guidance, and Françoise Ayzac and Christophe Paris for assistance in organizing the vacation pilot study. The author would also like to thanks all families and children for contributing to this study.

References

- Wing L (1996) Autistic spectrum disorders. *BMJ* 312: 327-328.
- Office for National Statistics (2005) Mental Health: 1 in 10 children has a mental disorder. Extracted from: Survey of the Mental Health of Children and Young People in Great Britain, 2004; Basingstoke: Palgrave Macmillan.
- Carvill S (2001) Sensory impairments, intellectual disability and psychiatry. *Journal of Intellectual Disability Research* 45: 467-483.
- Gillberg C, Billstedt E (2000) Autism and Asperger syndrome: coexistence with other clinical disorders. *Acta Psychiatrica Scandinavica* 102: 321-330.
- Giannotti F, Cortesi F, Cerquiglioni A, Bernabei P (2006) An open-label study of controlled-release melatonin in treatment of sleep disorders in children with autism. *J Autism Dev Disord* 36: 741-752.
- Fombonne E, Simmons H, Ford T, Meltzer H, Goodman R (2003) Prevalence of pervasive developmental disorders in the British nationwide survey of child mental health. *International Reviews of Psychiatry* 15: 158-165.
- Hare D, Chapman M, Fraser J, Gore S, Burton M (2003) The prevalence of autistic spectrum disorders in people using a community learning disabilities service. *Journal of Learning Disabilities* 7: 267-281.
- Holroyd J, McArthur D (1976) Mental retardation and stress on the parents: a contrast between Down's syndrome and childhood autism. *Am J Ment Defic* 80: 431-436.
- Donovan AM (1988) Family stress and ways of coping with adolescents who have handicaps: maternal perceptions. *Am J Ment Retard* 92: 502-509.
- Sharpley CF (1997) Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual & Developmental Disability* 22: 19-28.
- Bromley J, Hare DJ, Davison K, Emerson E (2004) Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. *Autism* 8: 409-423.
- Broach S, Camgoz S, Heather C, Owen G, Potter G, et al. (2003) Autism: rights in reality, how people with autism spectrum disorders and their families are still missing out on their rights. National Autistic Society.
- Office for National Statistics (2006) Society: Divorces. Basingstoke: Palgrave Macmillan.
- Schieve LA, Rice C, Boyle C, Visser SN, Blumberg SJ (2006) Mental health in the United States: parental reports of diagnosed autism in children aged 4-17 years, 2003-2004, United States. *Morbidity and Mortality Weekly Reports* 55: 481-486.
- Alik H, Larsson JO, Smedje H (2006) Health-related quality of life in parents of school-age children with Asperger Syndrome or High-Functioning Autism. *Health Qual Life Outcomes* 4: 1.
- Little L (2002) Differences in stress and coping for mothers and fathers of children with Asperger's syndrome and nonverbal learning disorders. *Pediatr Nurs* 28: 565-570.
- Gray DE (2003) Gender and coping: the parents of children with high functioning autism. *Soc Sci Med* 56: 631-642.
- Loynes F (2001) The Impact of Autism: A Report Compiled for the All Party Parliamentary Group on Autism.
- Järbrink K, Fombonne E, Knapp M (2003) Measuring the parental, service and cost impacts of children with autistic spectrum disorder: a pilot study. *J Autism Dev Disord* 33: 395-402.
- Kaminsky L, Dewey D (2002) Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry* 43: 225-232.
- Blanchard LT, Gurka MJ, Blackman JA (2006) Emotional, developmental, and behavioral health of American children and their families: a report from the 2003 National Survey of Children's Health. *Pediatrics* 117: e1202-e1212.
- Schor EL; American Academy of Pediatrics Task Force on the Family (2003) Family pediatrics: report of the Task Force on the Family. *Pediatrics* 111: 1541-1571.
- Anon (1998) All in the family: autistic spectrum disorders and sibling relationships. *Communication* 13-17.
- Bågenholm A, Gillberg C (1991) Psychosocial effects on siblings of children with autism and mental retardation: a population-based study. *J Ment Defic Res* 35: 291-307.
- Ghate D, Hazel N (2002) Parenting in Poor Environments. London; Jessica Kingsley Publishers.
- Office for National Statistics (2008) Social Trends No. 38 (2008 edition) Figure 6.10. Basingstoke: Palgrave Macmillan.
- Smith V, Hughes H (1999) Disadvantaged families and the meaning of the holiday. *International Journal of Tourism Research* 1: 123-133.
- Shaw G, Williams A (1994) Critical Issues in Tourism. Oxford: Blackwell.
- Dawson D (1988) Leisure and the definition of poverty. *Leisure Studies* 7: 221-231.

-
30. Urry J (2007) *The Tourism Gaze: Leisure and Travel in Contemporary Societies*. London: Sage.
 31. Department for Work and Pensions (2002) *Measuring Child Poverty: a Consultation Document*. London, Department for Work and Pensions.
 32. Jordan R (1999) *Autistic Spectrum Disorders*, London: David Fulton Publishers.
 33. Astor (2006) "Autism". *Hansard* 684, Part 4, C1442-C1445.
 34. Ryan S (2005) 'Busy behaviour' in the 'Land of the Golden M': going out with learning disabled children in public places. *Journal of Applied Research in Intellectual Disabilities* 18: 65-74.
 35. Ryan S (2005) 'People do odd, do they?' mothers making sense of the reactions of others towards their learning disable children in public places. *Children's Geographies* 3: 291-305.
 36. Nolan L (2004) *Once in August Long Ago: A Week in the Life of an Autistic boy*, Loughrea, Republic of Ireland: Greylake Publications.
 37. Murray P (2002) *Hello! Are you listening? Disabled teenagers' experience of access to inclusive leisure*, York, UK: Joseph Rowntree Foundation.
 38. Shelley P (2002) *Everybody here? Play and leisure for disabled children and young people*. London: Contact a Family.
 39. Sharma N, Dowling R (2004) *Postcards from Home: the Experience of Disabled Children in the School Holidays*. Ilford, UK: Barnardo's.
 40. Amet L (2005) Detailed assessment of communication skills of a child with autism, a parent perspective. *Good Autism Practice* 6: 57-70.
 41. Amet L (2006) Critical evaluation of Defeat Autism Now! (DAN!) biomedical intervention in autism; a parent perspective. *Medical Veritas* 3: 1-11.
 42. Howlin P (1997) Prognosis in autism: do specialist treatments affect long-term outcome? *Eur Child Adolesc Psychiatry* 6: 55-72.
 43. Freeman S, Dake LBA (1997) *Teach me Language: A Language Manual for Children with Autism, Asperger's Syndrome and Related Developmental Disorders*. Langley, Canada: SKF Books.
 44. Kaiser AP, Hancock TB (2003) Teaching parents new skills to support their young children's development. *Infants and Young Children* 16: 9-21.
 45. Maurice C (1996) *Behavioral Intervention for Young Children with Autism*. Austin, TX, USA: PRO-ED Inc.
 46. Schreibman L, Kaneko WM, Koegel RL (1991) Positive affect of parents of autistic children: a comparison across two teaching techniques. *Behavior Therapy* 22: 479-490.
 47. European Communities (2002) *European Social Statistics. Income, Poverty and Social Exclusion: 2nd report, Data 1994-1997*. Luxembourg: Office for Official Publications of the European Communities.
 48. Lovaas OI (2003) *Teaching Individuals with Developmental Delays, Basic Intervention Techniques*. Austin, TX, USA: PRO-ED Inc.
 49. Wing L, Gould J (1979) Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *J Autism Dev Disord* 9: 11-29.