

Access to leisure activities:

The perceptions of children and young people with
Autistic Spectrum Disorder or ADHD and their parents/carers.

Final Report

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1. Executive Summary

This report and its underpinning research, commissioned by Walsall Children's Fund through Walsall Teaching Primary Care Trust (tPCT), explore families' perceptions of recreational and short term break provision, for school-aged children and young people (C&YP) with Autistic Spectrum Disorder (ASD) and/or Attention Deficit Hyperactivity Disorder (ADHD). The perceptions of both the C&YP themselves, and their parents/carers of these two areas of provision, were explored through the following methods of data collection:

- two meetings of an 'expert group', involving 8 parents/carers
- telephone interviews with 44 parents/carers
- seven face-to-face interviews with 8 parents/carers, and one with a young person with ASD
- four focus groups involving 30 parents/carers
- four focus groups involving 19 children and young people with ASD/ADHD

The willingness of parents and young people to participate, and the strength of feelings expressed, clearly indicate the importance of these issues for families with a child with ASD/ADHD. There was great diversity of experiences expressed by families; family circumstances, relative ages of siblings and severity of disability in particular contributed to the broad range of experiences. Nevertheless, several strong themes emerged, which are listed in a summary of the main findings below.

Summary of main findings:

1. A minority of families used any type of short break provision; of those who did, the most common was holiday play schemes. Extended family provided a significant contribution to providing breaks for some parents.
2. The most common forms of leisure activity participated in by C/YP with ASD/ADHD were: bowling, swimming, library and cinema. Various clubs, groups and sports were also commonly mentioned. The majority of these

made use of mainstream facilities rather than those specifically designated for special needs; participation in these activities was mostly with the whole family, especially for the younger children.

3. The perceived barriers to uptake of short break and leisure provision overlapped considerably; some related to practical issues such as cost, travel, availability and opening times, and public attitudes. However the greatest barriers perceived by parents were:
 - the needs of C&YP with ASD/ADHD for routine, consistency and familiarity; difficulties with social interaction are also common to this group.
 - staff attitudes and expertise and the need for trusting relationships with the provider; concerns about the overall quality of care, and in particular, safety and behaviour management.
 - the need for facilities to be both age and developmentally appropriate for the child to have an enjoyable and positive experience
4. Many parents expressed limited awareness of and information about appropriate leisure and respite provision; this was a problem especially for those whose child attends mainstream school.
5. No clear consensus emerged as to what ideal provision would look like; however, provision must be flexible and respond to the needs of the whole family, including siblings. The buddy system was the one provision most commonly mentioned as successfully facilitating uptake of leisure activities and providing respite, but availability of buddies was seen as very limited.
6. Parents experience a tension between their desire for full inclusion of their child in the mainstream of life, and a pragmatic need for services to be tailored to their particular (special) needs. Furthermore, many parents experienced a dilemma of whether to disclose their child's disability, when accessing mainstream provision, due to concerns over stigmatisation and bullying.
7. A common picture is one of social isolation and inactivity, particularly for teenagers. Parental persistence and a willingness on the part of the young person to overcome fears and previous negative experiences are crucial.

2.0 Introduction

This report and its underpinning research were commissioned by Walsall Children's Fund through Walsall Teaching Primary Care Trust (tPCT); they explore the perceptions of 110 school-aged children and young people (C&YP) with Autistic Spectrum Disorder (ASD) and/or Attention Deficit Hyperactivity Disorder (ADHD) and their families of their access to leisure, play and recreational provision in Walsall and the surrounding area. The report investigates the experiences of C&YP and their families of current leisure facilities, the barriers to access, and their future needs. In addition the report describes the families' current use of short term break provision and their perceptions of future need.

A telephone survey was conducted with all the families on a database of children and young people with ASD and/or ADHD provided by NHS Walsall Community Health. The emergent themes arising from this survey were followed up in 4 focus groups with parents and carers; the findings were then explored in more depth during 7 individual interviews with a range of parents/carers. Four focus groups were also conducted with children and young people in order to elicit their views of access to leisure and short breaks and any perceived barriers; one interview was conducted with a young person. The research process was informed by a series of discussions with a group of parents/carers and professionals, termed the 'expert group'.

Research Aims

The research seeks to address the following questions:

- which types of leisure facilities do the C&YP currently engage with?
- which types of leisure facilities would C&YP like to engage with?
- are there barriers for the C&YP and their families in their current access to recreational facilities?
- what type of recreational facility would parents/carers like for C&YP with ASD/ADHD?
- do the families currently engage with short break provision and, if not, would they like to?

- what are the perceived barriers to engagement with short break provision?
- what are the effects on families, and particularly siblings, in relation to leisure and recreation when a child or young person has ASD and/or ADHD.

This report seeks to highlight the voices of the C&YP and their families in response to government policy (DfES 2007b), the Every Child Matters agenda, and the mission statement of Walsall Children's Service which aims *to make growing up in Walsall the best it can be.....*by ensuring that stakeholders views are central to the development of local services.

The report supports the Walsall Teaching Primary Care Trust (tPCT) consultation with families and their children with ASD/ADHD and the research aimed to enhance their participation in any decision-making processes relevant to defining and fulfilling their needs.

3. Background/context

3.1 Local context

As an active member of the Walsall Strategic Partnership and as commissioner of quality services across Walsall, the Teaching Primary Care Trust continues to achieve proficiency in partnership engagement, public and service consultation and effective management of knowledge and assessment of needs and was recently commended for “the clarity which links the vision/goals and initiatives” (Worldclasscommissioning panel report, 2008).

The Trust continues its commitment to prioritising and promoting Disability Equality, ensuring consultation with disabled people informs service design and delivery to facilitate and maximise their participation in society (Walsall tPCT Disability Equality Scheme, 2008). Encompassed within this is the aim of improving quality of life for children and young people with ASD and/or ADHD through cultural, sporting and other leisure activities.

Data from NHS Walsall Community Health indicates the numbers of C&YP in the Walsall region diagnosed as ASD and/or ADHD and the type of educational setting currently attended (see Table 1 below):

Table 1: Numbers of C&YP in Walsall region with ASD and/or ADHD

Diagnosis & type of educational setting	Total No. of Children
A.S.D at Mainstream School	180
Aspergers Syndrome at Mainstream School	32
A.D.H.D at Mainstream School	12
A.S.D at Special School	85
Aspergers Syndrome at Special School	4
A.D.H.D at Special School (these children are also included in the A.S.D. as they have both conditions)	4

(Source: WCH Disability Database)

Strategic and targeted activity in the region demonstrates a continued and effective multi-agency approach in ensuring that integrated and accessible services are in place and tailored to meet the needs of C&YP and their families as laid out in Walsall's multi-agency strategy (2005 – 10).

3.2 National context

The document *Aiming High for Disabled Children: better support for families* [abbreviated as AHDC] (DfES & HM Treasury, 2007b) sets out the government response to the Disabled Children's Review and informed the comprehensive spending review which is underpinned by £340 million of investment. The Disabled Children's Review is one of the four strands of the Policy Review of Children and Young People (DfES/HM Treasury 2007a).

The AHDC document (2007b) builds on the Every Child Matters agenda and notes the programmes already committed to improving outcomes for those with a disability. It also highlights legislation, such as the Disability Equality Duty (2005), the Childcare Act (2006) and the requirement for most public bodies to support a Disability Equality Scheme. While much good practice exists, AHDC (2007b) finds that challenges remain:

- existing data does not show how the quality of provision differs according to area; some local authorities offer different levels and standards of care and “those most in need are not always the most likely to get support” (DfES 2007b, p. 14). Furthermore, many parents and young people are not sufficiently involved, informed or empowered.
- much existing provision focuses on high cost intervention at times of high need, thus limiting early support which may prevent such need.
- more needs to be done to coordinate services and develop multi-agency working.

The document outlines three areas of priority:

- access and empowerment: offering disabled children and parents/carers the ability to make choices and influence their own care and also local priorities.
- responsive services and timely support: improving early intervention and support when needed to prevent deterioration; to prioritise disabled children at both national and local levels.
- improving quality and capacity: boosting such services as short breaks, equipment and therapists.

3.3 Autistic Spectrum Disorder

Autistic spectrum disorder includes Asperger syndrome and is manifest in a triad of impairments of:

- social interaction;
- communication;
- rigidity of behaviour and thought (Plimley 2007, p. 2).

According to Blakemore and Frith (2005) autistic spectrum disorders affect approximately 6% of the population.

3.4 Attention Deficit Hyperactivity Disorder (ADHD)

This is characterised by impulsivity, inattention, and hyperactivity (National Institute for Health and Clinical Excellence [NICE] 2008). ADHD is commonly associated with other difficulties, such as sleep disorders, non-compliant behaviour, mood swings, aggression, literacy and learning problems, clumsiness, immature behaviour, motor tics and clumsiness (NICE 2008). While there is no biological test for ADHD, it can be diagnosed using the Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria (NICE 2008, pp. 18-19).

3.5 What is short term break provision?

Prewett (2000, p. 1) offers a Mencap (1999, p. 3) definition of short break or respite care as “services that give disabled people and their carers a break from the usual routine of daily life”. Although this can include overnight breaks, residential services, and befriending/sitting schemes, there is no overall complete picture of the total, including residential provision, in the UK (DfES 2007b, p. 48). Prewett (2000, p. 6) notes how the definition of short breaks has widened to include “day care, sitting and befriending services as well as in-home (domiciliary) support”.

According to the Shared Care Network Report (2006) not only are there only 188 family-based short break schemes for an estimated 9,194 disabled children in the UK, but 90% have lengthy waiting lists for such breaks, with many waiting for up to a year (DfES 2007b).

Local authority short break provision currently varies in its flexibility and in its efficiency. Difficulties include a lack of staff, a need for training and support for carers and a need to develop the guidance to meet the needs and regulations to cater for children with a disability. Furthermore, AHDC suggests “capacity difficulties in some areas, with insufficient attention given to ensuring that there is a level playing field between public, private and voluntary sector provision” (DfES 2007b, p. 49).

Good practice includes examples of holiday play schemes, after-school clubs, care in the home, weekend care as well as overnight breaks, direct payments and support for young carers. Furthermore, good practice involves family choice in the type of break appropriate to the disabled child, siblings and parents/carers.

3.6 Short breaks

Disabled children are “disproportionately represented within the looked after population...” (DfES 2007, p.45); families, including parents and siblings, are subject to high stress levels and often interrupted sleep, thus short breaks for the disabled child may allow some respite and time with other children. Mencap (2006) found that 80% of families “with children with severe or profound learning disabilities had reached breaking point due to the lack of short breaks” (DfES 2007b, p. 46). Short breaks are also seen as enabling

disabled children to overcome social isolation, enjoy some leisure activities, and develop new friendships and networks. They may also promote development.

Flynn (2002), researching the needs of Black disabled C&YP, noted that they may be doubly disadvantaged by their race and by their disability; moreover, Black families with a disabled child are over-represented on waiting lists for family based care and as non-users of short break provision. Flynn (2002, p. 18) further notes few studies in the literature reviewed which “focused specifically on the management of culturally competent and ethnically inclusive services”. Persistent themes which emerged from Flynn’s research were of low expectations of access to services and a lack of information about them; he also noted a lack of ethnically diverse sitters, carers and providers of short breaks.

Hussein et al. (2002), in their study, challenged the stereotype of the extended family as carers, finding that disability was often negatively perceived within the family and created a tension and a barrier to family relationships.

The cost of providing short term breaks must be balanced against such potential costs as family unemployment, health costs of family stress, educational costs of siblings with behavioural/emotional disorders, foster care for family breakdown, the cost of marital breakdown and family separation, and the potential cost of caring for a disabled child outside the family (New Philanthropy Capital 2007). The AHDC (2007b) document also suggests that benefits of short term breaks, such as happiness and social inclusion, although not readily measurable, must be taken into account.

3.7 Inclusion

Prewett (2000, p. 5) noted an increasing number of children from ethnic minority communities or regarded as ‘hard to place’ waiting for short break or respite provision; she further states that access to services by minority ethnic communities is complicated by a “lack of information about available services, [and] concerns about services not being culturally sensitive...”. Children perceived as ‘hard to place’ include children with complex health needs and/or those displaying challenging behaviour (Prewett 2000).

While legislation is in place to promote the inclusion of children with a disability, parents responding to the consultation for AHDC (2007b) noted that this means more than inviting a child to attend a group; parents claim that staff do not have the knowledge or skills to deal with some children with a disability. AHDC specifically notes that specific areas in which staff across all services lack preparation and training include “communication and interpersonal skills, communicating directly, expertise in behavioural management (especially with Autistic Spectrum Disorder and challenging behaviour)...” (DfES 2007b, p. 56).

3.8 The Every Child Matters (ECM) agenda

This agenda set out five specific, targeted, aims for all children in England; the ensuing research report contributes to the following aims:

- be healthy;
- stay safe;
- enjoy and achieve;
- make a positive contribution;
- achieve economic wellbeing. (DfES 2004, p. 9)

The DfES (2007b, pp. 11-12) note poorer outcomes for children with a disability, compared to non-disabled peers, across a range of indicators, such as “...lower educational achievement, poorer access health services and therefore poorer health outcomes, more difficult transitions to adulthood and poorer employment outcomes”. Improved leisure and recreational facilities, together with short break provision, for C&YP with ASD and/or ADHD and their families may encourage physical and mental health and wellbeing, encourage enjoyment and promote self-esteem in a safe environment, encourage and develop positive behaviour and nurture friendships and relationships; as a result, C&YP may fulfil their potential as young adults and engage in further education and employment.

3.9 Consulting with children and young people

The Childcare Act (2006) placed a duty on local authorities to have regard to the views of young children in the design and implementation of services relating to them (Dickens 2008). Disabled children and young people are subject to a higher number of interventions, more vulnerable to abuse, more likely to be assessed, and more likely to be excluded by their difficulties from consultation, than their non-disabled peers (Dickens 2008).

Involving children and young people with a disability in decision-making is important and viewed as positive by the children and young people themselves (DfES 2007b). Bryson et al. (2008, p. 6) note that data can be collected from “children with high levels of support needs, communication and learning impairments”; they state that although parents welcomed this in principle, many had concerns about how this would work in practice.

4. Methodology

This project used a variety of mixed methods as follows:

- formation of expert consultative group (8 members);
- telephone survey (44 contacts);
- focus groups with adult parents/carers (30 adults);
- face-to-face interviews with adult parents/carers (8 parents/carers);
- focus groups with C&YP (19 participants);
- interview with YP (1).

The data collection involved collating the perceptions of a total of 110 adults and children.

Using a variety of methods enabled triangulation of the data to enhance validity, to add to the richness of the data and to achieve a more comprehensive understanding of the needs of the families and their children. While focus groups provide data from context-dependent group interactions, individual interviews offer participants the opportunity to explore the issues in greater depth and from a personal perspective (Lambert and Loiselle 2008).

4.1 The expert group

We stated in our bid that we wished to establish an “expert group”. The aim was to introduce an element of empowerment to people with a vested interest as parents/carers of children with ASD/ADHD and to enable a dialogue between researchers and participants. Walsall Carers Centre assisted this process by offering expertise, access to parents/carers, and hosting three focus groups. The first expert group meeting consisted of five parents/carers; the second of three parents/carers.

The two meetings were important in terms of identifying many of the barriers to leisure and short breaks and informing the research team in their design of the rest of the project.

4.2 The telephone survey design

A number of factors informed the design of the survey (see appendix 1), including:

- the scoping exercise
- feedback from the expert group
- discussions of the research team
- the need to acquire baseline data on ethnicity, and permission for focus groups.

In all 127 phone calls were made, resulting in 44 telephone interviews. (For a breakdown of the telephone contacts, see Table 2, appendix 1a, p.79)

Parents/carers were asked if they would be interested in attending a focus group or interview to discuss the issues further, and also if they would give their consent to the research team asking their child if s/he would be happy to participate in a focus group at school.

4.3 Focus groups

As a result of the telephone survey and contacts via Walsall Carers' Centre, four focus groups with parents/carers were conducted (for breakdown of details, see Table 3, Appendix 2a, p. 82):

The 30 participants, all White, included mothers, fathers and grandparents, all of whom are involved directly with the care of a child or young person with ASD and/or ADHD.

The adult focus groups were conducted at a local community centre (3) and at a public house (1), venues where parents/carers meet regularly for a support forum.

4.4 Interviews

Seven semi-structured interviews (for interview guide, see appendix 2) took place with 8 parents/carers in their own homes; in one interview, a father, a mother and a friend chose to use a group interview format (for demographic details of interviewees, see Table 4, appendix 2c, p. 83).

4.5 Children and young people

Initial selection of schools was based on those where parent/carers had given informal consent during the telephone interviews for their son/daughter to be involved in the discussion groups however there were problems with school availability and the small numbers of proposed participants. Therefore the project team selected further appropriate schools to include a range of ages also a range of levels of disability broadly related to placement at special or mainstream school. Two special schools (1 catering for complex needs: ages 2 to 11yrs, 1 mild/moderate needs: ages 4 to 19yrs) and 2 mainstream schools (1 primary: 1 secondary) were selected.

Explanation of research intentions and request for consent letters were distributed to parent/carers via the school and collected prior to focus group. Initial consultation with school staff enabled discussion of pupil profiles including variables such as likelihood of challenging or aversive behaviours and an assessment of augmentative communication approaches: pictorial symbols and Makaton signing supported the discussion for non-verbal participants. Questions were differentiated to include all participants (see appendix 3). Table 5 (appendix 3a, p. 86) offers demographic details of participants and schools.

One individual interview with a 15 year-old male occurred spontaneously. On arrival at the parent/carer interviewee home, it was assumed by both parents that their son was to be interviewed. The son was also expectant and willing to participate in a one to one discussion. Research intentions were reiterated to all parties and signed parental consent was sought.

4.6 Ethics

Children and young people are viewed by the University of Wolverhampton as a 'vulnerable' group and therefore any research with them requires full Category B approval from the School of Education Ethics Committee. Children and young people with a disability may be even more vulnerable, thus every effort was made to ensure that the participants would not be exploited. The following ethical issues were considered:

- Informed consent was sought from parents/carers of the children and young people, and from the participants themselves; it is accepted that, for reasons of age and/or disability, this may take the form of assent for some participants.
- The research aims and dissemination were presented to the children and young people in a way which is appropriate to their age, development and understanding. This was after consultation with the parent/carer, school and expert group;
- Every effort was made to ensure that the interviews and focus groups were as inclusive as possible. Advice from the parents/carers was sought at every stage of the research. We used participatory research methods, taking into account the communicative abilities of the child/young person, and also advice from the parents/carers and school staff. The research team includes a speech and language therapist with experience of alternative communication methods. (From our submission to School of Education ethics committee).

Communicating with young people with a disability may be problematic in that the views of some may, of necessity, be mediated through a parent/carer or teacher. This raises issues about power relationships and bias in the research findings; to overcome any bias in the research, focus group facilitators and interviewers remained sensitive to the voices of the children and young people and allowed that extra time may be needed for pupils with communication difficulties to express their views. In addition, using the school as a site for the C&YP focus groups enabled us to access some expert advice and support from teachers/assistants and to capitalise on their existing close relationships with the individual C&YP.

Shevlin and Rose (2008) state that including C&YP with special needs in decision-making is fraught with difficulties and lack of participation in decision-making is a significant issue for them. In our research, augmentative communication has supported the inclusion of C&YP in making decisions about their choices and to enable the inclusion of the voices of the C&YP with communication disorders.

All participants were assured of anonymity and confidentiality, however this cannot be assured within focus groups; ground rules were set at the beginning of the sessions to enhance confidentiality. Participants were informed of the purpose, aims and potential dissemination of the research before each process; they were also advised that they could refuse to answer any question and/or withdraw from the research at any stage. Pseudonyms are used throughout this report.

5. Findings: expert group discussions

Initially, at least, there appeared some resentment to the “consultation exercise” as group members discussed the need to direct money to front line services, this was mentioned briefly again at the second group meeting.

The two discussion groups resulted in the emergence of the following themes:

- lack of provider and public awareness of the specific needs of the C&YP;
- lack of training of providers and lack of understanding that the C&YP with ASD/ADHD have problems with behaviour;
- the need to develop consistency, continuity and trust with providers;
- a need for dissemination of information about the symptoms of ASD/ADHD;
- a need for addressing the many social, systematic and structural barriers to family access of leisure;
- tension around whether to explain the condition to leisure providers beforehand and the wish not to stigmatise or label a child;
- isolation of families and C&YP;
- insufficient short break provision;

In addition, the expert group noted the changing needs of C&YP and their families over time, including worries about periods of transition, for example going to secondary school.

The role of the family was highlighted, how carers relied on other family members to help out and provide support. This might be in terms of offering respite or helping to access facilities. If that is not there enormous stress is placed on the carer, especially without external support.

The expert group consultations enabled the research team to develop broad parameters for the data collection questions. The most significant conclusions from the expert group discussions became the focal themes of our telephone survey framework, interview and focus guides. This consultation also enabled a dialogic process with parents/carers to underpin the research process.

6. Findings: telephone survey

6.1 Introduction

The aim of the telephone surveys was three-fold:

- To contact parents/carers who may not attend support and other specialist groups;
- To obtain a wide range of useful data;
- To feed into the development of the focus group and interview questions.

Walsall Community Health sent information and consent details to all the contacts before the survey. Of the 150 contacts on the database, 5 opted out of the research and 18 had no telephone number, thus 127 potential contacts remained. Of these, we managed 44 telephone interviews.

6.2 Ethnicity

An attempt was made to gather baseline data regarding ethnicity; of the 44 who were interviewed all but two indicated their ethnic background as follows:

Table 6: Ethnic group of telephone respondents

Ethnic group	Number
White British	38
Asian/Asian British or Indian	3
Asian/Asian British or Pakistani	1

Thus 4 (10.5%) of respondents were other than “White British”. Ethnic background could not be determined from the database and it must be noted that the ethnic group of the interviewee may not be the same as that of the rest of the family. Therefore, we can draw no conclusions from knowledge of ethnic group, but we have taken it into account in our findings. None of the 4 respondents highlighted above were able to participate in a focus group.

6.3 Accessing Short Breaks

Q.1 Access to overnight breaks, weekend breaks, sitting schemes, holiday play schemes, before/after school care, other?

Responses can be seen in Table 7 (below), showing that 36% had accessed one or more of the activities.

Table 7: Short break access (n=44)

Activity	N of respondents
Overnight break	5
Weekend break	5
Sitting scheme (Child minder)	1
Holiday Play Scheme	9
Before / After School Care	4
Other	5

Responses of “Other” included a buddy, Boys’ Brigade/karate, (Action for Children) AFC Saturday Group, family support through grandmother as unpaid care. The holiday play schemes were mentioned and favoured by respondents.

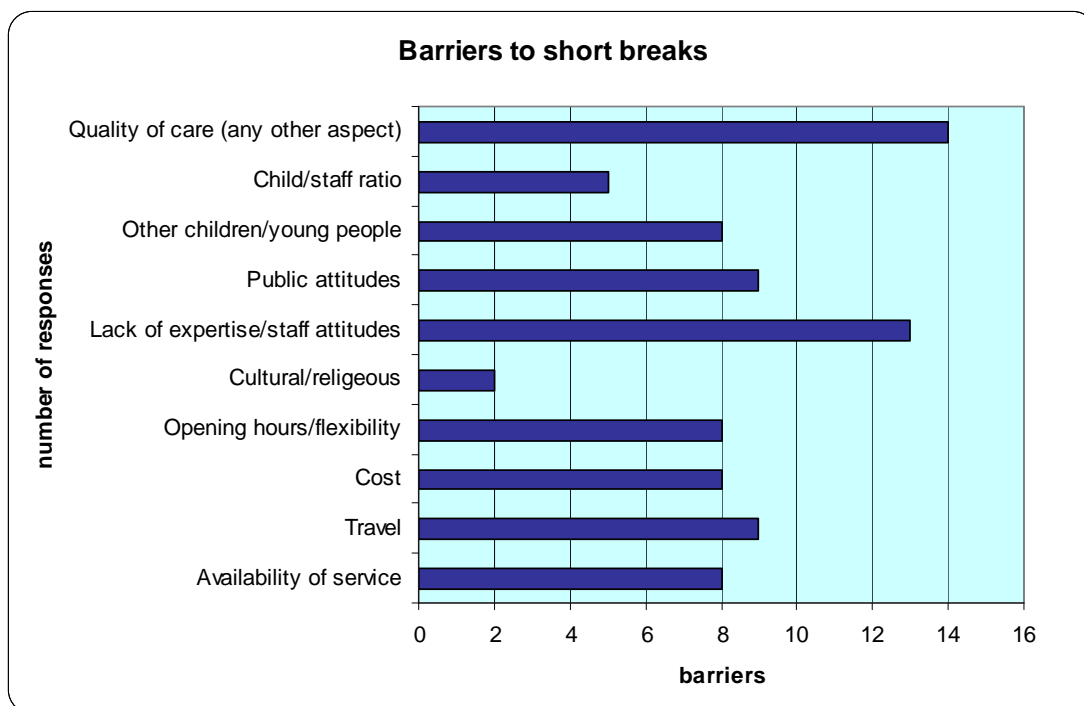
No clear trends emerged from this part of the survey and comments represented a diverse range of needs and issues. The data suggests a patchy response to the opportunities provided through respite care and short breaks, and a lack of knowledge and information about such opportunities.

We also asked about the frequency with which respondents engaged in the activities above. Whilst again there were few notable patterns, the “holiday play scheme” was the most popular answer (9), reflecting the data in the initial question.

Q2. Do you have problems accessing short breaks?

Thirty (68%) of our respondents answered “yes” and some identified several barriers. The following diagram (Figure 1) details the barriers perceived by respondent:

Fig. 1 Barriers to short break access.



Clearly, the single largest perceived barrier was “lack of expertise or attitudes of staff”. This was something subsequently explored in more depth in the focus group and one-to-one interviews.

Finally, respondents were asked to identify the most significant barrier from the choices made. In some cases respondents found it difficult to make one choice and repeated a number of options. “Public attitudes” (6) and “lack of expertise/attitudes of staff” (5) were the most frequent items mentioned. Flexibility and availability were also highlighted (4), and the lack of availability during the summer holidays was an issue that was specifically raised by some.

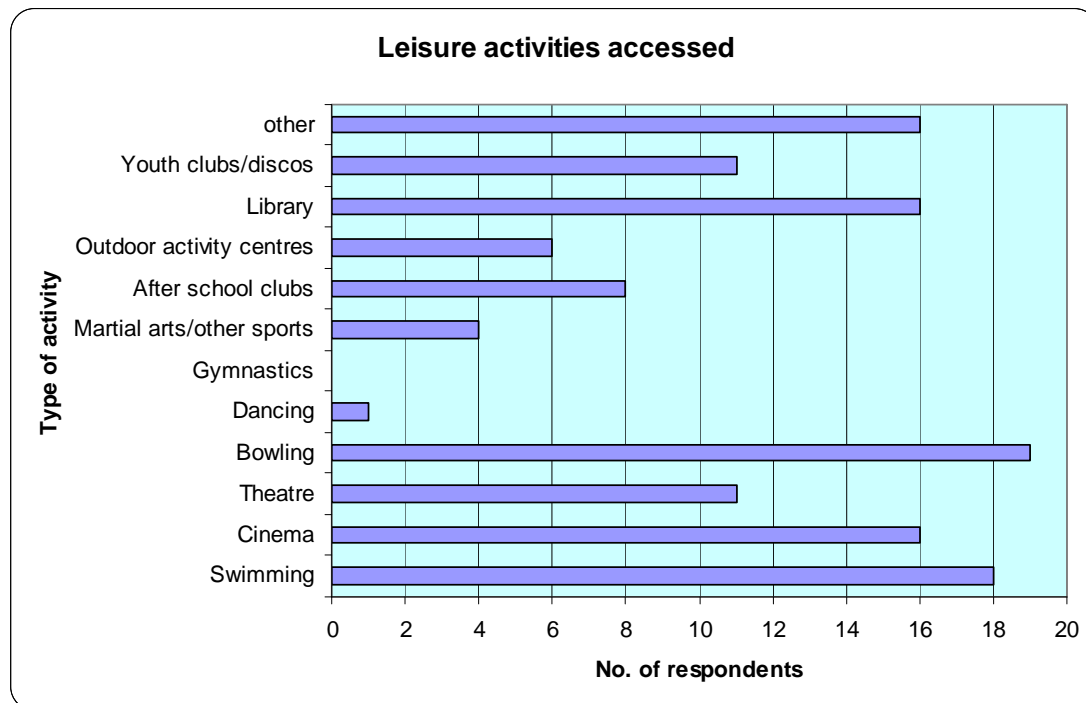
6.4 Leisure and Recreation

Q3 Do you or your child use any of the following leisure facilities?

Respondents were given the opportunity to state activities other than those provided in the set categories. They were also asked to consider whether

each activity was “mainstream” or “specialist” and whether they participated “frequently” or “occasionally”.

Fig. 2 Leisure activities.



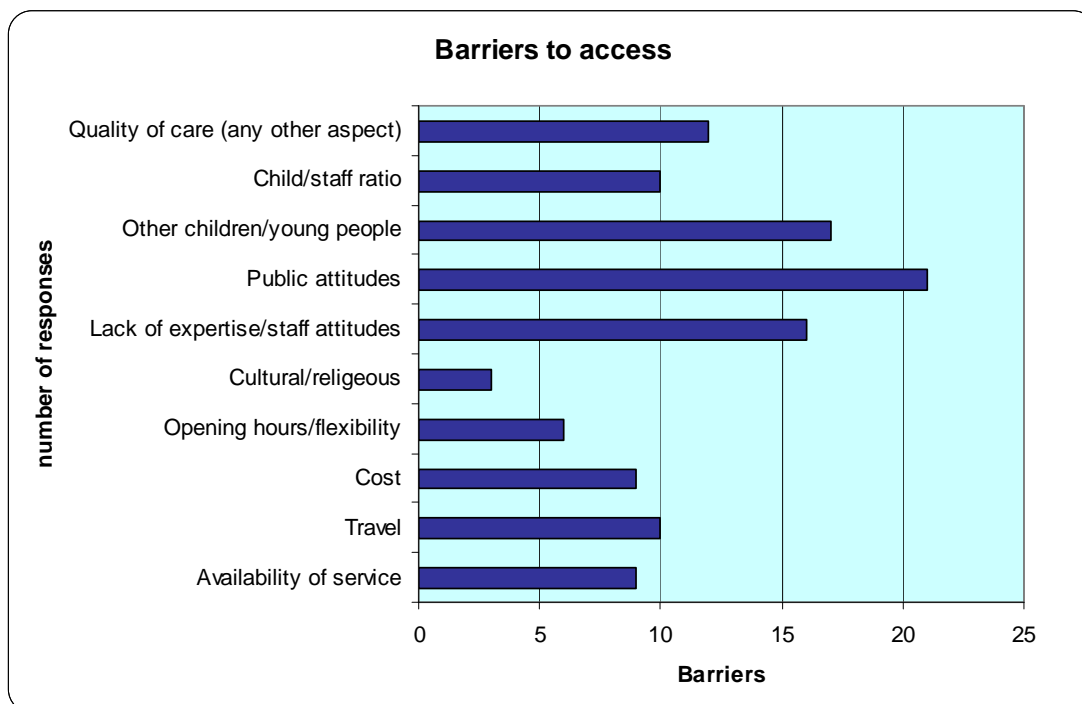
Clearly, bowling and swimming were the most popular activities, with cinema the library almost as popular. “Other” types of activities included NCH activities, Boys’ Brigade, eating out, activities through the school, and walking and playing in the park. Occasionally respondents elaborated on their experiences and talked about people’s “lack of understanding” and the difficulties “because of other children”; or the fact that their offspring preferred to spend time at home on their laptop or Play Station. Some respondents mentioned “Dizzy Kids” and “Snap” (Special Needs Adventure Playground) as being popular.

Whilst no clear usage patterns were evident, it was noticeable that the cinema, library, bowling and swimming were used by many people “occasionally” and to a lesser extent “frequently”. Only swimming notched up more “frequent” usage, as apposed to occasional.

Q4 Which are the barriers to your child accessing leisure and recreation facilities?

We allowed respondents to include other issues of quality of care we had not stated in our categories. Thirty-four respondents (77%) said that they had experience of one or more barriers, as shown in Figure 3 (below):

Fig. 3. Barriers to leisure and recreation.



Replies are in many ways similar to the responses to the barriers to short break access, focusing mainly on the lack of expertise and/or attitudes of staff, and also public attitudes. These two issues dominated for both short breaks and general leisure activities. However, it should also be noted that in Question Four the response was much higher regarding the barriers presented by other children and young people (17 positive responses as opposed to 8 in Question Two). This may reflect the fact that swimming, cinema and bowling tend to be mainstream activities and therefore families have more contact with the general public.

As part of this question, we asked our sample what they considered to be the most significant barrier. It is clear that both staff attitudes/expertise and public attitudes were the main concern (7 responses for each of the two categories).

Where people wished to comment further about their experiences we tried to accommodate their need to do this, resulting in richer and more qualitative data. One reply encapsulated a number of issues:

“Travel (an issue) as mom has to take every where. Cost - must have disability allowance. Lack of expertise frequently a problem. Public attitude an issue with other parents. Quality of care - Bullying in changing rooms an issue. Leisure centre do not have enough staff to put in changing rooms.”

Q5 *If you could wave a magic wand what would you most wish for?*

Thirty-nine (nearly 87%) respondents elaborated and provided a wealth of additional information. These responses have been coded into emerging themes and compared across the range of replies.

Responses were vary varied, with issues that relate to general care and general access to leisure, as opposed to short breaks or respite care. The matter of groups catering for special needs (of similar ability) was raised more than any other, on at least 7 separate occasions; comments included:

“Something for the autistic child, specialist group, eg. Swimming. No teachers available for autistic kids. Safety issues: he copies older children and takes armbands off, for example”.

“Concerned about what will be available for H as he grows up, i.e., what is for teenagers?”.

The Buddy system was the second most popular issue of concern (5). Comments included:

“Buddy system to be developed. [Child] would gain confidence and perhaps go swimming or to other leisure facilities with buddies”.

“Buddy system might get him out of his bedroom”

Q6 Of the 39 people who responded, 29 (74%) wanted to participate in further research.

Q7 Of the 40 people who responded, 31 (77.5%) agreed to allow their children to take part in focus groups.

6.5 Conclusions

The aim of the telephone survey was to apply a broad-brush approach that would give the research team a better understanding of some of the key issues and to develop ideas for further exploration in the next phase of the research.

The data accumulated in this phase of the research indicates that respondents were interested in discussing their experiences in accessing general leisure and recreation facilities in particular. 77% of the respondents had accessed activities such as swimming, cinema and bowling, whereas only 36% of respondents said they had participated in short break activities.

Despite this difference in responses, it was interesting to note that there were similar patterns of concern with respect to barriers to short breaks and leisure and recreation more generally. Of most concern were issues relating to staff attitudes/expertise. In terms of short breaks, the attitudes of public and other children/young people still featured, but much less so than with general leisure. General “Quality of Care” and “Other” issues featured strongly with respect to short breaks. Issues such as the Buddy scheme came to the fore and was raised on a regular basis, as was the wish to involve their children in interest groups that catered for the needs of children and young people of similar ability.

The emerging themes and issues, together with the discussions in the two expert group meetings, presented the research team with a substantial and significant amount of data to analyse and take forward to the next stage of the research: the focus group interviews.

7. Findings: adult focus groups

7.1 Introduction

Four focus groups with adults were facilitated on two different sites in Walsall. A total of 30 adults participated in an interactive dialogue (see Appendix 2, p. 80 for focus group questions).

The transcripts were analysed for emergent themes and a matrix used to analyse the data. The following discussion has been grouped into the themes which emerged from the focus groups; quotations from parents/carers are interspersed within the findings. In these findings, the term 'parents' will be used as shorthand for 'parents/carers' and includes the mothers, fathers and grandparents who attended the focus groups. The term 'children' is often used rather than 'children and young people', to enhance brevity and focus.

7.2 Current access to leisure and recreation

It is clear that children and young people with communication disorders are not a homogenous group, and neither are their parents/carers. The age of the child or young person has relevance to the facilities accessed, as does the severity of the disorder. Where the child is young and/or has fewer difficulties, there is access to a greater range of activities, such as bowling, trips to the Donkey Sanctuary or cinema, or attendance at SNAPS (Special Needs Adventure Playground).

The majority of the parents preferred to access leisure as a family, even though this brings its own complications. Parents have often had unhappy experiences with accessing mainstream leisure facilities, such as the participant whose son was excluded from a swimming class because the teacher could not cope. This parent now pays for private lessons.

For C&YP with ASD/ADHD the public swimming session can be a risky enterprise, with apparent chaos and loud and echoing spaces adding to the child's confusion; problems also arise where the carer cannot easily accompany the child in changing rooms or to lavatories.

Parents perceive the need for routine and structure to support the child's wellbeing, however not all leisure facilities provide this: a parent described

how his child (12 years-old with ASD) used to enjoy going to an NCH group (ex National Children's Home, now Action for Children) but outings were often cancelled at the last minute due to lack of numbers; the boy would have the outing on his calendar and the family prepare him for it, yet he sometimes ended up *"sitting in a room playing games"*. For parents who work, the timing of organised activities and play schemes can also be problematic.

Safety is a crucial issue for the parents and families, with parents noting:

"I think parents are so frightened that they (children) are going to wander off, because they don't see danger, there's the feeling that they (parents) got to be there".

Another parent finds it very hard to go anywhere as son (4 years-old) is very active and has no perception of danger thus it is hard to keep both children safe. Safety is a theme which is threaded throughout this discussion; it is also linked with the expertise of the parents and knowledge of their child and coping/managing strategies.

Parents, in the focus groups, were divided about the need for inclusive leisure facilities. While one parent finds a club for C&YP with special needs enables her two sons (10 and 11 years-old; with ASD and ADHD respectively) to access a range of activities, another 11 year-old (with complex problems) refuses to access, for example NCH, play schemes as he *"doesn't think of himself as disabled so doesn't want to do that sort of thing"*. Groups for children of similar ability however offered a side benefit to one mother (son, ASD, 4 years-old) who expressed her growing confidence:

*"I've started taking him out because **** used to attend mainstream which I found very difficult because I wasn't with like minded people but now he's at **** (special school) I've met other parents who have also got autistic children – I actually took him to the donkey sanctuary and also to SNAPS which I wasn't aware of"*.

In conclusion, parents and families vary in their take-up of leisure facilities, in some part due to the age of the child and nature/severity of the disabilities, however parents remarked on the problems they have with the appropriateness of the venue and activity, the knowledge and experience of the staff (discussed further later), and the need for planned, structured, routine activities. Many parents referred to problems with coordinating activities with their work commitments, indeed in one family, the mother and father have to “*take shifts*” in child care; holiday times are predictably difficult for working parents who cannot take 6 weeks holiday at once during the summer. The range of leisure facilities accessed is limited and the majority appear to be as part of a family outing; very few C&YP independently access recreation without a family member present as a support.

7.3 Buddies and other befriending services

The Buddy scheme is perceived as useful to parents and their children, however only three of the families currently access it. One of these parents liked the scheme but noted some difficulties with access since the Buddy required several days’ notice and was limited to only two hours with the child. This mother was desperate for some support with her child (9 years-old, ADHD) and for a weekend break since she was experiencing health problems; in common with a number of parents, she observed that the response from NCH was too slow and could take over a month. Describing the response as “*a slap in the face*” this stressed mother reports that she has been told that there are insufficient foster carers or rooms at NCH and that “*they are not taking any more children*”. She cannot call on an extended family and perceives NCH as uncaring.

The mother of an 11 year-old boy (ASD) stated:

“The problem with the buddy scheme and other specialist provision like that is you’ve actually got to get your social worker to ‘fight your corner’ to get you that provision and I wonder how many people round this table actually know who their social worker is?”

The parents participating in focus group A were generally despondent at the services provided for them and their children; the perception is one of being let down by the system and a parent went on to say that Action For Children had visited the family but 3 weeks later, the family had to chase up the outcome, to be told that there is a shortage of social workers. This parent expressed cynicism at the national television advertising campaign of Action 4 Children when their own experience had proved fruitless. The mother of a 15 year-old girl (ASD) stated:

“It took me 6 months to get (daughter) into the youth club – Action 4 Children and I only got her in there because in the normal youth club they found her in the toilet with a knife to her throat – and then they fast tracked her. Six months it was and I kept chasing and chasing and the thing is, because you’ve got a disabled child, you haven’t got the time or sometimes the energy to chase these things – you’ve got to fight for everything”.

This perception of the system may inhibit parents from accessing further services at a later date.

The role of Buddies, as perceived by the parents, is to take the disabled child out in order to give the parents a break, but one mother (2 children, including 4 year-old with ASD and severe learning difficulties) would prefer more flexibility; she would like to take both her children swimming, accompanied by the Buddy supporting the disabled child. The system, perceived by her, does not appear to allow this flexibility.

In conclusion, the most significant issue for parents in accessing befriending services is trust. In the focus groups, trust was raised as a significant issue, with parents expressing the need for consistency of befriender attendance and training, both professional and in relation to the child’s needs. Parents know that each child’s needs vary considerably, according to age and to disability, thus they are reluctant to leave their children in group sessions which cater for a wide range of special needs, fearing that their child will not receive the appropriate support. Many parents are aware that service

providers may perceive them as overprotective and this may inhibit them from voicing concerns about provision. However, as a parent notes:

“When you get a good one (Buddy), it’s fantastic and they do amazing things with them”.

7.4 Short break provision / respite care

In focus groups B and C, respite care arose as a separate issue to befriending. While some parents perceived short break provision (respite care) as only for the ‘severely disabled’, others had experienced its benefits and some disadvantages.

The mother of a 12 year-old boy with profound learning difficulties had previously accessed foster care for one weekend a month with “a lovely lady”. When her son became too big for the carer to cope, the boy was offered generous short breaks at a local authority centre for nights and for a holiday period. The mother, while grateful for the support, has some doubts about the current care offered: *“a friend’s son escaped once; my son lowered the electric bed onto his legs- a minor injury”*. She also finds the rigid adherence to guidelines problematic:

“Concern over medication; common sense stuff for example, they only have prescription things, won’t use nappy rash cream from supermarket and it takes four attempts to get Dr to write the prescription- it causes no end of stress...is it worth me sending him? It detracts from the value of the respite.”

The parents of a 10 year-old boy (ASD) spoke of the death of their daughter, thus creating extra (understandable) worry and anxiety about their son. The mother needs to meet any potential carer first and develop a relationship of trust; she also worries about issues such as the child’s ‘faddy’ eating and therefore his nutrition. If a relationship of trust were developed, the parents would consider short break provision. Another parent felt that attendance at such provision had caused a deterioration in her son (9 year-old, ADHD) since he was placed with other children with severe disabilities.

Finally, every parent's nightmare is described by the mother of two boys, a 10 year-old with ASD and an 11 year-old with ADHD who feels that her experiences of respite care are improving. Her 10 year-old son had previously been abused in a play scheme, which resulted in a court appearance. That negative experience led to a lack of trust which the mother feels has now been overcome, however, agreeing with the other parents in the focus group, she perceives the opportunity to get to know any support worker and develop a trusting relationship, based on knowledge of the child, is crucial.

7.5 Access to information

From the focus group discussions it appears that parents of C&YP in special schools have access to more, and a wider range, of information than the parents of less severely disabled C&YP in mainstream education. In focus group A, much information was exchanged during the session, leading to the comment *"This is one of the grudge bearers, isn't it? We aint told this stuff, we have to find out for ourselves and through school"*. Participants also found it difficult to keep up-to-date with the changes in service provision, providers and policy. Parents supported the idea of a directory of leisure, recreation and short break provision, together with an identifier which would demonstrate to parents whether C&YP with specific disorders could be catered for.

7.6 Barriers

Across all four focus groups the most significant barriers to leisure and short break provision were perceived as related to trust and to training.

The following comments were expressed by the grandparents of a boy aged 11 years (ASD, ADHD) and the mother of a 16 year-old boy (ASD):

"I think it comes down to a training issue. Unless you feel comfortable that you know people are trained – because they wouldn't be able to deal with the problems you've got. Then it's no fun for you or your child – you worried – watching them all the time".

"I haven't had that but friends have. Where they send them to a group – they are supposed to know what they are doing. And the child's "kicked off" and

they've said they can't deal with them. So you can't deal with them with special needs then who else can? – That becomes a pointless treadmill”.

“I did sent T [Child] to a specialist unit who knew all this and had training – was there for half an hour and he was supposed to be there for a week. They couldn't cope – his behaviour got extreme but they didn't nip it in the bud. Went out of control – they didn't want him back”.

These comments demonstrate tensions which arise when families are attempting to access provision. Many parents noted a lack of care staff, swimming supervisors, and Buddies for their children. One parent highlighted the problems with changing facilities for her son: her husband had to accompany them to swimming to ensure that the boy could change appropriately, however the father had to take time off work to do this. Health and safety can also be an issue, as the same mother shows:

“He likes horse riding but because he's so big...I don't know where to go. He likes trampolining, there's all the safety risk and he needs a harness so you think well where's he going to go to get access to that? He likes rock climbing which they've done at school but then there's the health and safety when he goes and the people to help him access it...so children can do things but it's everything else around him that prevents him from doing it”.

Perhaps inadvertently, this mother illustrates the social model of disability (Swain et al. 2003) and the need for more acceptance of what C&YP with ASD/ADHD *can* achieve, rather than the deficit model which currently inhibits their leisure and recreation. While the focus group participants did not view access to buildings as a barrier (perhaps because their children had fewer mobility problems than other groups of disabled C&YP), they did comment as follows:

“The thing is, we have the Disability Discrimination Act which makes public buildings and everything – they've got to be accessible to disabled people but the people who run the buildings don't have to have any training of any sort”.

Children and young people were also observed to create personal barriers to 'going out', as this mother of a 7 year-old (ASD) explains while discussing her son's anxiety about leaving the house:

"It's getting something that clicks with him that makes him think 'I'll go out for that'...so it's difficult to think of things for him to do".

Disliking and distrusting change and noise, many C&YP with ASD are confined to their bedrooms with computer games and the television for company. Furthermore, even when families do access leisure and recreation, they find that the sessions may not be appropriate to their age and development, as the following excerpt illustrates:

"He used to go to gymnastics but he ended up with the group being 3yrs old and he's 12- because he didn't progress. Needs facilitation to participate in physical activity; at PE at school (mainstream) probably just stands there as there is no one to help him".

Many parents also spoke of late development in using a lavatory for children with ASD; provision is made for baby changing facilities but there appears little provision for older children who may need a change of clothing. All of these difficulties combine to make accessing leisure facilities impossible for some families.

7.7 Barriers: conclusions

Families need to be able to develop trusting relationships with leisure facility staff who are well-trained and aware of the needs of C&YP with ASD/ADHD. Despite an appearance of 'normality', many exhibit inappropriate behaviour particularly when confronted with a new situation. A well-planned, structured, introduction to the activity may overcome some of the tensions in the situation for the child and the family; furthermore, adaptations to age groups, toilet and changing facilities, and an observable routine, drawing on parental expertise, may encourage greater access and greater stability for the child.

7.8 Transport

This was not of great significance to the majority of the adult participants; parents noted that some facilities were almost impossible to access via public transport.

The parent of a 16 year-old (ASD) spoke of the difficulty of balancing her son's need for fore-knowledge and routine with the vagaries of public transport. Another parent focused on the problems of fixed school transport and after-school clubs, making attendance difficult.

All in all, the problems with planning routes and transport add to the difficulties of parents in accessing leisure and recreation for their children with ASD/ADHD. Furthermore, the transport needs of other family members, especially siblings, may often conflict with those of the child with special needs.

7.9 Attitudes

Focus group participants and their families have been hurt by many attitudes:

“We’ve had to be very careful because a lot of groups you start her in, the people who take the groups aren’t very Autism Friendly. We took her to a dance class once and the teacher ended up telling the rest of the class that she (daughter) had got something wrong with her brain. So we never went back”.

Parents spoke of how often their children are perceived as badly behaved and how they, as parents, are seen as not controlling deviant behaviour. The following interchange demonstrates some of the difficulties parents have in deciding how to react to this:

“They just see there is a naughty child – they don’t see there is a problem. – Because you can’t see – they are not walking around with a label around the neck – they just see the naughty child”.

“Why should they wear a label?”

“ I have no problem with flagging my child up because I want them to know there is a problem so they are not going to say he is naughty – he’s out.

With a wider group it’s more difficult because you don’t want them to be different from all the other children – want them to be accepted as a child and not as a child with a problem. – but the leader should know – I’ve got no problem with the leader knowing. – Because they should be trained to deal with that sort of thing”.

This perhaps is the crux of the issue and is conceptualised as ‘the dilemma of difference’ (Minnow 1985). While labelling C&YP with a disability may mean extra resources, or understanding, it can also lead to stigmatisation and poor self-esteem for the child. The parent of a 6 ft tall 14 year-old boy spoke of her difficulty since he has no sense of danger and she needs to hold his hand when out. While the only solution to attitudes among the general public is education and increased awareness, the parents and families in the meantime cope with the consequences, as the parents of an 11 year-old boy (ASD) demonstrate:

“It’s (ASD) very hidden until it manifests itself and then it’s very dramatic when it does manifest itself. :

Whatever actions they (staff) take, so whether it be a work place or play scheme or anything else, whatever actions they take will directly affect what happens in the home”.

7.10 Staff training and expertise

Parents describe negative experiences with staff at leisure facilities; lack of staff expertise was a recurring issue. Parents offered many examples of the ways in which they and their children had had negative experiences due to insensitivity or ignorance of staff. Sometimes such experience deterred the parents from returning and sometimes the children reacted by not wishing to return. One parent thought it crucial to establish a relationship with staff before her child accessed the facility; another parent described her strategy as firstly confiding in staff and explaining her daughter’s needs, then secondly:

“because she has an issue with bullying – children bullying her and she’s very, very vulnerable so they have to watch out for her. Some places it works some places it doesn’t. We’ve tried so many things that we’ve found a combination that does”.

Parents also were irritated by staff who ignore their knowledge and experience of their children:

“The thing that irritates me the most and really gets my goat is professionals and staff who talk to me like I don’t know. I’m not an expert on Autism and I’m not an expert on my child but I know him and very often we’re spoken to like we’re stupid”.

Participants perceived the training given as often inadequate and not relevant to the needs of C&YP with communication disorder, as these mothers explained:

“You need people to be trained not just to address physical problems. If children have learning disabilities and have emotional problems like Aspergers and ADHD (especially a terrible problem) – you can’t get people to understand it – they see a naughty child but that child’s got problems and is like that for a reason – it’s not fair. I now view naughty children in a different light. People aren’t trained to look after that sort of thing – trained to look after normal children”.

“Physically you can see the disability – sometimes think I think you get more understanding if you have a physical disability or cancer. If you have child who is angry and wound up”.

Identifying the triggers for inappropriate behaviour, or accepting behaviour as appropriate in the situation, needs a level of expertise and knowledge of the child which many parents perceive as absent in leisure facility staff. Moreover, parents have problems with casual staff recruited for many holiday play schemes:

“Sometimes people come in to do the holiday schemes but they didn’t have the training. Defeats the object if you are sending your child to specialist”.

.”My kids didn’t have any respect for them because they was nearly as old as them”.

Another parent complemented this discussion of young mentors:

“Trouble is these mentors – why get them out of the schools – because they can’t have training/understanding – they would be alright pushing wheelchair – but learning difficulties/ complex needs a problem”.

A parent suggested using videos about the specific types of disability, to help staff understand that C&YP with ASD/ADHD are not being naughty or deliberately misbehaving; participants also expressed concern about the minimal checking of staff once they have received some training and the use of leisure staff whose level of fluency in English language may be low:

“some of the agency staff can barely speak English; how can you expect them to understand challenging behaviour or anything; so how can you expect them to take care of your child who is so extremely vulnerable.”

Again, many of these concerns focus on the trust which parents need to feel in the three-way relationship between the provider, the child and the parents.

An insider viewpoint was described by the mother of three boys, one of whom (7 years-old) has learning difficulties and the youngest (3 years-old) has ASD; this mother is also a swimming instructor. Although she acknowledges the problems of including C&YP with ASD/ADHD into mainstream lessons, she is also hurt by the attitudes of other instructors who refuse to have a child with a communication disorder in their class. The policy arrangement appears to suggest that a class of 12 children should be reduced to 8, if a child with ASD/ADHD is included. She has heard instructors shout at children, even shy

ones, and states *“attitudes have got to change”*. During this discussion, another participant revealed that she chooses not to disclose her son’s autism because of fear of unfavourable attitudes from staff and public, especially other parents.

In conclusion, parents state that they want to be sure that their vulnerable children are cared for by qualified staff with whom they expect to build a relationship focused on the particular needs of the child. Parents perceive staff to need more training, especially around emotional issues and challenging behaviour, and they do not want their children stigmatised for the disability. As parents suggest:

“You can’t just, like, treat them differently from everybody else. They’ve got to be treated the same – they wanted to be treated the same – that’s a training issues as well. – It’s just a word of praise – you are doing that really good”.

7.11 Effective provision

The key to effective provision is perceived as provision which caters for children with ASD/ADHD and listens to their needs and those of their families. The mother of an 11 year-old boy with ASD had an excellent experience at Crash, Bang, Wallop (a mainstream soft play centre):

“They are willing to listen and willing to hear! We used to struggle leaving Crash Bang Wallop and I mentioned to them about having a sensory room or some kind of calming down space and they took that on and said ‘well actually we’ve got a lots of children that will access this - what a good idea”.

Another parent added *“I think that’s the key really – to make the industry and provision more accessible and inclusive and to be a bit more understanding”*.

Participants spoke of the numerous play schemes “out there” but noted that not all are willing to “take children on that have a problem”. This links with the earlier suggestion of a directory of provision which accepts children with special needs.

A number of parents suggested that providers use the excuse of 'health and safety' issues to exclude children with special needs:

"This thing about health and safety has got out of hand – I think people use that as an excuse. "we can't do it because we've got health and safety". Or "we haven't got the funding" or "we haven't got the amount we need – we can't afford that". Seem to be a lot of "lame" excuses".

Participants also discussed the perceived need for sessions for children with similar needs:

"Would be great if there was some sort of group just for children who have got the same sort of problem, like ADHD/Aspergers. Some sort of group that could take them out on trips – I know it would probably be so expensive it wouldn't happen. – "Our children fall through the cracks because they are not physically disabled"

However, while this may be helpful for some families, other C&YP may not wish to be part of a special needs group and may feel stigmatised by this. As much of our data shows, young people, particularly those with Asperger Syndrome, develop an awareness of their 'difference' as they mature and dislike being labelled.

In conclusion, there were few examples of really effective provision, however this may more accurately reflect the difficulties families have in accessing leisure and recreation and also the perceived lack of information about facilities.

7.12 Parents' wish list:

Participants made the following suggestions for ways in which their access to leisure and short breaks could be improved:

- specialist trained staff;
- specialist groups for families which include a child or young person with ASD/ADHD;
- support for siblings, perhaps trips;
- direct payment to ensure continuity of carers;
- an end to lame excuses for exclusion from activities;
- an end to unequal entitlements, such as travel, for example, to one play scheme but not another;
- group meetings to air concerns;
- information freely available.

Finally, parents want their children to be safe, to be cared for by responsible, trained staff, and, above all, to be accepted.

7.13 Conclusions of focus groups

In this section we have reviewed the perceptions of thirty adult participants in four focus groups. These build on, and raise, similar issues to those found in the expert group consultation and the telephone survey: the need for a more extensive Buddy system; issues of trust around relationships with leisure and short break staff and providers; a perception of a lack of staff training; a need for more information and for more availability and flexibility of leisure and short break services. The issues of trust in staff/experts and training/education seem to be closely linked, for where staff have training in strategies to support C&YP with ASD/ADHD and put these into practice, then families develop trust that their child will be safe and will be expertly cared for. Unfortunately, there are far more examples of poor practice than of good practice. These findings confirm those within the AHDC document (DfES 2007b) which specifically note that areas in which staff across all services lack preparation and training include “communication and interpersonal skills, communicating directly,

expertise in behavioural management (especially with Autistic Spectrum Disorder and challenging behaviour)...” (DfES 2007b, p. 56).

Participants held a range of views about whether activities should be inclusive or not; some young people refused to be stigmatised or labelled by accessing recreation facilities for those with special needs and yet the majority of parents perceive specialist groups as a way forwards, particularly if staff have expertise in coping with challenging behaviour and parents feel that the child will be safe in the environment. While cost and transport are important to participants, they are not the most significant factors in accessing leisure facilities and short breaks.

Parents need more information which details provision with expertise in ASD/ADHD. Parents with children attending special schools seem to access more information than those in mainstream schools: this was also found in the telephone survey.

Focus groups provide data informed by dialogue and discussion within the group therefore the data is relational and must be viewed in context. In order to explore some of the themes in more depth, and to offer participants the opportunity to give information in a more private environment, the research team conducted one-to-one interviews with a further group of participants. The findings from these interviews are discussed in the following section.

8. Findings: parent/carer face-to-face interviews

Semi-structured interviews were conducted with seven parents of children with ASD/ADHD. The interviews followed the themes of the focus groups (see appendix 2, p. 80) in order to explore the themes in more depth and to add context and richness to the data (for demographic participant details, see Table 4, appendix 2b, p.83).

8.1 Current provision

Interviewees reinforced the findings of the focus groups, speaking of their lack of awareness of appropriate leisure activities for their children; as the focus group findings suggested, parents with children in special schools seem to be more aware and access more information about leisure and recreation than those with children in mainstream provision.

Swimming was mentioned by four parents but all noted difficulties with this, perhaps encapsulated in the following comment from the mother of a 9 year-old:

“Swimming is a nightmare – he’s had four different swimming teachers and he’s still not getting anywhere because what I find is he can’t cope with a big open space and it’s noisy and lots of children and the teacher can only focus on one child at a time and he cannot behave himself whilst waiting. He can’t wait”.

This inability to wait, together with a dislike of open, noisy spaces, is common to children with ASD/ADHD; leisure facilities need to be mindful of the specific needs of these children. The mother of a 12 year-old boy further echoed the focus group findings, highlighting that her son became reluctant to attend swimming when he became aware of the age difference between him and the other swimmers in the group. Amin’s father echoed the focus group findings, stating that Amin (13 years-old) loves swimming but any change in routine, such as a different teacher or the bus breaking down, upsets him. This reinforces the need for activities which are age and developmentally appropriate for C&YP who may have considerable disparity between their

chronological age and their physical abilities. It also highlights the need for routine and consistency for the C&YP.

Parents are protective of their children, which sometimes takes the form of a barrier to activities. The mother of Joanne (13 years-old), for example, observes that Jo enjoys dance at school but the mother is not prepared to risk exposure to bullying or stigma in out-of-school classes because of Jo's clumsiness. Jo's mother explains that Jo is unlikely to be embarrassed by her clumsiness, but her mother wants to protect her. In interview, Jo's mother identified the tension between needing others to be aware of Jo's difficulties and not wishing to label Jo, or *"magnify the problem"*. Jo refuses to attend after school club but has attended the NCH resource centre three times; she now refuses to go there, probably (according to her mother) because she has little in common with the severely disabled children who attend.

The children of five of the interviewed parents spend most of their free time in leisure activities within the home: using computers, Play Stations, and participating in family activities. The mother of Simon (9 years-old) details the fights she has had to enable him to join in activities:

"I've had to work hard and it's trial and error. He goes to Brigade except I've had to become an officer because I can't leave him".

To enable Simon to become an active member of the Boys' Brigade, she has joined herself and become an officer. Simon's mother also takes him to karate, where he has a very understanding, committed teacher who listened to her and persevered despite problems in the second week. This has given Simon a boost:

"He needed a skill – something that he could develop -something that was disciplined".

However difficulties had arisen in other activities, such as the tennis club, where Simon was teased and so withdrew.

In conclusion, the interview data on current access resonates with that of the focus group data, demonstrating that families lack awareness of suitable provision, and, when they do access leisure activities, they have problems with bullying, misunderstandings and stigma, and thus frequently withdraw children. The interviews also raised the need for activities to be accessible long term so that parents can 'dip in and out' of them, as they would for their other children. A child (or the parents) may not be ready for a Buddy at a younger age yet this could be a crucial friendship for a teenager.

8.2 Buddy and befriending services

No interviewed parent had accessed the Buddy scheme and most were unaware of its existence or how to access it. Tariq's mother had heard of the scheme but feels he is too young and too attached to her to benefit; the mother of Abdul (13 years old) noted that it would be important for her to be able to trust any potential Buddy or befriender. Leo's mother felt that:

"(Leo) is very funny if he don't take to it he won't do it again".

Parents see the need for any potential Buddy scheme to be developed as a long-term commitment to enable time for a trusting relationship and continuity to be developed; it is crucial for the wellbeing of C&YP with ASD/ADHD that the routine is consistent and predictable.

8.3 Short breaks and respite care

Parents perceive the term 'short breaks' as synonymous with 'respite care'. Joanne's mother perceived Jo's only recent ability to remain 'dry' at night as a barrier to overnight care or to activities such as camps or residential field trips. If short break provision is to become a support to these families, we suggest that the terms may need re-defining in relation to the parents' existing understanding. It is also notable that there is considerable overlap between leisure and break/respite provision, and the distinction is not necessarily one made by the parents.

8.4 Accessing information

Throughout all the data collection, we found that that parents do not find it easy to access information about leisure facilities and short break provision. This is particularly the case for parents whose children attend mainstream educational provision. Jordan's mother, for example, expressed her difficulty in knowing what is suitable for him; she also found it problematic accessing facilities appropriate to both Jordan and his sibling. She has located a quiet badminton session (mainstream) at the leisure centre which he enjoys, but found that the noise and unpredictability of swimming sessions "*freaked him out*". As noted earlier, this then tends to trigger challenging behaviour.

While some families are internet users, many (like Jordan's mother) find the raft of potential key words and information overwhelming and confusing, however others, like Amin's father, claim that any information can be found on the internet. Tariq's mother spoke of time barriers to searching the internet for information; caring for C&YP with special needs is, in itself, a fulltime occupation and internet searching may not be a high priority for busy parents. When leisure facilities are identified, there may be no information which clarifies whether it is appropriate for children with special needs, other than wheelchair users.

Joanne's mother has no access to other families with children with similar disorders; this is a problem we find frequently when C&YP attend mainstream educational provision. Information is received currently from Joanne's hospital consultant but this will stop when Joanne is discharged from her care next year.

In conclusion and echoing the survey and focus group findings, parents need much more information and support about the availability and suitability of leisure, recreation and short break facilities, so that they can make an informed and appropriate choice for their children.

8.5 Barriers

The barriers to engagement with leisure provision appear to fall into three overlapping categories, each of which influences the others; we offer the following framework to clarify these:

- the particular needs of C&YP with ASD/ADHD for routine, consistency, quiet, unthreatening spaces, and not having to wait for long periods of time; this we term *'disorder specific needs'*.
- the perceptions of the parents of staff understanding, training and expertise and the emergence of a trusting relationship; conceptualised here as *'safety needs'*.
- provision of activities which overcome barriers of age appropriateness and allow the child to enjoy leisure, so that behaviour and development do not, *per se*, become barriers to engagement. This we characterise as *'child enjoyment needs'*.

8.6 Disorder specific needs

The specific needs of C&YP with ASD/ADHD for routine and consistency underpin all our findings, however it must be reiterated that many of our young participants had co-morbid additional medical and/or educational needs. One child, for example, regularly needed anti-coagulant medication, which brings its own difficulties to engagement with leisure and recreation.

Jordan's mother described his need to know exactly what was happening, thus ruling out any unknown or unplanned activities. In common with many C&YP with ASD, Jordan dislikes strangers and crowds and refuses to eat out of the house.

Abdul's mother identified a tension between keeping his life consistent, routine and structured, and allowing some natural deviation from this to help him to cope with change as he enters adolescence. Life can throw up some changes and challenges and, as she observes:

"Things don't always go according to plan and he needs to learn that life can't be completely rigid – some things are out of our control sometimes".

Specific provision for C&YP with ASD/ADHD could perhaps include graduated structured change, certainly for the older children, to support them in managing it.

Interviewees again identified the 'hidden disability' as a factor in barriers to the child's access to leisure, exemplified by Amin's father:

"You have to remember that Amin looks normal – so people think he's been naughty – they give you dirty looks".

He perceives the only way round this problem is to have activities with other SEN children.

Joanne's mother found that the normal challenges of adolescence were magnified for her daughter; Joanne's poor social skills, clumsiness, poor personal hygiene, temper tantrums and inappropriate behaviour, together with her limited perception of danger, all acted as a barrier to engagement in the recreations other teenagers perceive as 'normal'. She also raised a useful point, which appeared to often underpin the narratives of other participants:

"It's very frustrating. When she was younger there was nothing suitable. And then because she's not done it since she was little, it's probably now difficult for her to do it. It's outside of her comfort zone."

For children with ASD/ADHD, perhaps more engagement with leisure needs to be available at a young age so that they can incorporate it into their routine; providing some taster sessions, which gradually 'grow', for children of similar abilities may enable the family to develop a relationship with the providers which can be maintained as the child matures.

8.7 Safety needs

For these parents of very vulnerable children, safety, in its widest context, is of prime significance and affects whether or not they are prepared to engage with a facility. Because the children can act unpredictably, parents feel the need for constant supervision; Amin's father explained how they needed to still hold their 13 year-old son's hand in shops, to *"keep him out of trouble"*.

The majority of interviewees have had some negative experiences of leisure provision, from which the child has either been excluded or withdrawn. This is as a result of staff not coping with the child's behaviour, thus the parents view training and expertise as crucial to the success of the engagement. Parents also saw no reason why, for example, pictorial timetables and other communication aids could not be used to enhance the potential successful engagement for the child.

In settings where the parent retains responsibility for the child, such as family swimming sessions, the demands of ensuring the safety of their disabled child may make it impossible for them to take their other child/children along too. The unavailability of additional support or care may therefore make an activity effectively unavailable.

8.8 Child enjoyment needs

As noted in all our findings, the children in this study do not readily conform to age, developmental, and behavioural norms; if they and their families are to become regular users of leisure and short break provision, providers need to think 'outside the box' and develop facilities which allow these C&YP to engage at an appropriate level.

Amin's father described how his son longed to be able to ride a quad bike, like his brother one year older, however health and safety regulations were invoked to prevent this. Amin also wanted to use an inflatable slide for younger children and his parents had to wait for a quiet time when other small children would not be using the slide. Amin, his father feels, is not able to understand why his brother, or other children, can engage in activities and he cannot.

Joanne's mother tried to obtain access to respite provision (via the hospital consultant), for her older sister; since Joanne attends mainstream education, this was refused when, as Jo's mother reports:

"that group would have really helped [older sister]. That was such a shame, that was. That she was not eligible, because you're not disabled enough".

As Jo's mother explains, it is not just the child affected by the disability but the whole family. Some flexibility of service provision would have enhanced the wellbeing of this family who are struggling to cope.

8.9 Transport

For most interviewees transport is not of significance, however the timing of transport often clashes with collecting other siblings from school, which can cause problems. Parents also noted that activities 'miles away' could prove difficult for transport, but in general local activities were fairly accessible to the seven families interviewed. One parent noted that since her son is taken to, and collected from, school she worries about his lack of exercise however family activities, such as dog-walking, encourage him to take physical exercise. Parents also note the danger of allowing children to walk unaccompanied, since the C&YP often have little perception of danger and may not negotiate routes very accurately.

8.10 Attitudes

Data from the interviewees resonated with that from the focus groups and telephone survey, demonstrating how families' difficulties are compounded by the attitudes of some of the public and also, in some cases, by other family members. Abdul's mother expressed her problems with her extended family:

"I think - with an Asian background as well – Asian people don't sort of take to a child that's different very well because I think they expect everybody to be kind of – I don't think they understand different illnesses and different problems very well and different disabilities very well".

Abdul's mother then described how she dreaded extended family functions such as weddings, followed by this interaction with the researcher:

Interviewer: would you say that this is something that is linked to your Asian culture?

“It is – they look at somebody and if they are severely disabled they think ‘right – ok – that’s how they are’ – I don’t think a lot of people fully understand – I think close family do but the older generation don’t always fully understand. I have spoken to other people who have got children who are maybe hyperactive or have got other problems and people don’t really understand those things. They expect children to all be more or less the same”

This statement echoes the findings of Hussein et al. (2002) who challenged the ‘extended Asian family as carers’ stereotype, and suggest that a negative perception of disability frequently leads to tension within families. Abdul’s mother perceives negative attitudes as influenced by culture, however the other two Asian families did not make this link. Tariq’s father noted general problems with public attitudes with people *“looking at you, staring”* which inhibited his wife from going out with Tariq. This is put down to a lack of awareness among the public, rather than a cultural attitude to disability.

Amin’s father cited a specific incident at a theme park ride when Amin tried to grab a seat from a small girl and get into the seat; the mother of the girl *“was OK but the father went off on one”*. Amin’s father has some sympathy for the other father yet was obviously upset by his attitude. This returns us to our underpinning thread of ‘hidden disability’ which influences so much of our families’ access to mainstream/public leisure. As Simon’s father rightly perceives:

“I think it is because they [children with ASD] look so normal they like-people can’t see beyond”.

Joanne’s mother is aware of the growing understanding her teenage daughter has of negative attitudes, particularly from peers; Jo has been subject to bullying at school and this is obviously difficult for the family. As children become young adults, they seek the approval of their peers (Rudolph et al,

2005) and this may be particularly problematic for those in mainstream schools.

8.11 Staff expertise and training

Parents report similar difficulties and problems to those of the previous participants, from a child managing to abscond for 45 minutes from a crèche at 3 years of age, to a child collected from an NCH activity soaked in his own urine, despite a clear explanation of his needs from the parents to the relevant staff.

Providers of activities need to have training and develop expertise in the needs of the children attending; if not, parents will not trust them to supervise and understand their children and will not use the facility. The argument continued among the interviewees about whether inclusive mainstream or specialist activities were more appropriate for their children. While parents long for their child to be included, they acknowledge the difficulties:

“It’s a fine balance because you desperately want them to be mainstream – to mix with ordinary children but obviously if you haven’t got the right people running it, you haven’t got a hope!”

Interviewer: So what’s the answer?

“I think really what you need to be doing is having small groups like if you had for example as a starting point you had one ASD child and two mainstream children – get them working together, understanding things, learning about each other and then gradually increase the size of it [groups]”.

This leads us into parental views of effective provision; does it exist and, if so, what does it look like?

8.12 Effective provision

As Simon and Leo’s parents describe above, effective provision needs to be flexible and in short, structured, sessions. The use of pictorial timetables and diagrams would greatly help children with communication disorders. These

parents would also like to be present, but at a distance, and be able to socialise with other parents.

Jordan's mother would also like more support for parents; she feels badly let down by the Parent Partnership service. Tariq's mother finds the NCH "*brilliant*" and she notes that the racial prejudice she encounters in other settings is non-existent there. Parents are very supportive of Lego Land's initiative whereby on presenting proof of autism, a parent/carer is admitted free; the child's hand is stamped with a symbol which enables him/her to avoid queuing and be admitted to the ride without waiting

Few parents can provide examples of effective leisure provision although most have plenty of negative examples; most positive examples relate to an individual who, with understanding and commitment, has enabled a child to gain access to and pleasure from leisure or from recreation facilities.

8.13 Wish list

Parents spoke of their need for support and practical advice; many had found this from parents of similar children but some parents are very isolated and have little idea how to access information about support. A drop-in centre for parents of children with ASD was suggested by the parents of Simon and Leo, knowing how much support they had received from their own friendship.

The majority of parents interviewed view specialist leisure activities as a way to engage their children with recreation although sometimes this pragmatic opinion runs counter to their more abstract wish for inclusivity. The greatest 'wish' however is for more understanding of the needs of this group of children:

*"I think more than anything, just people understanding her [son] and children like him – their situation really and just making allowances for them really (...)
the word autism to most people is the complete extreme isn't it – to them it's like the film 'Rain Man' or somebody you can't have a conversation with them – you can't communicate with them. That's the far end of it – there's so much more". (Mother of Abdul)*

8.14 Conclusions from interviews

The interview findings confirm the themes which arose as significant during the focus groups, however the interviews have enabled us to explore them in more detail and to be confident of our findings. While the focus group participants appeared to be ambivalent about whether mainstream or specialist leisure experiences are more appropriate for the C&YP, in the interviews parents had the opportunity to develop their arguments further and, although wishing for inclusivity for their children, perceive the benefits to the children and to the families of some specialist provision.

Parents were also able, during the interviews, to raise issues around siblings and the extended family. The stereotypical supportive extended Asian family is shown to be as mythical as the White nuclear family; misunderstanding of the consequences of a communication disorder abound and add to the difficulties of the most families and children living with the diagnosis. Siblings are shown to suffer, particularly when support is unobtainable and their needs unaddressed. We had hoped to organise focus groups for siblings within this research but time and ethical constraints prevented this. This is however a topic that should be addressed in any future research, and could also include a further study of the support needs of the parents.

Parents expanded on the issues of staff training and expertise and confirmed that these were essential to a trusting relationship between them and the leisure provider: they need to be sure that their children are safe and are able to enjoy any recreational activity. Introducing taster sessions at an early age and enabling families to dip in and out of them as appropriate, introducing small group sessions for children with similar problems and abilities, and above all, listening to parents will enhance the access of families. As noted on the section on barriers, leisure providers must take into account:

- specific needs relating to the disorder and to any co-disorder (routine, consistency, continuity, small groups, pictorial information).

- safety needs (staff training, small group numbers with adequate supervision, staff experience, a relationship of trust with the child and family; toileting facilities suitable for male/female parents/carers).
- child development needs (what the child enjoys, rather than the age norm for the activity and what the child is capable of achieving, rather than the child's deficit).

As some of the interviewees show, with commitment and understanding, C&YP with ASD/ADHD can achieve skills, knowledge and enjoyment via leisure.

9. Findings: C&YP focus groups

9.1 Introduction

Four focus groups were held in four schools (see appendix 3a, p.86 for details) during which the research team aimed to capture the perceptions of as wide an age and disability range as possible (for guide to questions, see appendix 3, p.84).

9.2 Current access

The first question asked C&YP what they like doing after school or at weekends; three of the older pupils (School A) claimed that they did nothing other than play computer games and surf the internet. One of them said that he would like to go out but no-one ever asked him. Two other pupils enjoyed family activities such as dance class, foreign language lessons, and paintballing.

The younger pupils (School B) enjoy a variety of activities, mostly family orientated (shopping, playing in the garden) and mentioned swimming as an enjoyable excursion. Pupils swim regularly with their families, however one boy (9 years-old) no longer visits the leisure centre since he was upset by a *“girl falling in the pool by herself”*. Whether this results from the boys’ fears or from parental anxiety was unclear but reinforces the need for supervision and also the fears which children and their families have about safety. Pupils also attend Brownies and Guides and one is involved in a rugby tournament.

The pupils in School C, now young adults, like those in School A, participate in few leisure activities; they mostly spend time indoors alone, or with their family, mothers in particular. Two attend the after-school club, however difficulties emerge with transport since transport is not provided.

Asked if they would like to engage in other activities, one boy replied *“No, my mum won’t let me. I don’t go in the street”*. This boy had previous difficulties relating to other youngsters in his area so now stayed indoors. Another spoke of keeping his head down to avoid gangs; his mother had encouraged him to go out more but now has given up.

Most 'outside' activities, such as bowling, are accessed via the school, perhaps indicating that parents and young people feel these are safer than public sessions.

In School D, none of the children attended organised activities although they play at home with siblings, go occasionally to the cinema or bowling, and (via symbols) one child stated that he sometimes goes to SNAPS with his mother. Friends are not visited out of school as they all live too far away, a common problem when children attend a special school not in their home area.

These findings show that the majority of C&YP are limited to activities within the family; as the children become young adults, they seem to lose the desire to go out and spend most of their leisure time on computers and Play Stations. Previous data from parents confirms these findings, with many parents describing the isolation of their teenage children and their desperation to include them in other leisure and recreational activities.

9.3 Exploring the options

The next question tried to find out what C&YP would like to do, however this was limited by their lack of knowledge of potential leisure pursuits. The limited response led the interviewer to suggest that, following the boys' personal interests, taster sessions in gaming or electronics might trigger an interest especially in the older boys who spend so much time alone on the computer or Play Station.

Asked about friends/peers, a boy offers the following reasons for his lack of friends:

"Some of them are [alright with me] but some just don't talk to me whatsoever. They like put up a false front when they are around me, pretending to like me, but they just, like, ignore me".

This demonstrates the difficulties in social interaction of the majority of youngsters with ASD. Reading social cues and non-verbal communication

can be extremely difficult for them, also aspects of communication such as listening and turn-taking.

The younger cohort of children (School B) appear also to have few friends outside school, although they participate in sport (1), Brownie/Guides (1) and one girl enjoys discos at parties and would like to go more often. Of the five children, one had been on a sleepover and enjoyed it and another would like to try a sleepover. A pupil expressed excitement at a planned trip to an outdoor activity centre in Wales, which gave rise to a discussion of fears and anxieties. The fears related to being without parents, a very normal fear at primary age, and also to road safety with children stating:

"I need to go with my mother so I won't go dangerous because I might walk on the road with cars".

and

"I always stay with my mum and dad to keep safe".

Parents, during the focus groups and interviews, stated their difficulties in keeping children safe, particularly when the child had little perception of danger and/or few skills of finding the way. It is difficult to come to any conclusions here about the children's fears and anxieties, since the data pertains to a small number of children and it is suggested that these fears are common to many children at this age.

In School C, the interviewer asked the pupils if they had any worries or concerns about how they are treated by others, giving rise to the following exchange:

"I get that kind of abuse every night I walk home – I just ignore them"

"Yeh - stick ya head down and walk on"

This type of abuse may be a common experience for many children on their way home from school, but it emphasises the isolation and the lack of friends of the majority of the pupils in the focus groups. A boy (KS3) enjoyed visiting a local snooker club but, as the following excerpt shows, found independent travel a significant indicator of the social anxiety experienced:

“ I go to the snooker club that’s where I go...by myself. It aint far from my house...I bike it...If there’s no-one round in the street you can just get there by yourself.

Again, in the above example, we see echoes of social anxiety.

Like their peers in School A, the pupils in School C had little idea about possible future interests or potential leisure activities, however when asked what would help them to do activities, a pupil suggested:

“Yeh – plenty of information on whatever I’m thinking of doing. I like to gather information before I do anything...I never make a move with anything without gaining as much information about it first, so I can make the best choice possible....you don’t always know what’s round the corner”.

The focus group and interview data clearly demonstrated the need of the C&YP for consistency, routine and planning for successful leisure engagement, therefore it is perhaps rather unfair to confront pupils in an interview situation and suddenly ask them for their views on potential leisure pursuits; in any further study, pupil response may be enhanced by offering C&YP information about possible pursuits well before the focus group, thus allowing them time to consider the options.

In School D, despite the fact that some participants had severe communication difficulties, they showed an awareness of leisure possibilities. Asked by the interviewer what they would wish for, a boy (10 years-old) demonstrated non-verbally, using symbols that he would love to go camping; he confirmed this by body language. He also communicated that this would

preferably take place with 'Dad'. Other wishes included a trip to SNAPS, playing in the woods, friends, and riding a donkey, horse riding and dancing. Another child selected the symbol for ballet, which she would like to attend with her 'Mum'.

An 8 year-old boy with minimal speech expressed a wish to play football, as demonstrated in the following exchange:

*Interviewer: what would ***** like to learn? I want to.....*

Child studies symbols in turn

Interviewer: which one? Show me?

Child selects symbol for football

Interviewer: would you like to go to football?

Child affirms this non-verbally.

This demonstrates, as Bryson et al. (2008, p. 6) suggest, that data can be collected from "children with high levels of support needs, communication and learning impairments"; they state that although parents welcomed this in principle, many had concerns about how this would work in practice. Similarly, we found that many parents who participated in the telephone interviews were willing for their children to participate in focus groups, but also expressed concerns about the practicality of this in relation to the children's communication impairments. The excerpt above, one of several such instances, shows that children with severe communication problems can be enabled to express their views and participate in communicating their needs.

When asked about overnight trips, a 9 year-old boy stated that:

"I don't like Elden house...because I miss my mummy"

However another 10 year-old boy attends Elden House and enjoys friendships and activities there.

9.4 Conclusions of C&YP interviews

This section of the report demonstrates the wide range of needs and interests of the children who participated in the focus groups. With small numbers in each age range, conclusions cannot easily be drawn from the data however patterns can be discerned. As noted earlier, it is likely that some of the most severely learning disabled or communication impaired children may have been excluded from the focus groups by well meaning parents and school staff, who were not confident of the researchers' assurances of skills and expertise in communicating. The findings presented here may well be biased towards an over-representation of the views of those most articulate.

The younger pupils, (KS 2), appear to take part in a broad spectrum of activities mostly within a family environment, which is unsurprising at this age; however we know from our data that many parents have had to fight for appropriate facilities for their children.

In the older age group the participants appear to have few friends, difficulties with peer relationships, and few interests other than computers and Play Stations. Drawing on the data from the survey, the focus groups and the interviews, we know that this is of concern to the parents. Furthermore, the C&YP appear to have little knowledge of possible leisure pursuits. It is likely that past experiences have excluded them and safety is a prime concern of theirs as well as of their parents. Their poor social and communication skills make developing peer group friendships in mainstream settings and public spaces problematic. These youngsters may benefit from short, structured, taster sessions around interests common to all teenagers: electronics, computer skills, gaming, and sport. We feel also that this age group would benefit from advance information about such sessions; this will help to fulfil their need for time to adjust their plans and integrate new ideas in a structured way. As we know from the literature (Reid 2007) and from their parents, change has to be introduced slowly to pre-empt challenging or unwanted behaviour.

Our data leads us to suggest two possible hypotheses for the teenagers' lethargy: firstly, it is possible that the implementation of such legislation as the Disability Discrimination Act (2005) and other policy changes have improved children's access to leisure and therefore the younger children and their families are benefiting from these recent developments; however in view of the data from parents, demonstrating long struggles and negative attitudes, this seems unlikely. Secondly, that the older children and their families have been subject to so many negative experiences, which may even have threatened their safety, that they have retreated to a safe zone of home. The experience of discrimination and abuse, unsuccessful attempts at social interaction, fears and anxieties of protective parents, may all combine with the lethargy and increased media obsession of 'normal' adolescence to confine the young people to the safe haven of the bedroom. It may be that offering information and short taster sessions in a safe environment will encourage these young people to extend their horizons and access new leisure pursuits.

10. Findings: interview with young person

While we were interviewing his parents, 15 year-old David (Asperger Syndrome) expressed a wish to be included in the interview, however he refused to talk in front of his parents. The parents gave consent to this and the interviewer explained the aims of the research and proposed dissemination to David who then consented to the researcher including his perceptions as part of the research study.

David stated that he does not go out or attend any interest groups or activities although he attends a school club one afternoon a week. He is very interested in 'nature' and has attended voluntary work experience with a veterinary surgeon. David, like many with social/communication problems, noted that animals are easier to 'get on with' since *"they don't have any complex rules"*. David has not attended any interest group or leisure facility since he was 8 years-old when he had swimming lessons. The interviewer explored David's interest in joining an activity, resulting in the following exchange:

David: "Sometimes I want to – sometimes I've felt like that...but sometimes I feel like I can't..."

Interviewer: What do you feel is stopping you?

"I don't feel particularly normal. If I was ['out there'] I'd be on my own"

So you feel like you wouldn't fit in?

"Yeh"

So what if there was a group of like-minded people with the same sort of worries and difficulties as you – would that interest you?

"If it was a place like one of those psychologist places where you air your problems then no. My parents forced me to one once and I stopped"

But if it was a group that pursued different interests together – had outings together – a group of like-minded people who shared anxieties about mixing with a wider group of people - would that work for you?

“Probably but then again, what would a group of socially awkward people be like?”.

Adolescence is a period in which young people are concerned with issues of identity and developing peer relationships; for David these issues are magnified by his awareness of his disability and his feeling of not fitting in. As much of our data from parents and young people demonstrates, C&YP with high functioning ASD and Asperger Syndrome are aware that they are different both to those with complex disabilities and also to others around them. David went on to say:

“I don’t have any friends.....You don’t want to embarrass yourself so you just don’t try”

Interviewer: The people your age – what are they like towards you?

“It varies. Some like to make fun when I do something with my leg. Some of them try to help me. Humans are very complex beings”.

David has spent time on the internet researching his disorder and shows awareness of his difficulties; he encapsulates the dilemma for so many of the children and young people in this report when he observes:

“I don’t ‘fit’ in mainstream and I don’t fit in specialist – I’m in between”.

11. Implications for Walsall

The report discusses the perceptions of a diverse range of 110 parents/carers and C&YP who participated in the research. The data provides an insight into the needs of the families and the C&YP with ASD/ADHD, a group often marginalised by the juxtaposition of their apparently 'normal' appearance with hidden disabilities.

While we have discovered few examples of effective inclusive leisure provision, we have listened to a far greater number of accounts of negative experiences. Where families and C&YP had successfully engaged with leisure facilities this was mainly due to determination from the parents/carers and the commitment and understanding of one or two exceptional members of the leisure staff. Parents/carers wish to build a relationship of trust with leisure staff, and this is dependent on the parental perception of the staff understanding, training and expertise in relation to their child's abilities and disability. These findings confirm those of other researchers (DfES 2007b).

Parents/carers spoke of their own support needs and those of the other siblings. While parents/carers of C&YP attending special schools access information from the school and by 'word of mouth', the families of C&YP in mainstream educational settings find gaining information and support more problematic.

Very few parents had access to the Buddy scheme or to short break provision; many parents/carers perceived this as a benefit available only to C&YP who are more severely disabled while others distrusted the expertise of providers. Previous negative experiences of leisure groups appeared to contribute to the parent/carers' perceptions of a lack of understanding and expertise among short break providers. The Buddy scheme was also regarded as inflexible and too subject to a lack of continuity for the specific needs of C&YP with ASD.

We found that the trend towards younger children enjoying leisure activities in the home or as part of a family outing diminishes as the children enter

adolescence; the older adolescents interviewed engaged in very few leisure activities outside the home and this was confirmed in the data from the parents. This isolation will inhibit successful engagement with a job or with further education or training as they enter adulthood; a concern expressed by many parents in the focus groups and interviews. Very few of the C&YP interviewed had relationships with peers and some of the older youngsters had experienced social difficulties in public spaces, including abuse and bullying, leaving them anxious about going out. Furthermore, as parents had also noted, some young people are aware that they can be easily provoked into acting inappropriately and are anxious about the potential effects of this in public. Safety, as an issue, is related to:

- the child or young person's perception of their own physical and emotional wellbeing;
- parental perceptions of safe relationships, safe environments and trust in the leisure/short break provider;
- the confidence of the leisure provider in managing health and safety;
- The perceptions of the general public of behaviour which may appear inappropriate, intimidating or threatening.

Perhaps one of the most useful findings of this research relates to the discussions about whether C&YP need more access to mainstream or to specialist facilities for leisure. While we found that in principle, the majority of parents would wish their children to be included in mainstream leisure provision, in practice negative past experiences and the nature of the child's difficulties led many parents to perceive some specialist provision as necessary. From our data, we find that families need flexible and varied opportunities for leisure and short breaks; these could, in line with parental feedback, be taster sessions which perhaps include a small number of C&YP without disabilities and one or two C&YP with ASD/ADHD. This would offer the opportunity for all the participants in the activity to develop understanding of the disability as well as possibly enhance peer relationships.

Leisure providers should consider our three categories of need into account when planning provision for C&YP with ASD/ADHD:

- Specific disability needs;
- Safety needs;
- Enjoyment needs.

Described in more detail earlier (see pp. 49-73) these include needs for routine and consistency, an unthreatening venue, staff with expertise and understanding of ASD/ADHD, and flexible provision which may cross the existing boundaries of age and development. Some provision may need to be made for C&YP with similar disabilities while other provision could offer some integrated mainstream recreation but in small, introductory sessions. Families, including the C&YP, need the opportunity to develop trusting relationships with the staff organising the activity.

To increase the take-up of short break provision, providers need to address the needs of C&YP with ASD/ADHD for pre-planning, continuity, and stability; without these, C&YP may jeopardise the relationship by exhibiting challenging behaviour and/or withdrawing from the activity. Buddies should be available at a planned time, for a reasonable period of timed support and the provision should be continuous; once the relationship is established, Buddies could be potentially available in an emergency situation. Families need easy access to information about short break provision, in an easy-to-read format which takes into account literacy and language skills.

Finally, we find that many families of C&YP attending mainstream educational settings lose out in accessing information about leisure provision and support groups; as the children grow older, they perceive themselves as not fitting into categories of 'normal' or 'disabled' thus creating issues of identity management and magnifying the usual challenges of adolescence. Young people, particularly with Asperger Syndrome, appear to be a hidden group with a hidden disability, isolated on the margins of their peers' teenage social

life. Their transition to adulthood will be greatly improved by engaging with leisure and recreation, being supported to develop friendships with peers, and developing interests which may lead to skills.

Families of C&YP attending mainstream education need information to be more widely accessible. As a research team, we should also note that poor literacy levels were evident during some of the focus group activities; these should be taken into account when disseminating information to all families, together with translations (when appropriate) for people for whom English is not their first language.

For these and all the children, young people and families who contributed to our research, and all the other families of C&YP with ASD/ADHD we could not contact, we make the following recommendations:

12. Recommendations

The recommendations are three-fold relating to children and young people; parents and carers; and providers as follows:

Children and young people:

- Provision needs to follow the interests of the child, particularly for older teenagers, providing short taster sessions in an unthreatening environment;
- Provision needs to be flexible, drawing from our three categories of need; it should be available in some specialist groups (for C&YP with similar levels of disability), small integrated mainstream opportunities, and full, public, mainstream activities such as Lego Land, which actively makes engagement easier for C&YP with ASD/ADHD, taking their needs into account;

Parents and carers:

- Support groups, specifically for families of C&YP, should be further developed;
- Parents need access to easy-to-read literature which details leisure and short break provision suitable for the specific needs of their children; where this exists, parents need to be informed of the access point;
- The needs of siblings should be further explored and support services, appropriate to a range of ages, provided;

Providers:

- The difference between respite care and short break provision should be clarified and entitlement to access defined, so that families understand who can, or cannot, engage with the provision;
- The Buddy system and befriending services must be consistent, flexible and long-term to cater for the specific needs of families and C&YP;

- Providers of leisure and short break provision for C&YP with ASD/ADHD need greater understanding of the disorders and education and training in coping strategies; this will enhance parental trust and enable C&YP to successfully engage with more activities and interests;

Our three point framework of needs could form a basis for the development of a strategy to support mainstream and specialist providers of leisure, recreation and short breaks and a means to evaluate whether they can offer appropriate, effective facilities for the C&YP with ASD/ADHD.

In addition, we suggest that Walsall tPCT could build on its existing good practice in listening to the voices of these children, young people and families by considering further research specifically into the needs of the C&YP who live on the margins of mainstream: the families of children and young people with high functioning autism, including Asperger Syndrome, who attend mainstream schools.

References

- Blakemore, S-J. Frith, U. (2005) *The learning brain: lessons for education*. Oxford, UK: Blackwell Publishing.
- Bryson, C. Elam, G. Gray, M. Pickering, K. Purdon, S. Speight, S. Turley, C. Read, J. Blackburn, C. Spencer, N. Abbott, D. Gordon, D. (2008) *Development of a survey on services for disabled children*. DSCF-RB053. London: DCSF.
- DfES and HM Treasury (January 2007a) *Policy Review of Children and Young People: A discussion paper*. London: DfES & HM Treasury.
- DfEs and HM Treasury (May 2007b) *Aiming High for Disabled Children*. London: DfES & HM Treasury.
- DfES (2004) *Every Child Matters: Change for Children*. Nottingham, UK: DfES Publications.
- Dickens, S. (2008) *Listening to young disabled children*. London: National Children's Bureau.
- Flynn, R. (2002) *Short breaks: providing better access and more choice for Black disabled children and their parents*. Bristol: Policy Press and York: Joseph Rowntree Foundation.
- Hussain, Y. Atkin, K. Waqar, A. (2002) *South Asian disabled young people and their families*. Bristol: Policy Press & York: Joseph Rowntree Foundation.
- Lambert, SD. Loiselle, CG. (2008) Combining individual interviews and focus groups to enhance data richness. *Journal of Advanced Nursing*, **62**(2), pp. 228-237.
- Mencap (2006) *Breaking Point: Families still need a break*.
- Minnow, M. (1985) Learning to Live with the Dilemma of Difference: Bilingual and special education. *Law and Contemporary Problems*, **48**(2), pp. 157-211.
- New Philanthropy Capital (2007) *What price an ordinary life? The financial costs and benefits of supporting disabled children and their families*.
- NICE (2008) *Attention Deficit Hyperactivity Disorder: Diagnosis and management of ADHD in children, young people and adults*. National Clinical Practice Guideline No: 72. (Uncorrected proof) London: National Collaborating Centre for Mental Health.

Plimley, L. Bowen, M. Morgan, H. (2007) *Autistic Spectrum Disorders in the Early Years*. London, Thousand Oaks, New Delhi: Sage Publications.

Prewett, B. (2000) *Committed to caring: the views of short break carers for children who are 'hard to place'*. York: Joseph Rowntree Foundation.

Reid, R (2007) *Moving On Up*. Negotiating the transition to adulthood for young people with autism. National Autistic Society.

<http://www.nas.org.uk/content/1/c6/01/39/64/Moving%20on%20up%20%28England%29.pdf>

Shared Care Network. (2006) *Still Waiting*. Report.

Shevlin, M. Rose, R. (2008) Pupils as partners in education decision-making: responding to the legislation in England and Ireland. *European Journal of Special Needs Education*, **23**(4), pp. 423-430.

Swain, J. French, S. Cameron, C. (2003) *Controversial issues in a disabling society*. Buckingham: Open University Press.

Towards the Children's Trust. Walsall's Multi-agency Strategy for Children and Young People with a Disability 2005-10.

[http://www.walsall.nhs.uk/library/governance/disability%20multi-agency%20strategy%20\(2\).doc](http://www.walsall.nhs.uk/library/governance/disability%20multi-agency%20strategy%20(2).doc) Accessed 28.3.09

Walsall Primary Care Trust Disability Equality Scheme 2006-2008

<http://www.walsall.nhs.uk/library/equality/walsall%20teaching%20pct%20disability%20equality%20scheme.doc> Accessed 4.4.09

Worldclasscommissioning (2008) Panel report: Walsall tPCT.

<http://www.walsall.nhs.uk/Library/Communications/WCCFinal.pdf> Accessed 28.3.09

APPENDIX 1**Walsall tPCT Phone Survey**

Section 1 - General Information	
Ref No:	RE-ARRANGED TIME?...
Name of Interviewee	
Relationship to child	
Name of Child	
Gender of Child	
Siblings	
Condition (ASD/ADHD)	
How would you describe your ethnicity? (Circle)	
White British	Chinese
White Irish	Other Asian Background
Other White background	Mixed White/Black Caribbean
Black or Black British Caribbean	Mixed White/Black African
Black or Black British African	Mixed White/Asian
Other Black background	Other Mixed background
Asian or Asian British – Indian	Other ethnic background
Asian or Asian British – Pakistani	
Asian or Asian British – Bangladeshi	

Question 1

Have you had access to any of the following	NO	Frequency - tick as appropriate			
		More than once a week	Weekly	Monthly	Other
Overnight break					
Weekend break					
Sitting scheme (Child minder)					
Holiday play scheme					
Before/After school care					
Otherm - Please specify					

SHORT BREAKS**Question 2**

Do you have any problems accessing short breaks? Which of the following would apply to you?...	tick as appropriate	
	YES	What would you consider the most significant?
Availability of the service		
Travel		
Cost		
Opening hours / flexibility of service		

Cultural / Religious considerations (please specify)		
Lack of expertise / attitudes of Staff		
Public attitudes		
Other children / young people		
Staff – Child ratio		
Quality of care (Any other aspect?)		

Question 2a

Are there any barriers or facilities which are not mentioned on the list?

LEISURE & RECREATION

Question 3

Do you or your child with ADHD/ASD use any of the following Leisure facilities	tick as appropriate				
	NO	Frequently	Occasionally	Mainstream	Specialist
Swimming					
Cinema					
Theatre					
Bowling					
Dancing					
Gymnastics					
Martial Arts					
After School Clubs					
Outdoor Activity Centres					
Library					
Youth Clubs/discos/cubs/scots etc..Church Groups/ Classes					
Other.....					

Question 4

Which are the following are a barriers to your child accessing Leisure and Recreation facilities...	tick as appropriate	
	YES	What would you consider the most significant?
Availability of the service		
Travel		
Cost		
Opening hours / flexibility of service		
Cultural / Religious considerations (please specify)		

Lack of expertise / attitudes of Staff		
Public attitudes		
Other children / young people		
Staff – Child ratio		
Quality of care (Any other aspect?)		

Question 5

If I could wave a magic wand what would you most wish for regarding access to facilities

If you could change anything?....

Question 7		
Would you be interested in participating in further discussion groups for this research?	Yes	No

Question 8		
Would you be willing to grant permission to allow your child to be interviewed as part of this research?	Yes	No

Appendix 1a: Telephone response rate**Table 2: Telephone response rate**

Total number of telephone contacts	127	100%
Total number of agreed interviews	44	35%
Disconnected lines or incorrect number	26	20%
Number of calls made with no response	47	37%
Number who declined interview	10	8%

Appendix 2: Focus group and interview guide (adults)

What barriers do you encounter when trying to access leisure facilities and out of school activities?

- attitudes
- access to information
- choice of times and type of activities
- flexibility – e.g. levels of organisation and supervision need to be gauged by type of need
- sibling/family involvement permitted where desired?
- financial
- transport –costs of public transport. Inflexibility of subsidised transport with regard to attending after school activities
- trust and confidence (issues for staff awareness of children’s needs and staff training)
- ‘Buddy’ or support worker availability
- safety – group size an issue? Staff/child ratio? Boisterous members a worry?
- distance - Needs may determine time/distance able to travel

What are your experiences of leisure facilities and out of school activities that you have attended to date?

- public/staff attitudes
- appropriate provision:
- lifting equipment, changing facilities?
- do they cater for severe and complex needs?
- can they manage particular behaviours?
- continuity of staff and familiar routines?
- full risk assessments/policies in place?

Is your son/daughter in receipt of respite care? If so, what are your experiences of this provision?

In your experience, have you and/or your child used a type of provision that you found to be good? What were they?

What were the features of this provision that you consider particularly 'good'?

Appendix 2a: Focus group participant details**Table 3: demographic details (adult focus groups)**

Focus group	No. of participants	Gender female	Gender male
A	10	7	3
B	4	3	1
C	10	9	1
D	6	5	1
Total	30	24	6

Appendix 2b: demographic details of interviewees

Table 4: Demographic details (interviewees)

Parent	Ethnic group	Child's age In years	Child's gender	Child's disorder	Child pseudonym
Father	Asian	13	M	Severe autism	Amin
Mother + father	WB*	9	M	ASD (high functioning)	Simon
Mother	WB	9	M	ASD challenging behaviour	Leo
Mother	WB	14	M	ASD	Jordan
Mother	WB	13	F	ASD	Joanne
Mother	Asian	8	M	ASD	Tariq
Mother	Asian	12	M	ASD	Abdul

*White British

Appendix 3: Pupil focus group questions¹

1) What do you like doing when you are not at school?

After school I like to.....

2) How do you get there?

I get there by.....

3) Who do you go there with?

I go there with.....

4) Do you enjoy going and have fun?

5) Is there anywhere you would like to go to?

¹Prior consultation with teaching/support staff will inform of intended areas of questioning whilst offering the interviewer opportunities to gather pupil profiles/communicative or other support needs and any pupils likely to present challenging behaviour and strategies to be implemented should this arise.

Semi-structured approach will allow for opportunities to expand lines of inquiry.

Question delivery determined by pupil's age and level of cognitive ability (pre-determined where possible by prior discussion with support staff).

For older pupils, further differentiation will be applied where appropriate e.g. terms used such as 'hang out with your mates' as oppose to 'play with friends'.

Where appropriate, symbols will be used to support the discussion for non-vocal pupils or those pupils that prefer to interact via symbols. Makaton signing will also support the discussion where appropriate.

I wish I could go.....

6) Do you play with your friends?

7) Where do you go in the summer holidays?

In the big holidays I go.....

Appendix 3a: details of C&YP participants and their schools

Table 5

Type of school	Key Stage of participants	Age	Gender	Disorder	Total
Special: primary	KS 2	8 yrs	M	ASD minimal speech	4
	KS 2	9 yrs	M	ASD	
	KS 2	9 yrs	F	ASD	
	KS 2	10 yrs	M	ASD non-verbal	
Special: 4 to 19yrs	KS2	11 yrs	F	ASD	6
	KS3	13 yrs	M	ASD/ADHD	
	KS4	15 yrs	M	ASD	
	KS 4	15 yrs	F	ASD	
	Post 16	16 yrs	M	ASD	
	Post 16	17 yrs	M	ASD/Aspergers	
Mainstream: primary	KS2	9 yrs	M	ASD/ADHD	4
	KS2 (IQC)	10 yrs	F	ASD	
	KS2 (IQC)	11 yrs	F	ASD minimal speech	
	KS2	11 yrs	M	ASD	
Mainstream: secondary	KS3 (IQC)	11 yrs	F	ASD	5
	KS3 (IQC)	12 yrs	M	ASD/ADHD	
	KS3	14 yrs	M	ASD	
	KS3	14 yrs	M	ASD	
	KS3	14 yrs	M	ASD	
IQC = Informal questionnaire consent				Total	19