

contact a family

We're Listening

I hope that something comes of it.

Birmingham Parent

My child is now 17. During his childhood there was very little help and support. I hope this will be different for new parents.

Parent from Bartley Green



A consultation with families of disabled children on how they would like resources allocated in 2003 to 2006.

Written by Sarah Chandler, Regional Development Officer for
Contact a Family West Midlands

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About Contact a Family

Contact a Family is a national registered charity founded in 1979 for families with disabled children. At our heart is a unique and powerful combination of:

- Expert and comprehensive knowledge about rare disorders and all aspects of disability
- A wealth of personal experience and contacts
- An approach driven first and foremost by parent's point of view.

We provide information on; parents' groups, local, regional and national organisations and services; medical information; newsletters; workshops and events; publications on a wide range of topics around disability and much more.

Our aim is never to dictate to families but always to enable them to organise their own systems of support and contact. It is this enabling rather than running approach that allows us to deliver social change far beyond our resources and size.

Contact a Family West Midlands is the local regional office set up in 1999 with a Regional Development Officer, now Sarah Chandler and Regional Information Officer, Kirsty Mayo. For three months of the consultation process there was also a part-time assistant, Gemma Wood.

The West Midlands office is also supported by a team of volunteer local area representatives who act as the local contact point in their area. They are all parents of disabled children. They are:

- Sharon Baker in Worcestershire
- Rizwana Pathan in Warwickshire
- Sonia Tooray in Birmingham
- Val Barrett in Staffordshire until March 2003

We all work closely with a range of partner organisations throughout the West Midlands including a large number of parent support groups, whose work is invaluable.

Summary of findings

1. Who responded to our survey and how

We asked parents and children for their views in a variety of ways and the following numbers responded:

- 861 parents via postal questionnaires (19% response rate)
- 23 disabled children and siblings via focus groups
- 166 family members who attended the family events
- 12 parents attending two focus groups
- 11 one to one interviews with parents

Of these

- approximately 21% were Asian
- children had a range of disabilities
- approximately a third of children were in mainstream schools

2. The services they used and what they thought of them

Statutory services

The highest use was made of doctors (63%) followed by speech therapists (54%). The least used was Sure Start (2%).

Of those who commented, the most useful statutory service were the Child Development Centres.

• Voluntary Organisations

The most used voluntary organisation was Contact a Family (19%) followed by Kids West Midlands and Autism West Midlands.

Of those who commented, Contact a Family was the most useful voluntary organisation.

In both cases, parents said that what they found most useful in good services was access to information, advice and support.

Conversely, what was missing from poorly rated services was information and support.

3. Play and leisure for children

Leisure is usually the most requested service for children.

Parents said that:

- The biggest barriers to leisure were lack of information about what is actually available (51%) and lack of actual services (43%).
- The best ways of improving outdoor play would be to have supervised play areas such as: adventure playgrounds (45%) supervised play (45%) and cleaner parks (44%).
- The type of play and leisure they most wanted for their children was a range of specialist and inclusive mainstream provision such as family events (60%), specialist holiday clubs (48%), swimming clubs (40%), mainstream holiday clubs (40%) and inclusive holiday clubs (35%).

Parents want a range of specialist and mainstream activities and opportunities for their children but even here, information on what exists is cited as a vital and unmet need.

4. What new or expanded services parents would like

For their children parents mainly want friends, support and information:

- Opportunities to make friends (67%)
- Accessible information (51%)
- One to one support (45%)

For parents themselves, they want information in a variety of ways and breaks from caring;

- Drop-in desk for information (49%)
- Local directory of service (48%)
- Regular breaks (43%)
- Opportunities to meet other parents (41%)
- One to one support (38%)

The themes were clear and consistent. Parents want information and support for themselves and more play, leisure and friends for their children.

5. Families from minority communities

Asian families

Asian families (21% of our sample) wanted the same things as other families as well as:

- opportunities to meet families from the same religious or cultural backgrounds.
- someone to talk through information with them.

Newly arrived families

Our small sample showed that they need:

- help in understanding the system and their rights
- medical information
- practical information in caring responsibilities for their children.

6. Disabled Children and Siblings

Through a Design a T-shirt activity at three Family Fun Events we involved 23 disabled children and siblings.

Disabled children and siblings want more sports activities, opportunities to go to parks, have trips and outings and they need to be able to have the opportunities to develop friendships. They want the same things that their parents are saying they need for their children.

7. Parents' priorities

The role of the Parents' Forum was to weigh up the evidence from the findings and judge the priorities for parents of disabled children and their families in Birmingham. Not surprisingly, they agreed that these were:

- Information for parents – co-ordinated and delivered in a variety of ways through written information, drop-ins, key workers and support groups
- Support for parents – via drop-ins, helplines, parent networking, key workers and higher awareness of parents' needs
- Leisure and play activities for disabled children and their siblings.

Recommendations

Parents from across multi-cultural Birmingham have spoken and their messages are consistent and clear.

They want:

1. Accessible information delivered in a variety of ways
2. Emotional support in caring for their child
3. Breaks from caring responsibilities
4. Inclusive mainstream and specialist leisure opportunities for their children.

Recommendations

1. Accessible information

An information strategy should be developed by Birmingham City Council to ensure that all service providers take responsibility for providing information about their service to parents of disabled children.

Birmingham Children's Fund and/or other providers could assist by providing or funding:

- A guide to services in Birmingham for all parents of disabled children with telephone numbers of key services. Guides need to be translated into other languages.
- A regular newsletter for parents of disabled children
- A central Birmingham website for disabled children and their families with links to key providers of information such as the Contact a Family website.
- A page in every Parent's Child Health Record directing parents to central sources of help if their child is disabled.
- Training of all health social care, education and leisure staff in understanding families' information and support needs.
- Training for staff in Sure Starts and Children's Information Centres about how to access information for families
- On-going consultation with parents about their information needs
- Training for workers involved with asylum seekers and refugees in the help available for their disabled children
- Funding of well established and valued information services such as Contact a Family.

2. Support for families

A city wide support strategy for all families of disabled children should be devised. Providers could provide or fund the following:

- A get together of parents, local groups and voluntary organisations to explore how drop-in services could best be provided to parents.
- A drop-in information service for families – for example a monthly drop-in surgery provided by a voluntary organisation in a central part of Birmingham and funded by social services and health.
- Easily accessible funding for local support groups for parents to cover room hire and other modest on-going costs.
- Workshops for parents to get together and share ideas, knowledge and develop skills.
- Advocacy and family support workers for Asian families.
- Development and implementation of a key worker system of care by statutory providers.

3. Breaks from caring

Many parents miss out on respite care, especially those who do not qualify for help from the Disability Team. They could be helped by:

- Development of a flexible Direct Payments scheme which is actively promoted.
- Baby sitting services.
- Developing a guide to breaks services in Birmingham that shows families existing services and how to access them.

4. Leisure Services

A strategy is needed in Birmingham to increase play and leisure opportunities for disabled children and their siblings. Statutory organisations could provide or fund voluntary organisations to provide the following:

- A directory of mainstream and special needs sports facilities which include and welcome disabled children.
- A guide to accessible and good days out for families of disabled children (such as museums, cinemas, etc).

- A website with up to date information on accessible and inclusive clubs and facilities for disabled children.
- Specialist swimming lessons at swimming pools to help disabled children learn to swim and then safely use mainstream pools.
- Family fun events for families of disabled children.
- Training for staff working in mainstream leisure services on welcoming and including disabled children.
- More supervised parks and playgrounds.
- Accessible parks and playgrounds (including accessible parking and toilets).

Finally..

Birmingham has many experienced and knowledgeable parents who are willing to give time and energy to improving life of fellow-families. Birmingham should fund a parent led forum which would supply feedback to providers and could be consulted on service delivery. Such a forum, would have authority from representing a wide parent body and enable a strategic approach to consultation. It would prevent duplication and make more effective use of parents' energies. An excellent model exists in Leicester (the parent and Carers Council) and this will be recommended as a model by the Children's National Service Framework.



Background To The Consultation

Birmingham Children's Fund was set up in 2001 with Government funding to improve lives of children in the city.

The Birmingham Children's Fund set up a number of working groups to fit with identified priorities including Disabled Children. In November 2002 the Disabled Children's Themed Group commissioned Contact a Family to consult with families to help them allocate resources for 2003 to 2006 as well as provide evidence of need to other funders.

The Consultation Process

Contact a Family West Midlands received confirmation of the funding to carry out the consultation process in mid December 2002 and the work had to be completed by 31st March 2003. This gave just over three months to plan, organise and carry out the consultation work – a very short space of time and a real challenge for the two officers in the West Midlands team.

The work plan was agreed and work began in December 2002 to organise the consultation.

We combined:

- Qualitative information gathering from one to one interviews, parents forum meetings and other events.
- Quantative data from a large scale postal survey and surveys undertaken by other organisations.
- Snapshot techniques at family fun events including: feedback from families on the back of invitations, design a t-shirt consultation with children, family wishes and face to face recorded interviews with parents and carers at the events.
- Targeted work to find out the needs of hard to reach groups such as traveller families and minority ethnic groups.

This gave a clear picture of the experiences of families, disabled children and siblings and their views about future services and support.

The Survey

A. What we did

The survey was designed with help from colleagues in Contact a Family South West London who had gained considerable experience and expertise working with the Children's Fund in their area. We also sent the survey to members of the Disabled Children's Themed Group for their views.

The survey was then sent out to 4456 families, of which 4080 were families on the Disabled Children's Register and 376 were families on the Contact a Family mailing list living in Birmingham.

Included with the survey were the following:

- A letter to introduce Contact a Family, Birmingham Children's Fund and the survey.
- Information about the survey and confidentiality.
- Information about Contact a Family and the services we offer.
- A reply slip for families to request further information and to be added to Contact a Family's mailing list.
- Entry form to a free prize draw.
- The Survey
- A Birmingham Children's Fund pen!
- A reply paid envelope.

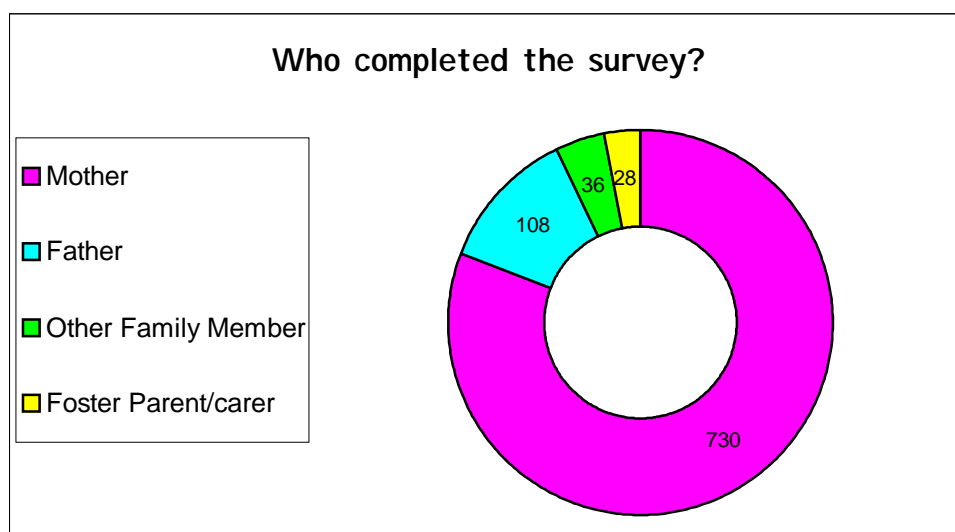
Results of the Survey

861 forms - 19% were returned by the closing date.

418 families - 49% requested more information and to be added to our mailing list.

It is important to note that not all families completed every section of the survey.

B. About the families who responded

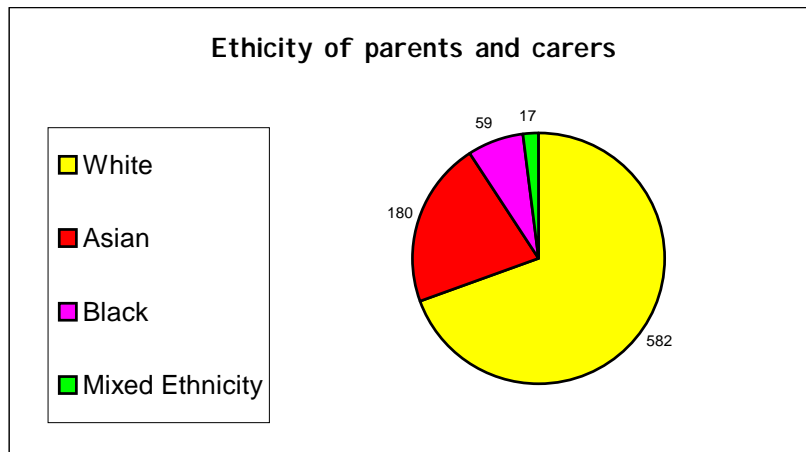


Where they live

Northfield	84	Yardley	40
Sutton Coldfield	60	Small Heath	36
Hall Green	57	Edgbaston	36
Erdington	51	Hodge Hill	28
Perry Barr	50	Spark Brook	26
Selly Oak	47	Ladywood	16

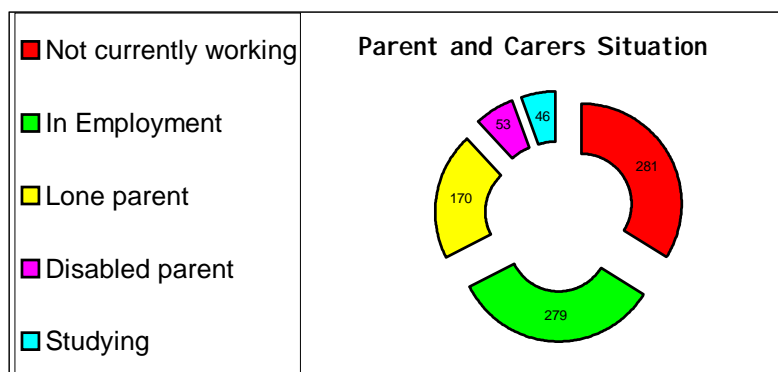
The area where people live was based on constituency areas and data shows that families who completed the form live right across the City. The respondents also included a good number of families from the Birmingham Children's Fund priority areas including Small Heath, Yardley, Hodge Hill and Erdington.

Ethnicity of parents and carers



This chart shows that 68% of families were white and 21% of surveys were from Asian families.

Parents and Carers Situation



We also found that of those who completed the survey:

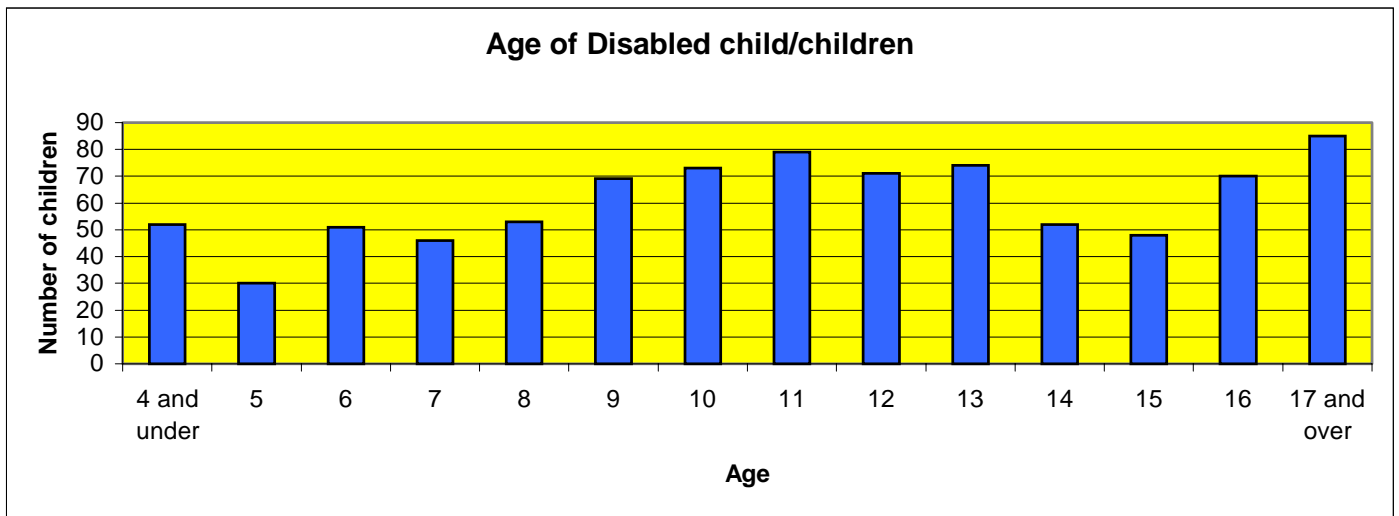
Mothers not working	250
Mothers in work	249
Lone parent mothers	149
Fathers not working	32
Fathers in work	36
Lone parent fathers	6

Number of families with more than one disabled child

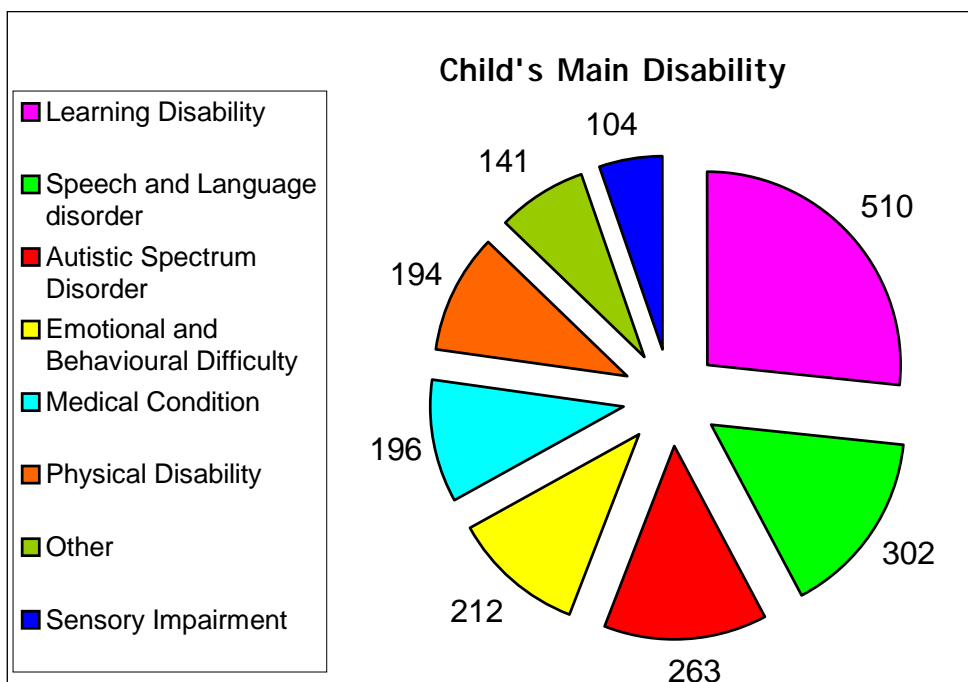
16% of families have two disabled children	140 in total
2% of families have three disabled children	21 in total
0.6% of families have four disabled children	5 in total

About the disabled children

Child's Age

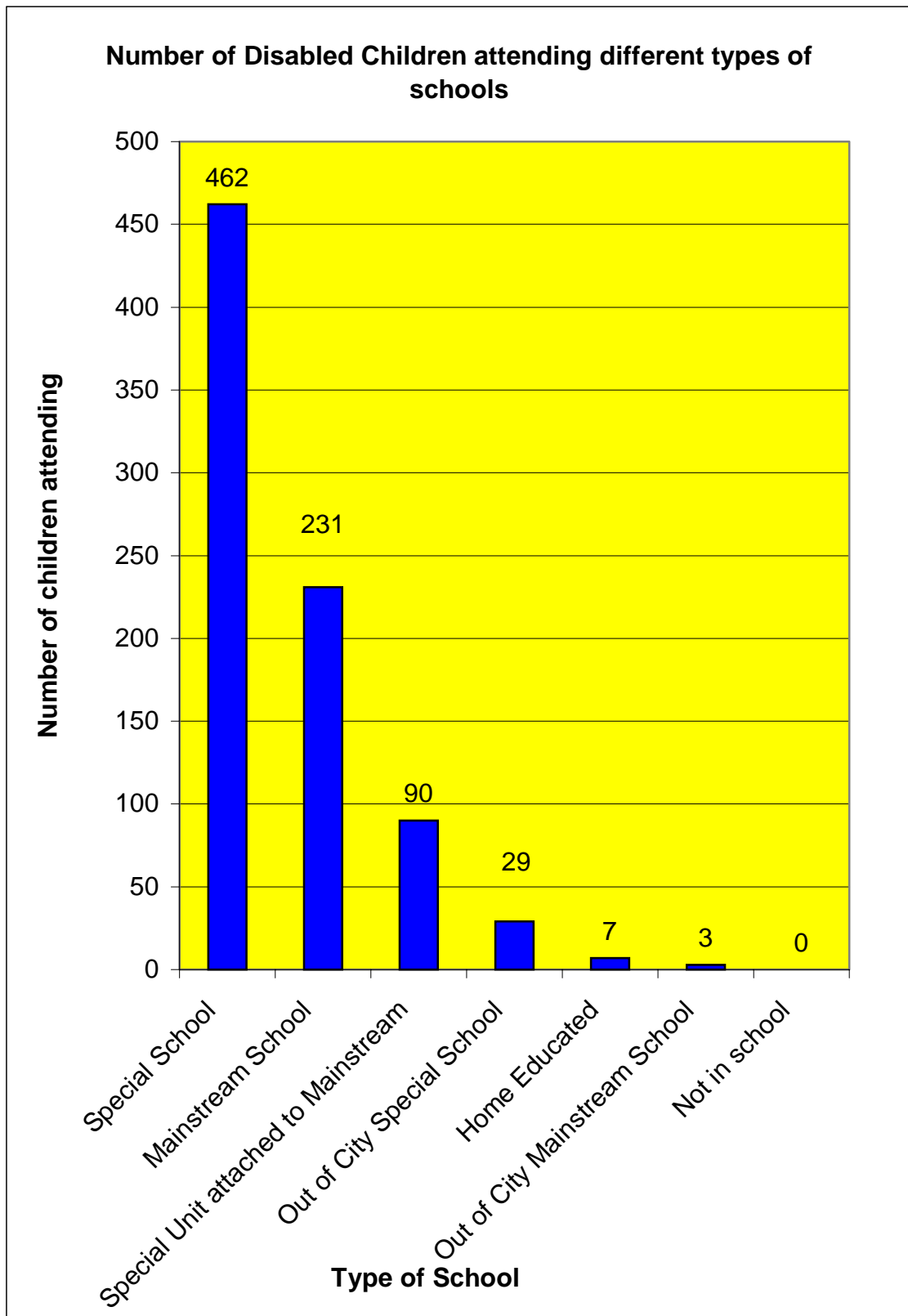


Child's main disability



The other section included conditions such as Cerebral Palsy, split chromosome abnormality, Downs Syndrome, Attention Deficit Hyperactivity Disorder, Goldenhar Syndrome, Marfan Syndrome, Dyspraxia, Cystic Fibrosis, Worster Drought Syndrome, Myalgic Encephalomyelitis and Epilepsy. It is important to note that some children had more than one type of disability or special need.

C. Statutory Services Used by Families



Statutory Services used by families

We asked families which statutory services they had used and gave a range of options and space to write other services used.

Doctor	550
Speech Therapist	469
Child Development Centre	360
SENCO	300
Disabled Children's Register	318
Health Visitor	273
Physiotherapist	265
Social Worker	261
Occupational Therapist	238
Portage Service	114
Parent Partnership Service	107
Help at home	76
Carers Support Initiative	54
Children's Information Service	44
Sure Start	23

A higher number of families had used health services with 550 families saying they had used their local GP and 469 using a Speech Therapist.

Voluntary Organisations used

Parents were asked which voluntary organisations they had used and were given a range of options with space for them to add other organisations.

Voluntary Services used by families

Contact a Family	164
Parent Support Group	121
Kids West Midlands	99
Autism West Midlands	99
Birmingham Carers Association	97
Citizens Advice Bureau	67
Mencap	62
Scope	31
Young Carers Project	8

Parents' Comments

This section of the survey was open for families to complete based on their experience. Not all comments made by parents and carers were specific about what they found 'useful' or 'not useful'.

We analysed comments in two ways:

- Counting useful and not useful comments by service provider, e.g. Social Services, Doctor etc.
- Through reading comments and devising categories of what was useful or not, then counting the number of comments for each category.

This method gave us very good quantitative information directly from the parents about which service providers were useful and not useful, as well as the specific aspects that made them useful.

510 families made comments. Some commented on more than one service. There were 462 comments about services that were useful and 182 comments about services that were not useful.

Out of the parents/carers who made comments the following shows how many families said specific services were useful or not useful.

Statutory Services

	Useful	Not Useful
Child Development Centre	106	10
Doctor	85	12
Speech Therapist	75	19
SENCO	64	6
Social Worker	54	79
Portage	49	1
Health Visitor	48	9
Physiotherapist	46	5
Occupational Therapist	42	16
Parent Partnership Service	29	5
Disabled Children's Register	23	4
Help at Home	12	3
Carer Support Initiative	9	1
Sure Start	6	0
Children's Information Service	4	0

Other services mentioned by a small number of families as 'not useful' were the Local Education Authority, Child Mental Health Services and the Visiting Teacher Service.

Voluntary Services

Out of the families who made comments about voluntary services the following table shows the number of comments about specific services being useful and not useful.

Voluntary Services	Useful	Not Useful
Contact a Family	44	0
Kids West Midlands	43	4
Parent Support Group	40	3
Autism West Midlands	35	5
Birmingham Carers Association	23	0
Mencap	14	5
Citizens advice Bureau	14	1
Scope	12	0
Young Carers Group	1	0

There were also a number of services that received individual comments that they were useful. These included a range of organisation such as Crossroads, Sleep Over Service, Home Start, ServaCare and the Dyspraxia Foundation.

There were very few comments from families saying that voluntary services were not useful. More families had said they used statutory services than those that said they used voluntary services.

Categories of Comments

What was useful

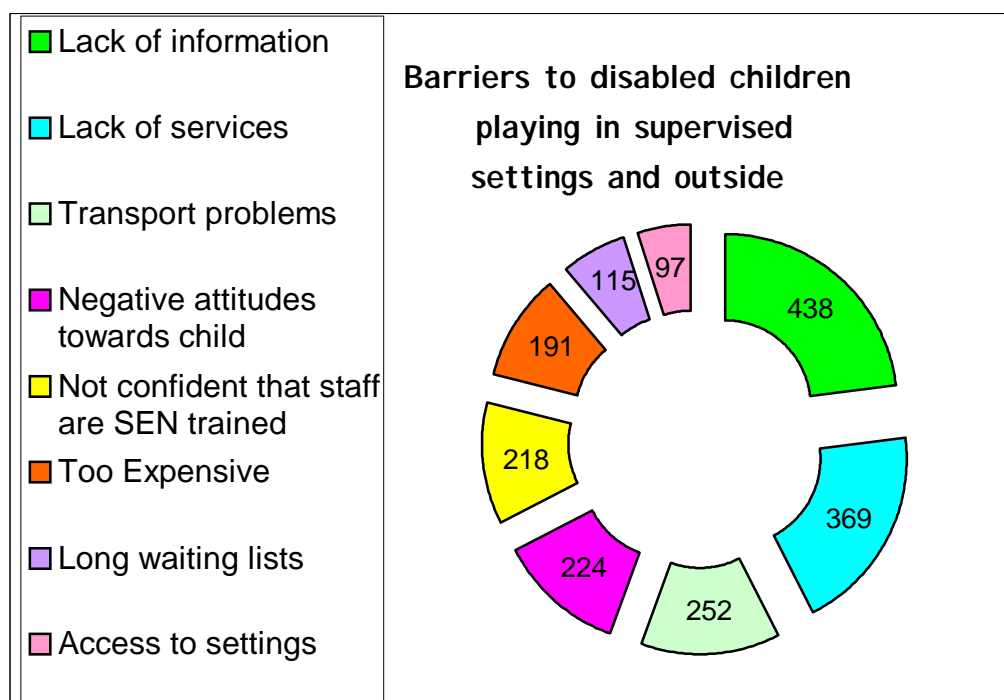
Information and Advice	142
Support	96
Helping their child to develop	92
Activities for disabled children	65
Help to access services	64
Meeting other parents	54
Medical Check ups, monitoring and diagnosis	53
Events and Training for parents	42
Providing Equipment and adaptations	40
Breaks from caring responsibilities	38
Help in School	19
Funding	17
Help at home	9
Form filling	7
Child Care	5
Help with siblings	1
Inclusion	1

What was not useful

No Support or information	42
Lack of funding	37
Poor staff attitude	31
Slow response and waiting lists	24
Not keeping to commitments	21
Not Listening to parents	20
Difficulty contacting staff	20
Lack of disability awareness	20
Poor procedures	16
Pressuring into action	14
Family don't meet criteria	13
Lack of carer awareness	5
Poor communication	3
Failure to diagnose condition	3
Lack of joined up services	2
Incorrect advice	1

D. About play and leisure opportunities

We asked parents what barriers there are to their child playing in supervised settings and outside. Parents were given a number of options and an opportunity to state other barriers.



52% of families said lack of information was a barrier to their children accessing supervised settings and outside.

101 families made specific comments about barriers they felt important. The main comments were about:

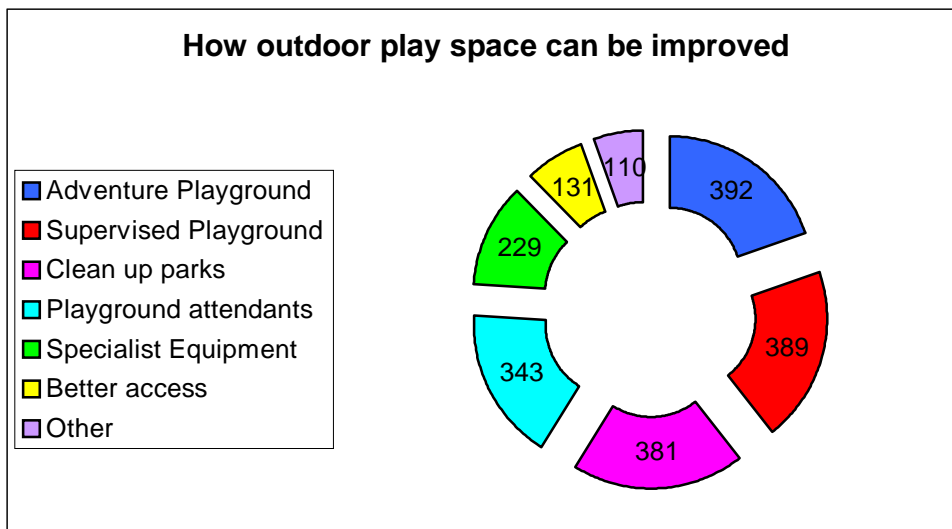
- lack of specialised or trained staff or unwelcoming staff (23%)
- lack of schemes (20%)
- children being excluded because of their behaviour or medical condition (17%)

Other negative comments were about lack of information, lack of one to one support, bullying, safety issues and hostile public attitudes.

In contrast, some positive comments show that services can get it right. *"Kids West Midlands are first class. We have used their playgroup and daybreak service."* *"Out and About is a great scheme."*

"The social worker was useful because she organised places and funding for respite care and play scheme for my child."

We asked families how outdoor space in their area could be improved. We gave a range of options and space for their own views.



99 parents made comments about improving outdoor play space in their area. The majority of comments mentioned:

- The need for more facilities and equipment for disabled children – 63%. 18% of these comments highlighted gaps for older children.
- The lack of spaces and staff to supervise children - 14%.
- The need to make spaces safer and cleaner, whether through having dog free zones, cleaning up from drug users or crime prevention strategies - 10%.

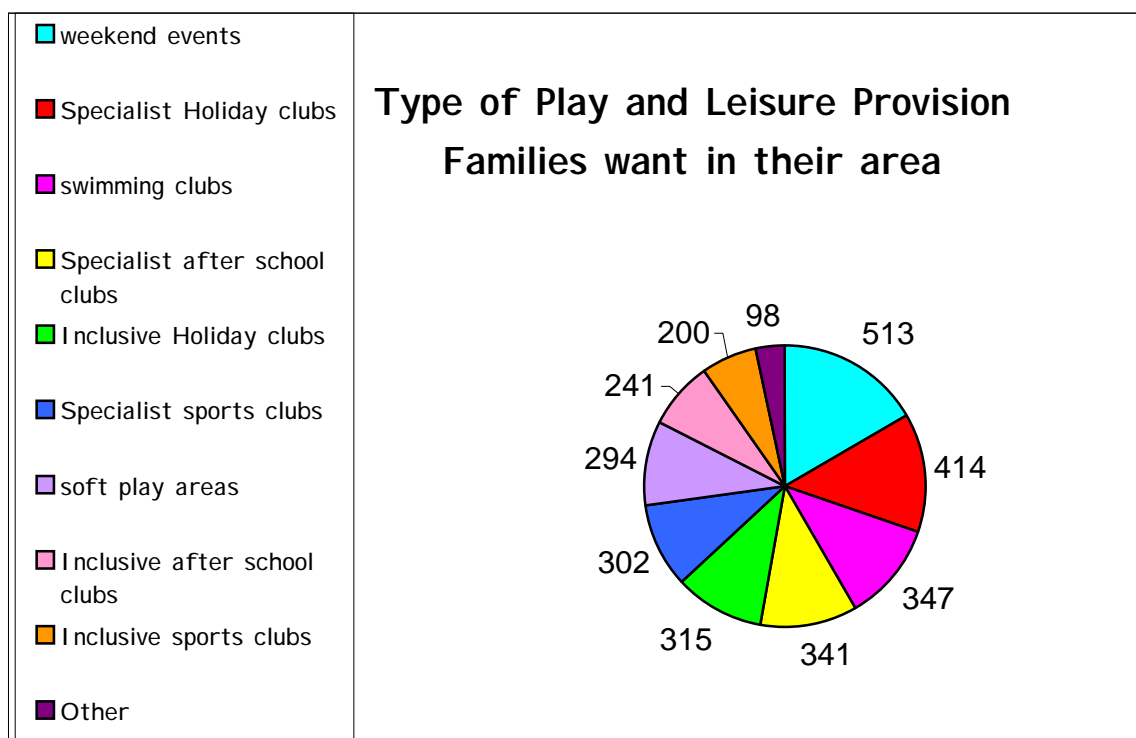
"In my area, entertainment is totally adult dominated. We live near an area of wall to wall night clubs, flanked by high crime fringes. Crime is a major worry so my daughter's respite care is usually based on outings."

"Soft surfaces and graded activities. We have only one play space near where we live and there are very limited activities which my son finds too difficult or because of his size are unsuitable."

"The local park is good – it has park keepers."

There were a number of individual comments including having enclosed play areas to prevent children running away, making the road crossings safer and having someone to accompany disabled children to play areas.

We asked families about the type of play and leisure provision they would like more of in their area. We gave families a range of options and an opportunity to state their own ideas.



87 families made comments about improving play and leisure provision in their area. The main comments were about:

- The need for more clubs and activities including, swimming, music, dance and football - 53%.
- Adequate staffing and trained staff who are positive about disabled children and able to sign - 21%
- Transport to and from activities - 6%

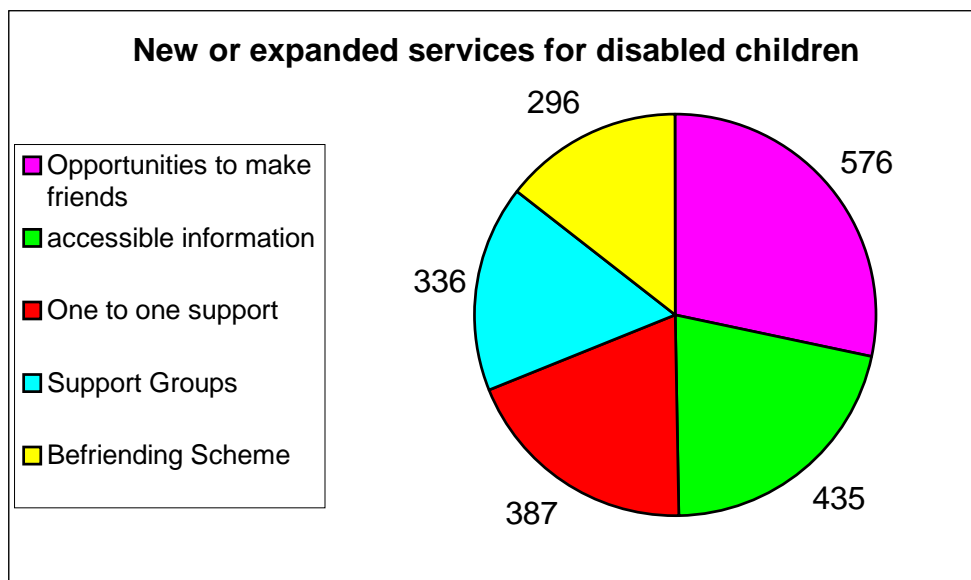
"Clubs where he could go with friends -'disabled or not', discos, activities, holidays maybe like all other teenagers."

"A place where children with special needs could play along side mainstream siblings, family and friends, in an atmosphere of acceptance and understanding."

Other comments included the need for weekend activities, family events and information about leisure opportunities, smaller group activities and cheaper provision.

E. New or expanded services in Birmingham

We asked families what new or expanded services they would like to see more of for parents of disabled children.



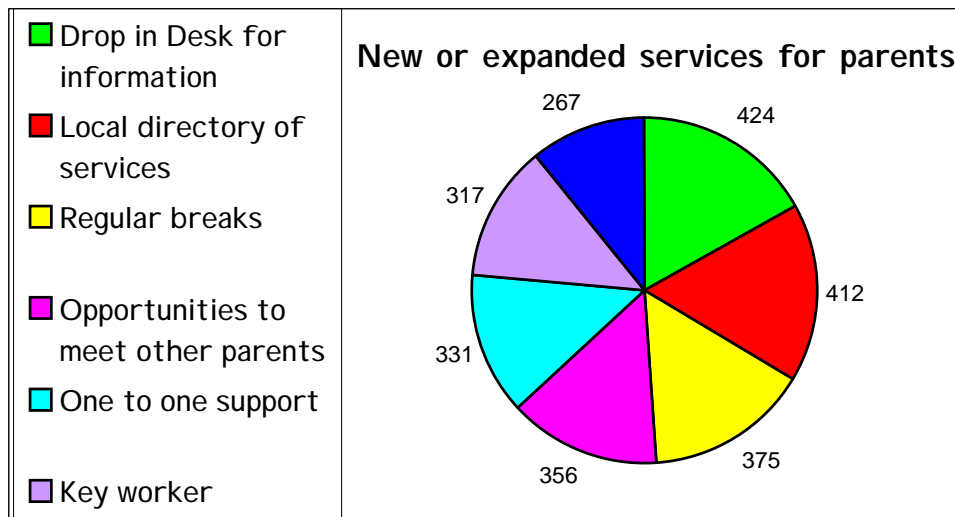
There were 58 comments from parents in this section. Analysis of these comments showed that the majority were about:

- Children making friends – either at home or out and about – both for fun and peer support – 24%.
- Activities and clubs after school, weekends and during all school holidays – 19%.

"Some after school facilities to enable my daughter to get out into our local community to meet other children, which at present is non-existent. She does not have the opportunity to socialise outside school hours as she attends school in the north of the city." Parent from South Birmingham.

A number of other comments were from families wanting respite, support for parents, playgroups and weekend activities.

We asked parents what new or expanded services they would like for parents and carers. We gave a range of options and an opportunity for parents to give their own ideas.



Information was the biggest need identified by families.

There were 57 comments in total with the main points as follows:

- Information and advice - families especially want someone to tell them what they would be entitled to - 32% .
- Breaks from caring responsibilities - 14%.
- A Key Worker - 14%

"This is very difficult as my daughter and I have always done things together. I have never gone out even to Bingo. I don't consider myself as she always comes first."

"To be more than just mom sometimes would be cool, that's my pipedream."

"A local drop in desk for help with filling in forms for benefits for people who know what they're doing."

"Regular breaks for parents and siblings but with good quality, stimulating environments for the disabled child or support with disabled child whilst on holiday."

F. Conclusion from this section

- Families are looking after families with a range of conditions across the city. A good number of families are looking after more than one disabled child.
- Families are dealing with a range of demands including work, study, looking after more than one disabled child, needs of siblings and demands of relationships and family.
- The survey shows that many families have had positive experiences of statutory services, the exception being Social Services who had more negative comments than positive.
- Families said that information, advice and support to families and helping their child to develop are the most useful aspects of service provision.
- Parents cited lack of information and support, lack of services and funding, poor staff attitude, slow responses and long waiting lists as being the major causes of frustration and dissatisfaction.
- The survey showed that most families feel that outdoor play spaces need to be improved with more adventure playgrounds, supervised and cleaning up parks coming high on the list.
- Most families wanted weekend events. More families wanted specialist holiday clubs, after school clubs and sports clubs than those wanting inclusive provision.
- When asked about new or expanded services for disabled children most families want more opportunities for their disabled children to make friends and accessible information.
- When asked about new or expanded services for parents most families wanted a drop in desk for information and a local directory of services. Other priorities included breaks from caring responsibilities and opportunities to meet other parents.

Family Fun Events

Three Family Fun events were set up in Shard End, Camp Hill and Sutton Coldfield and incorporated a range of activities including arts and crafts, bhangra dancing, mehendi painting and face painting.

Attendance of each event is shown below.

Venue	parents	disabled children	siblings	Total
Shard End	15	12	14	41
Camp Hill	19	16	21	56
Sutton Coldfield	26	22	21	69
Total	60	50	56	166

Disabled children attending had a range of conditions including Autism, Attention Deficit Hyperactivity Disorder, visual and hearing impairments, Dyspraxia, Aspergers, Cerebral Palsy, Sturge Webber Syndrome, Downs Syndrome, Polycystic Kidney Disease, William Syndrome and a range of rare disorders.

Through the Family Fun events we gave families four ways to tell us what they wanted:

- An opportunity to feedback on the invitations – this also gave families who couldn't attend a chance to have their say.
- Family wishes.
- One to one interviews about their thoughts about services they need.
- Design a t-shirt children's Consultation.

All the information gathered from the invitations, family wishes and one to one interviews showed the following were important areas for development mentioned by families:

Information

"We wish that the system for getting your child both diagnosed and stated was easier, not so long winded, not such a battle, not so emotionally draining and that information on the process was readily available from one source."

"A service for parents to be directed to after diagnosis - to let you know what you're entitled to."

"I'd like somewhere I can go on the spur of the moment just when it's too much - where there's information. It's nice to sit with someone in the same situation."

Support to families

"If I can let it out and talk about it with someone else for an hour or so then I go home and I'm much better...calmer....destressed. It's the most distressing thing having a disabled child. I've never had to cope with anything like this. It's all the time, constant. You need to talk about it with people who understand so you don't feel you're on your own, whereas most of the time when you're in a situation where you haven't got that you feel very lonely."

"Support at diagnosis with trained counsellors helping parents to connect and meet and help each other."

Family events at weekends

"Today has been one of the best weekends I've ever had with my kids. Every time I go and see my kids we're bored and have to stay near toilets because of my children's condition. It's saved me sitting at home with them with nothing to do, staring and getting angry with myself. Today my kids have been happy and I've been happy. I wish it was like this every Saturday up here, but it's not."

"We wish we could have more places or events like this where others understand or where we can feel ordinary and 'normal'."

"Weekend events are excellent especially bringing siblings, I t's good for fathers to come along and let off steam. You wonder how you're going to keep them occupied for two days so having a weekend event and mixing with other families in the same situation is great and helps siblings too. This is really tuned into the family needs – providing a facility for all those needs – it's fantastic. Thank you."

Leisure and play

"We usually do swimming and Wacky Warehouse, but he rips his shorts off or pushes people. I ring the pool and tell them we're coming and he's autistic. I've tried going to different places, but when he starts having a tantrum.....I've been shouted at so many times and looked at, it's really hard work trying to find fun things to do."

"To have a playground where disabled children in wheelchairs could have a fun experience on suitable equipment."

"The guilt of not taking the children out. They're asking for Drayton Manor or the park for an hour or so, but then when John gets bored you have to stop, but if you could get a Saturday once a month for him then I could spend some time with the others. You can't get monopoly out when John's trying to join in. It's not his fault and I don't want the kids to resent him so we've stopped saying, 'We can't do that because of John.'"

Conclusion from this section

Information, support, family activities and leisure and play are the key needs identified by families who attended the family fun events.



Parents' Forum

We held two meetings for parents to get involved in discussions about their issues and experiences of services, as well as to design parent friendly services to meet their priority needs.

10 parents attended the first meeting and 12 parents attended the second meeting. Parents attending have agreed to attend meetings of the Disabled Children's Themed Group.

Priorities agreed by the parents' forum were as follows:

- Information and communication
- Support to parents
- Leisure and play

Parents then spent some time designing services around the top two priorities as follows. This was their dream:

An information and support service for families which:

- Is an independent drop-in service centrally located and co-ordinated with local places for parents to meet up and find information.
- Would network all relevant information in sections of the service.
- Provide a family support worker to give medical information and emotional support.
- Have staff and volunteers prepared to call parents back where needed (as calls can be very expensive)
- Include a crèche for all ages in the central building.
- Is staffed by a mixture of specialist workers and volunteers with personal experience.
- Provides information professionals who could allocate other services and resources to a key worker.
- Include information about activities and clubs for disabled children and their siblings
- Offer outreach services, a resource pack for parents and a crisis helpline.
- Have not just female but also male staff to give support and information to fathers.
- Involve other organisations such as Autism West Midlands and Contact a Family.

There would also be available:

- information and training for professionals and parents
- a professionals' and parents' forum.
- awareness raising of the public and to service providers such as mainstream schools to the needs of disabled children and parents.

Support for parents would take the form of:

- support at diagnosis
- support groups for parents and other forms of networking among parents
- opportunities for parent to parent support
- Counselling support, groups for siblings and help for other family members needing information.
- Babysitting and holiday help service.

The ethos would be:

- Based around parents' and families' needs
- With full information always supplied to parents as equals
- With effective communication and no jargon or assumptions.
- And power behind it to ensure that resources are passed on to families.

Activities and clubs should be advertised and known all around by parents.

Conclusion from this section

Information, communication and support to parents are the most important needs identified by the forum. Services to meet these needs should have a central base with local service provision giving outreach support and information as well as opportunities for parents to get together and act as volunteers. The organisation should be run by an organisation independent of statutory authorities.

Hard To Reach Groups

We identified Asian, Newly Arrived and Traveller families as being hard to reach groups and tried a range of approaches to gather views of parents and carers in those groups including use of existing reports, contact with other organisations and workers, identifying ethnicity in the survey and one to one interviews.

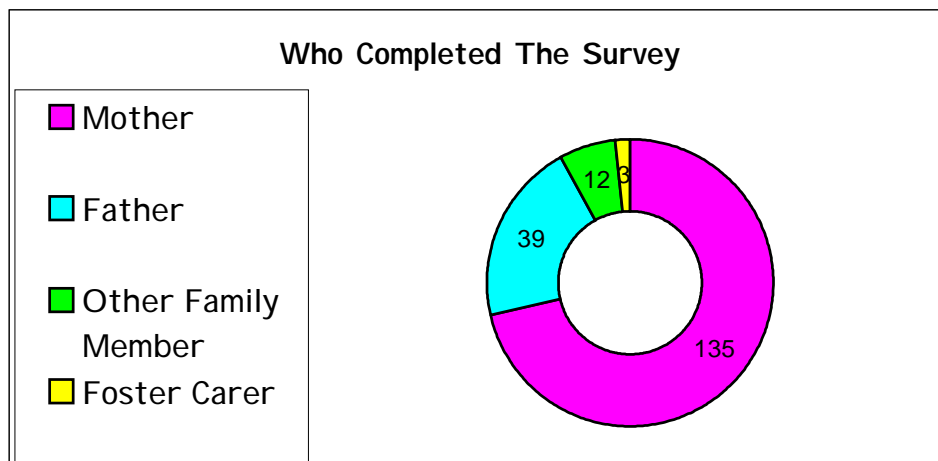
Asian Families

We reached Asian families through the survey, family fun events, one to one interviews and material from a survey of Asian Parents views completed in 2001.

Findings from the survey

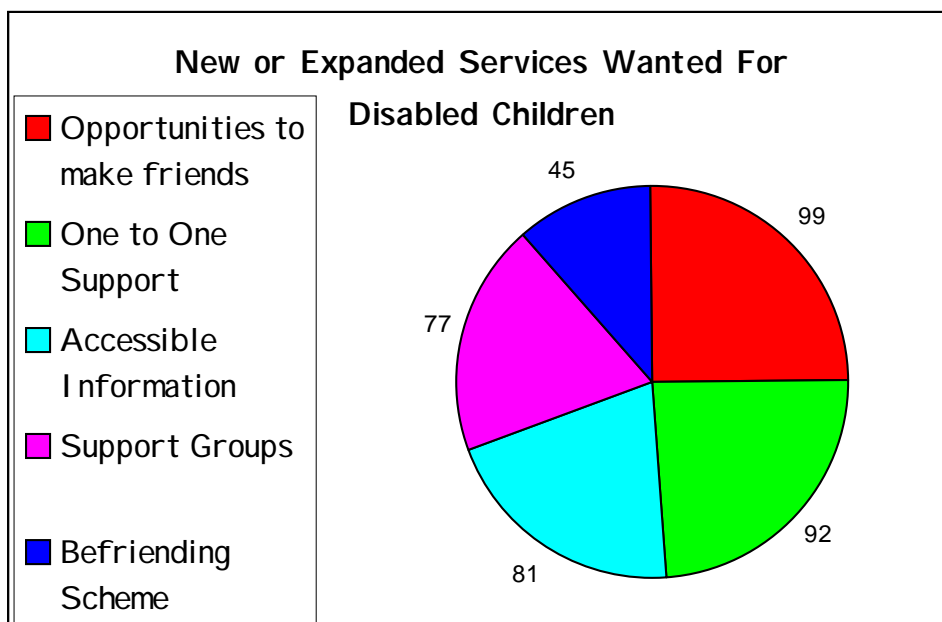
From the survey we found the following:

180 surveys - 21% were completed by Asian families.



Asian families who completed the survey came from all constituencies in the City apart from Sutton Coldfield. They were also looking after children with a range of disabilities and special needs.

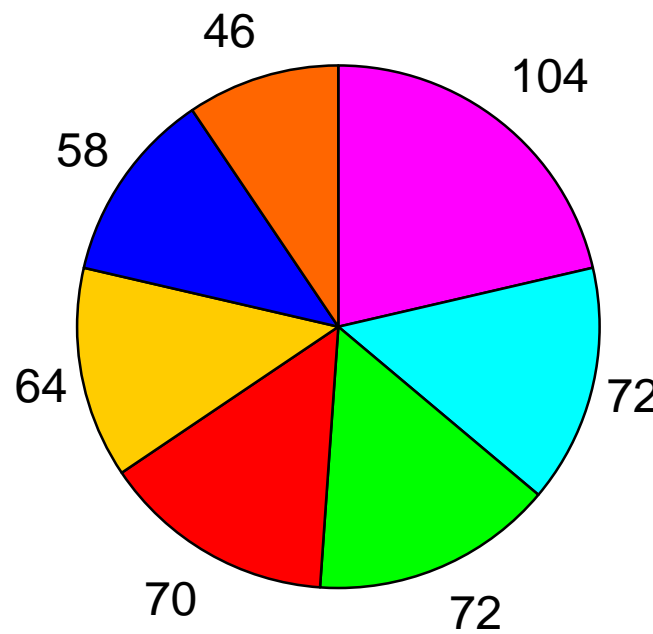
We looked at what new or expanded services they would like for their children. The chart below shows the findings.



We also looked at what services and support Asian families want for themselves. This chart shows their views.

Expanded Services wanted for Asian Parents and Carers

- One to One Support
- Drop In Desk for Information
- Local Directory
- Regular Breaks
- Opportunities to Meet Other Parents
- Key Worker
- Baby Sitting Service



Family Fun Events

Our Asian Volunteer Local Representative, Sonia Tooray was also an excellent source of information and ideas to make the events and consultation accessible to Asian families.

Publicity was distributed to local libraries, shops, mosques and health centres. 11 Asian families attended the events including 13 parents, 12 disabled children and 14 siblings. Their views are included in the main section of this report.

One to one interviews

Through the range of activities and events during the three month consultation period we were able to talk to 6 Asian parents about their views and experiences. Although this is a small number of families, their views have given us some insight to add to the whole picture of what Asian families want.

Some families expressed different perceptions and approaches to disability in their different communities. Some talked about feeling that the disability was something to feel ashamed about and hidden away. Other families spoke about the disability as a special gift to be thankful for and the disabled child is treasured.

"There's an element of embarrassment for Asian families to be open about problems. Asian society can look down on families - there's a stigma attached to disability. You're looked down on in the extended family, by attitudes and what they say. The family don't understand the difficulties of living with a disabled child - his father never understood and picked on the children."

Some families felt that the stigma has had an impact on their approach to dealing with their disabled child, making it more difficult to find information and sources of support.

Some Asian women wanted to be able to talk to others from the same religious background and be able to speak in their own language.

"It's good to meet other single parents with similar backgrounds - especially from your own culture. It would be good to meet other muslim women - it would be nice to see more people."

Families spoke about the need to talk to people to find out how to help their child develop social skills and emotionally.

"I want to find strategies on how to deal with my child in a more positive way. I need to be able to talk through how to say no – sometimes it's easier to back down."

Families also spoke about the need for holiday and after school clubs.

"Holidays can be very difficult. He gets very bored and has a lot of energy. It would be good if the local community centre had something to do."

Parents' Forum

5 Asian parents attended the parents forum and contributed to discussions and group work. Their views are included in the general section.

SNAP Report

The Support Network for Asian Parents (SNAP) Steering group set up in Sparkbrook established in 2000 to research the support needs and preferences of Asian parents who care for disabled children in the Greater Sparkbrook area of Birmingham and produced a report of this work in 2001. Contact a Family West Midlands was represented on the Steering Group and wrote the report.

This report has proved an invaluable back up for the work we did for this consultation. The SNAP recommendations are as follows:

- Support for parents needed to be local, informal and attached to existing services.
- Parents wanted informal drop ins to coincide with playgroup, school and clinic sessions.
- Consideration should be given to setting up a home visiting support scheme in the area.
- Parents need to receive regular up to date written information about services, entitlements and local activities in the form of a regular newsletter delivered to the family home and in the language chosen by the family.
- Children should have access to playschemes in their area, particularly during school holidays.

Conclusion from this section

Asian families need the same things as other families such as information, support, help to enable their child to develop and after school and holiday activities. It is important that services that are developed give a range of options to families – both to access services provided in the wider community and to have opportunities to meet families from the same religious and cultural background and to be able to talk through information with people.

Newly Arrived Families

We contacted the Newly Arrived Team to see if they could help us identify families of disabled children who they worked with to find out their views. The team leader felt that they were too new to the work and couldn't help us at the time.

We were subsequently contacted by a health visitor who wanted to know if we could help two Somalian fathers of disabled children who had been in the country for about eighteen months and were looking for organisations to help them meet the needs of their disabled children.

We agreed to see what Contact a Family could do to help and also felt it would be a good opportunity to find out their views about existing services and needs for the future. After a few weeks contact was made and a meeting arranged.

Somalian Families

An informal discussion with two leaders of the Somalian community who were both parents of disabled children found that there were a number of families looking after disabled children or older relatives.

They said that a number of families were afraid that their children would be taken away from them and that they saw their role as finding out information and taking it back to people in the community to inform them and build confidence in local services.

They wanted information about:

- Specific conditions and disabilities.
- Where to get help and information about local services.
- How to deal with the behaviour of children.
- How to get breaks from caring responsibilities.
- How to get help to create space in their homes for children to lose energy or cope with challenging behaviour.
- Information about the systems and their rights.

They had no access to the internet and they felt that this would be of great benefit to themselves and their community. The community leaders wanted training for themselves – either informally on a one to one basis or in groups of other parents. They could then share this information with others and they were also prepared to act as interpreters for their community.

They spoke very positively about their culture saying, "You're who you are and it's all accepted (the disability). Somalian women tend to feel badly if their child is disabled but Somalian culture is inclusive – the children play together and go to school together and learn from each other. Children with behavioural problems tend to end up as ok adults. Schools are inclusive."

Conclusion from this section

It is important for people from the Somalian community that leaders are worked with to ensure a wide range of information is able to be passed on to people in the community.

Training should be offered to the leaders on a range of topics.

Computer access should be available to the community either through the leaders or another agreed way.

Further work is needed to identify needs of newly arrived families of disabled children from other cultures and ways of meeting those needs.

Traveller Families

We made contact with Lucy Koniarska, Consultation Officer with the Midlands Save the Children, who was newly appointed and agreed to try and find out the needs of traveller families with disabled children. The following is her report:

In January 2003 the Birmingham Children's Fund project Support Services for Traveller Children were presented with the unusual situation of there being no mobile families with children in the city of Birmingham. There were Traveller children whose families had been recently housed and who were being supported in schools. None of the families that the service is currently in touch with have disabled children. However there are a few children who are recognised as having special educational needs and are under SENCO; and a couple of children who show behavioural problems which are currently being diagnosed by an Educational Psychologist.

In response to Contact a Family consultation leaflet one of the services Advisory Teachers wrote:

"What I would like Birmingham Children's Fund money to go towards is the provision of extra places readily available for Traveller children who arrive in Birmingham carrying a statement of Special Educational Needs from another LEA and requiring placements in Special School - short or long term. Extra support should be identified and financed promptly, thus ensuring reasonable continuity of education for those few identifiable pupils who move into or through the area."

Conclusion of this section

It has not been possible to consult directly with traveller families and more work needs to be done to find out the views of traveller families with disabled children or those with additional needs. However the need for extra support services to be put in place quickly is clear.

Consultation with Children

Introduction

This part of the report was produced by Martin Goodwin, a freelance consultant commissioned by Contact a Family to undertake the consultation with disabled children and siblings. This is an extract from his full report.

Aim of consultation:

- To consult with *disabled children* and siblings regarding the opportunities or service provision they consider important, the leisure opportunities they currently pursue and would like to access in the future

Consultation Method

The consultation took place at each family event organised by Contact a Family in February and March 2003.

In order to complete the consultation, the facilitator worked with disabled children and siblings on an individual/small group basis. Those who took part were asked to complete a picture record of what they do not and what they want to do in the future. The picture record was then used to design a t-shirt.

Children were encouraged to participate in the consultation by using a wide range of materials to:

- Explore the consultation questions and enable disabled children to give their view.
- Enable children who communicate using different methods and media other than spoken or written word to take part.
- Ensure that children could participate as independently as possible.

The following range of equipment and materials were used:

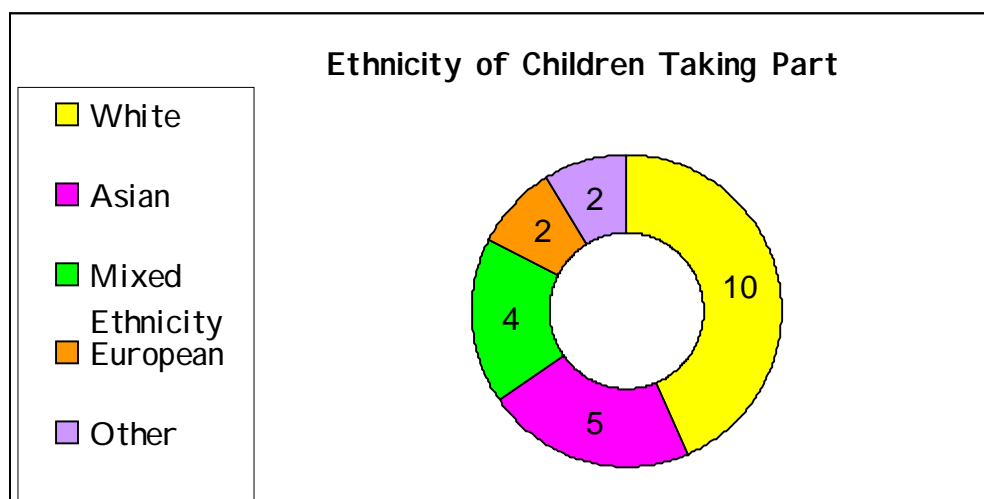
Digital camera, Colour printer, Polaroid camera, Laptop Computer, Microsoft Publisher, Widget software, Change Picture Bank Pre printed symbols - activities/ feelings/ places/ issues, Magazines/Catalogues, Tape recorder with microphone, Video camera, Glue, Scissors, Drawing paper, Poster Paper

Children's work was then used so that we could count and describe the types of activity disabled children and siblings of disabled children presently engage in and wish to pursue.

About the Children who took part

No of disabled children and siblings participating at venues

Venue	Number of Disabled Children	Number of Siblings
Shard End	5	5
Camp Hill	3	4
Sutton Coldfield	3	3
TOTAL	11	12



Children taking part had the following range of conditions.

- | | |
|--------------------------------|---------------------------|
| Autism | Polycystic Kidney Disease |
| Severe Learning Disabilities | Sturge Webber Syndrome |
| Speech & Language Difficulties | Downs Syndrome |
| Cerebral Palsy | 22 Q 11 Deletion |
| Visual Impairment | Heart Condition |
| Williams Syndrome | Epilepsy |
| Gross Motor Difficulties | |

NB: Some children have more than one condition.

Findings

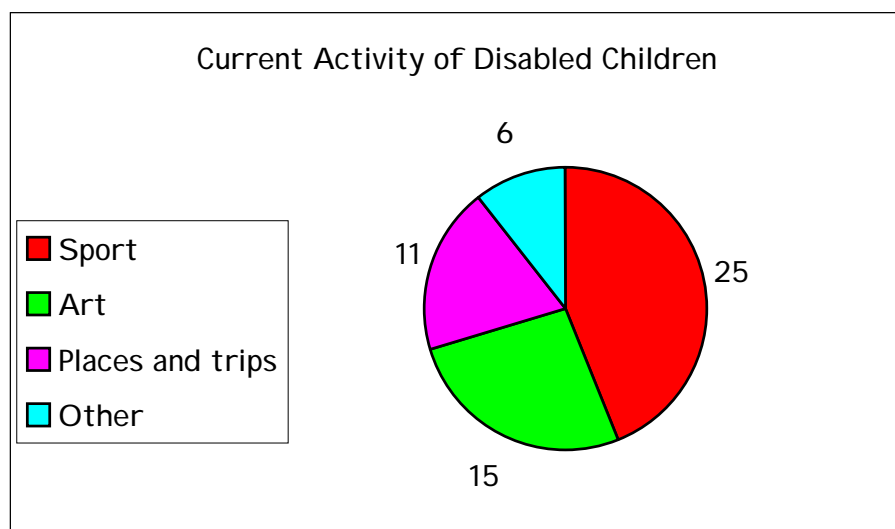
The findings are organised into Disabled Children and Siblings with findings from research including quantitative information and qualitative information gathered from informal discussion with children. Names of children case studied have been changed for confidentiality.

Children were asked what they do now and they produced pictures using a range of materials to portray their current range of activities. Activities were grouped into categories of Arts, Sports, Places & Trips and Other.

At the end of all the events activities were counted under each category.

As most children were involved in more than one category of activity charts will show more activities than children.

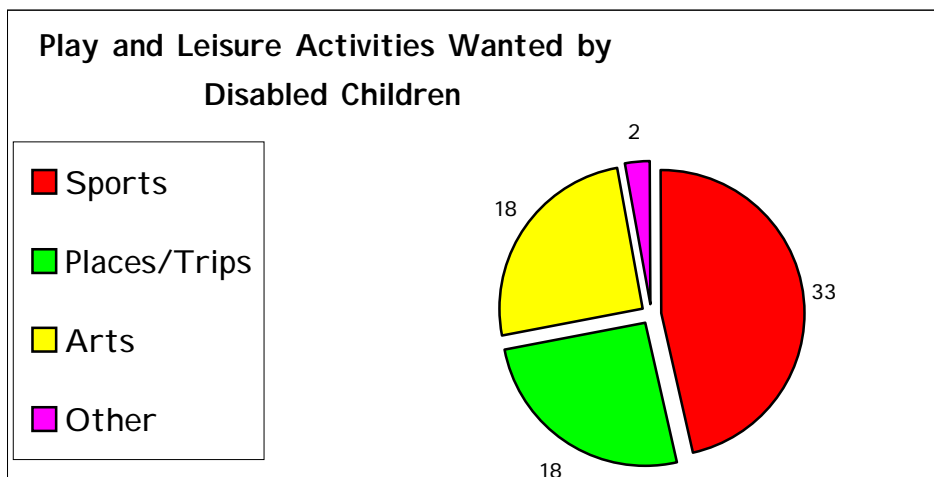
The first chart presents disabled children's current engagement in leisure activities.



The most common types of activity are as follows:

Category	Specific Activity
Arts	music and craft
Sports	swimming and football
Places/Trips	zoo and library
Other	computer

Play and Leisure Opportunities Disabled Children Want



The most wanted types of activity under each category are as follows:

Category	Specific Activity
Arts	Guitar and singing
Sports	Swimming and horse riding
Places/Trips	Park
Other	Playschemes, parties and bouncy castle

Case Studies

Catherine is 13 years old and indicated through pictures what she currently does and how she feels about the activity. She currently does



She also showed 18 pictures of other things she'd like to do, including;

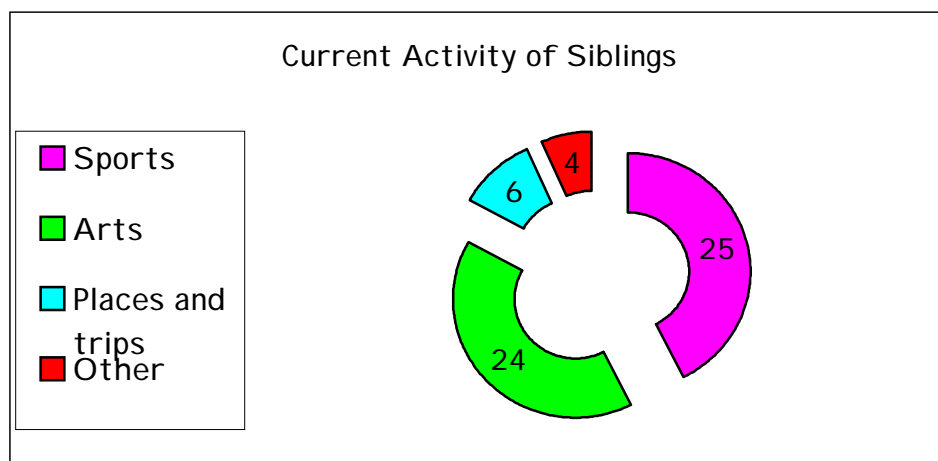


Joe is aged 8 and has Attention Deficit Hyperactivity Disorder. Currently Joe likes to bounce, run and jump and these activities are pursued in isolation around the home. In creatively thinking about what Joe likes to do and what interests and stimulates him it may be possible for Joe to go trampolining and parks so that he has freedom and space to run around. It may be possible to enable him to participate in ordinary community activities and to develop friends through meaningful activity and develop some social skills.

This illustrates the point that disabled children want more opportunities to try different activities and are not currently getting those chances.

Siblings

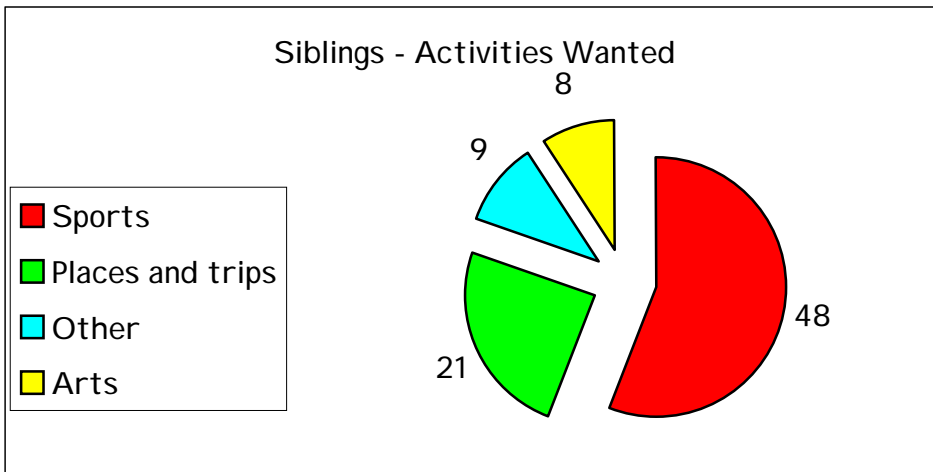
This chart shows the activities currently done by siblings.



The most common types of activity under each category are:

Category	Specific Activity
Arts	Music, dance and art
Sports	Swimming and football
Places/Trips	Park and cinema
Other	Computer and club

The chart below represents types of leisure activities siblings want to pursue.



The most wanted types of activity from each category are as follows:

Category	Specific Activity
Arts	Art
Sports	Horse riding and skiing
Places/Trips	Museum
Other	Computer

Siblings Case Study and Discussion

Ben is 8 years old and has a brother with autism. He currently spends time playing with friends and football or cricket with his brother. Whilst Ben enjoys these activities he additionally commented that they are around the home and mainly within the family. He also talked about wanting to go swimming and ride a bike.

The following is an extract from the conversation between Ben and the interviewer.

Ben

"I help with my brother... I do what he does at the weekend because he enjoys it and it keeps him happy....but I do enjoy it."

Interviewer

"What would you like to do, if I could wave a magic wand?"

Ben

"If I could do something every weekend it would be to go camping and going to a computer club. If I couldn't do that then I would like to go climbing."

Jennie is 12 years old and has a brother with a heart condition. During the discussion she said that most of the things she does are based around the home and the things she would like to do are away from the home and possibly in a club.

These examples show that whilst contented with current leisure activities a sibling may put their sisters or brothers leisure activity before their own priorities and wishes. Siblings also want to have opportunities to get involved in leisure and play outside of the home, but may not currently have the chance to.

Summary of findings

Our research has shown the following:

- Only 2 children spoke about time with friends.
- Disabled children and siblings want more choices in the opportunities available and to have experiences in the wider community.
- Some siblings do not have much opportunity to spend time independently of disabled brothers and sisters.
- Parks are only mentioned by a small number of disabled children in their current activity, but most want to be able to go to parks.
- Disabled children and sibling opportunities to access leisure and play are restricted.
- Disabled children currently do activities that isolate them from others such as computer, keyboards, music and craft. They want to do more sports activities and have trips and outings.
- Only three children spoke about time with friends.
- Siblings want fewer arts activities and more sports and outings.

Disabled children and siblings have asked for more sports activities, opportunities to go to parks, have trips and outings and they need to be able to have the opportunities to develop friendships. They want the same things that their parents are saying they need for their children.

Big Thanks to the following individuals and organisations who helped us complete the consultation:

- All the lovely children we met who shared their energy and creativity – events were never dull!!
- All the parents who took part – completing the survey, coming to the events and giving your views and especially the parent's forum who did a lot of thinking around the issues.
- Sonia Tooray – our Asian Parent Representative for giving us her expertise in planning the events and helping find very good contacts.
- Irene Grosvenor and Jean Ganderton who helped us at all of the family events with face painting and clearing up – we couldn't have done it without you!
- Martin Goodwin who completed the Children's Consultation.
- Doreen Wiffen-Jones from Birmingham Childrens Fund for helping with the Parents Forum events.
- Gemma Wood for doing all the hard slog with inputting data and keeping us going!
- Helen Thompson and Jo Winslow from Contact a Family South London.
- Nageena, Marisa and Anna from Birmingham Signposting Service who helped at our Family Fun Events.
- Bam and Kanchan who worked hard doing mendhi painting.
- Lucy Koniarski from Support Services for Traveller Children.
- Sue Tavares from the Naseby Centre for helping us think things through!
- Hilary McCarrick and Rosie Weaver for checking the survey.
- Everyone at the Disabled Children's register for sticking labels for our survey to go out and to everyone in the post room for franking.
- Staff at Shard End Community and Leisure Centre, The Bordesley Centre, and Fellowship Hall.
- Nachda Sansaar Bhangra Dancers for their energetic performances.
- Everyone at Playtrain.
- Healthy Appetites for keeping us fed and watered!
- Pauline Shelley for helping me with the report.

And last but not least huge thanks to Kirsty Mayo, Regional Information Officer who worked with me to carry out the consultation work.

Other Material We Used

SNAP - Report on a consultation to research the support needs and preferences of Asian parents who care for children with disabilities and special needs in the Greater Sparkbrook area of Birmingham.

We're Listening Children's Consultation - Written by Martin Goodwin - a full report of the consultation work undertaken for We're Listening.



For more information about the work of Contact a Family West Midlands or for further copies of this report please contact:

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