

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

contact a family

for families with disabled children

A consultation, funded by Birmingham Children's Fund, with disabled children, families and siblings to find out how they would like resources allocated in 2003 to 2006.

We're Listening Summary

Background to the consultation

Contact a Family carried out the consultation for Birmingham Children's fund to help them get parents views on how resources for disabled children should be allocated for 2003 to 2006.

From January to March 2003 we consulted families in the following ways:

A survey of 4,456 families through the Birmingham Children's Disability Register

Two parents forum meetings

Three Family Fun Events

Consultation with disabled children and siblings

One to one interviews

The summary of findings and recommendations is included in this document and the main report is now available from Contact a Family West Midlands.

Summary of findings

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

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.

Play and leisure for children

Leisure is usually the most requested service for families.

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.

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

Drop-in desk for information (49%)

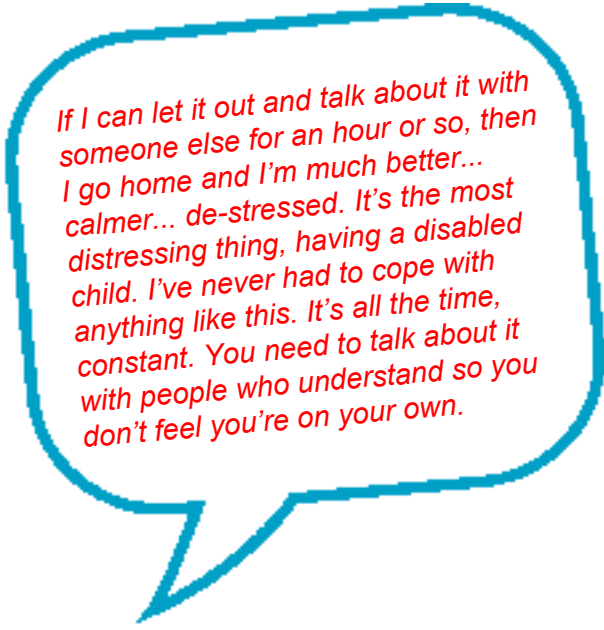
Local directory of services (48%)

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.



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... de-stressed. 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.

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

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:

Accessible information delivered in a variety of ways

Emotional support in caring for their child

Breaks from caring responsibilities

Inclusive mainstream and specialist leisure opportunities for their children

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 contact details 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

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 joint funded by education, social services and/or 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

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



Leisure Services

A strategy is needed in Birmingham to increase play and leisure opportunities for disabled children and their siblings. Providers 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 for 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. 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.

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