

Cefnogi Cynnar
Early Support

contact a family
for families with disabled children



Parent Support Group Survey 2012

Contact a Family provides advice, information and support to all UK families with disabled children, regardless of the disability or health condition. Through a national helpline and family support service, we provide advice on any aspects of caring for a disabled child, including help with benefits and educational issues. We help families get in touch with others in similar situations. We do this through family fun days and parent events, encouraging families to get out, make lasting friendships and support each other.

Introduction

A key cornerstone of Early Support is mutual support for parents of disabled children, having the opportunity to meet with other parents in a similar situation, to share experiences and to learn from other each other.

There are an increasing number of ways in which parents with disabled children can make and maintain contact with each other: online via social media sites such as facebook or twitter; as part of national or international support groups; at conferences and event for specific conditions etc.

However many parents still want to meet locally with other families in the same situation as them and one of the longstanding ways of doing this remains local parent support groups.

Contact a Family Wales as part of our involvement in Early Support wanted to find out about the role parent groups play in supporting families across Wales

This report presents the findings of a parent support group survey undertaken in early 2012.

Methodology

The views of parents and professionals across Wales were canvassed using an online survey via Survey Monkey (a paper version was also available). The survey was available in both English and Welsh and promoted in the Contact a Family Wales Spring newsletter and via our electronic mailing list.

Aims of the research

The purpose of the survey was to collect information about parent support groups throughout Wales for families with disabled children, mainly for children under 5 years of age. The aim was to capture parents' experiences of attending such groups; the benefits and drawbacks of taking part as well as what can help keep local support groups going.

Findings

We had 51 responses to the survey from parents (92%) and professionals (8%) from 11 counties across Wales. The majority of parents (70%) currently belonged to a local support group.

Child's age:

The majority of parents (63%) had children 0-11 years of age with most of these between 6 and 11 years, so we were unable to focus on the under fives as originally intended. The majority of groups respondents attended did not focus on a particular age range.

Child's condition:

By far, the highest number of parents had children with autistic spectrum disorders (68%).

Condition	Number of respondents
ASD	35
ADHD	5
Down's Syndrome	5
Other Conditions	7

Reasons for attending support groups:

Parents and professionals reported a variety of reasons for attending support groups. These fell into the following main categories:

To share their problems, gain advice and support

"When we meet we discuss our children or just have a relaxing hour away from the children, with an emphasis on just being people and not special needs parents! We support each other with information and advice sharing and many of us have become lifelong friends"

"Chat, offer each other support socialise without being judged, learn new things, have discussions, problem solving"

"It's online so you can post problem or comment on someone else's problem anytime day or night"

To feel like a normal family where they and children are not judged

"To socialise - kids can play in a safe environment where everyone understands and they feel comfortable together. Parents provide mutual support and encouragement, have a listening ear so we can let out fears and frustrations, and exchange useful information"

To undertake activities e.g. day outs, pamper days for the parents, going to cinema

"They meet informally at soft play centres or swimming, we can attend as a family, the children all play whilst we parents enjoy chatting to other parents in similar situations to our own"

"They arrange exclusive play groups for our children"

"Opportunity for the whole family (children with special needs AND their siblings) in play centres across Cardiff, Newport, Caerphilly, also day trips during school holidays. Separate events for older children/young people with additional needs. Siblings Group that goes for meals, bowling, cinema, etc"

For their children to play in a safe environment

"Safe play area for children where parents can relax"

Inviting guest speakers from relevant organisations to talk about specific issues or how they can help parents

"General chat and coffee; speakers invited along to talk about specific areas of interest"

An understanding environment

"They provide non judgemental environments for the children to play, socialise and be themselves"

"It means we can take our children without the worry of them been looked at for being different. Mums and Dads can get together and share issues they experienced"

General and condition specific groups:

Two thirds of the groups parents reported attended were general support groups with the remaining third for a specific condition. 9 parents attended groups for Autistic Spectrum Disorders (ASD), 3 parents attended ADHD groups and 1 parent attended a Down's Syndrome group.

Benefits of attending support groups:

Parents and professionals reported a range of benefits to attending support groups. These fell into the following main categories.

For mutual support

"Support, friendship, advice, information is all shared within the group. I can discuss things with other SN parents and they understand whereas my others friends might say they do but they don't"

"To be in an environment of like-minded people who understand the issues involved in bringing up a special needs child, and also to be in an environment where I'm never judged"

To pass on experience

"I attend so I can pass on things I've learnt along my path, so others don't have to spend so long fumbling in the dark. Helping others out makes going through the hard stuff easier you feel like there has been a point to it"

To feel less isolated

"To realise we are "not alone" and to be able to relax and have fun as a whole family"

"Before my involvement with this group, I did not know any other families who lived with autism"

"Being part of something like this makes you feel less isolated as being a parent of a special needs child can be very lonely sometimes"

"Can't overestimate the support that you get from good support groups, they are a lifeline"

To take part in family activities

"Somewhere for children to go to and not feel the odd one out. Enormous support that parents give to one another"

"It benefits my son he is a shy child and has low confidence and social skills but when he goes to these groups he fits in so well"

"Specialised activities for children, enable children to try and make friendships, those with significant learning disabilities are not going to have mainstream friends. Real support for parents"

"It means my child can play and express himself without prejudice. I can sit with parents who are in the same situation as me. We look after each other"

"People should come along to groups like Thrive it has been a real god send for our family and we have all made some great friends"

Drawbacks to attending support groups:

Although the majority of comments were positive, there were a number of drawbacks reported by parents and professionals to attending support groups.

"I find non-specific groups better than say just groups for ASD children. I find some parents to be rather clicky (some have very set beliefs on things such as diet/vaccinations/interventions and get very touchy if you disagree or have another opinion) whereas I feel that as a parent of a child with additional needs we are all in the same boat so to speak, with similar worries"

"Concerns, needs etc no matter what your child has been diagnosed with or if they haven't even had a diagnosis yet. I feel that for a support group to be successful there shouldn't be questions that are 'taboo'. One ASD group I was part of forbid members to discuss vaccinations and diet interventions for example. When you are in the early years of ANY diagnosis you want to find out as much information as possible so you can make informed decisions and choices for your child and not be dictated to"

"They are often in working hours and can cut off parents working a full time job from attending them"

Barriers to attending support groups:

8 parents reported that they did not attend a support group but most of these said that they would like to. The main barriers appeared to be a shortage of support groups in their area, poor information about what is available and time constraints.

"I haven't found any that I am able to attend"

"Not aware of any groups as yet. My son is not diagnosed with anything apart from poor speech development. I receive alot of help (practical and emotional) through speech therapy though"

"Finding where it is and has to be to local and during sociable hours"

"Time pressures and other commitments"

"I live in a valley. Too far to travel to attend groups elsewhere due to home commitments as a single parent. Need groups locally"

"(No) information through clinics such as CAMHS"

"A social group to meet other parents and training/learning about autism, however child minding problems may prevent our attendance"

"(There need to be more) groups for any disability and not just specific conditions"

"Groups start up but fizzle out maybe not looking at the long term or lack of attendance always parents starting them may need backing and support from associations etc"

"I would like a support group where you can take your children if you need to, that way they don't always have to be during school times which is when most working parents work"

Setting up and maintaining support groups:

A number of suggestions were made about what elements are needed to set up and maintain support groups. These fell into the following main categories.

Funding

"NAS seem to run lots in Conwy and apparently this is because Conwy Council give funds, only residents get chance to go. Don't know why Gwynedd doesn't support this"

"Financial reasons are really why we meet online no money to hire anywhere"

"More funding would help"

Support from professionals

"Help with getting good venues, help with publicity"

"Firstly it would be necessary to establish whether parents in the area would wish to support a group. Then general guidance would be needed to establish a suitable location, preferred time for people to attend and frequency of meetings. Would meetings be purely educational or more social functions? Who would come to the meetings, just parents, extended family, and the disabled children? Would siblings be welcome and how would they amuse themselves?"

"More professional support of our group would be great possibly allowing us to meet in our local children's centre. Getting professionals to make new families aware of us etc"

Suitable venue

"(Providing) free venue costs"

Promotion

"Volunteers getting word out and finding suitable venue"

"Help with publicity, venues, funding - and a high level of interest/commitment from parents/supporters"

"Advertising and publicity, facilities, financial support"

"There doesn't seem to be a way of finding out about opportunities, it's up to us to search. Recently found a local club that our child enjoys but it's purely voluntary and only I found out by chance. I think we need one place with a search engine where all parents can be directed to stuff in their area"

"A national link to resources or groups where a new group can thrive and prosper by knowledge from other groups on support, funding, survival, pros and cons"

Conclusion

The overwhelming majority of parents reported a positive experience of attending support groups; emphasising the benefits of mutual support; meeting other families in the same situation; passing on their experiences and feeling less isolated.

Others went on to describe some drawbacks and a number of barriers to attending groups; such as a shortage of support groups in their area, poor information about what is available and meeting times not ideally suited for working parents.

Government initiatives such as Early Support, Families First and Flying Start could improve the outcomes for families with disabled children by helping to set up and maintain support groups, especially for the under fives which are underrepresented across Wales.

About Contact a Family

Campaigning

We campaign for rights and justice for all families with disabled children.

Freephone helpline

Our freephone helpline for parents and professionals across the UK is staffed by trained parent advisors. It provides information and advice on a wide range of issues including welfare rights, education, short breaks, local services and local support.

Publications

We produce a wide range of publications including newsletters, parent guides and research reports, helping parents and professionals to stay informed.

Linking families

We put families in contact with others whose child has the same condition for support. We link them through existing support groups, our online social networking sites or using our one-to-one linking service.

Medical information

We produce the Contact a Family Directory – the essential guide to medical conditions and disabilities with information on over 440 conditions and UK support. Each entry provides an overview of the condition with details of support groups where available.

One-to-one support groups

We offer both practical and emotional support on a one-to-one basis to families with disabled children, through our family support service, volunteer parent representatives and through our local offices.

Local, regional and national offices

Contact a Family has a number of offices around the UK providing local newsletters, information, workshops and support.

Getting in contact with us

Helpline 0808 808 3555

Open Mon-Fri; 9.30am - 5.00pm

www.cafamily.org.uk

www.makingcontact.org

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