



Contact a Family North East & Cumbria

Information Survey July 2011

Contact a Family North East produce regular e-mail bulletins and quarterly regional newsletters.

During May/June 2011, details of an information survey were included in three copies of the bulletin and in the summer edition of the newsletter.

The aim of the short survey was to gather people's views on the information they receive from us to determine improvements that could be made and to find out what people think about the current formats with regards to content and suitability for families and paid workers throughout the North East and Cumbria region.

Method

The Survey Monkey website was used to devise the on-line survey. Within the newsletter, we also asked anyone who did not have access to a computer to contact us for a paper copy if they wanted to take part; no one took us up on this option.

Nine questions were included to capture both brief details of the people responding to the survey and their views on the information they receive. All responses were anonymous.

A total of **96** surveys were completed though not all respondents answered every question.

Key Messages from Survey

- 66% of respondents to the survey were parent/carers of disabled children
 - Of these, 71% have a disabled child aged between 6 and 12
 - 63% of children and young people have an Autistic Spectrum Disorder and/or Attention Deficit Hyperactivity Disorder
- 93% of respondents think the quarterly newsletter is useful to them; 97% think the email bulletin is useful
- More than three quarters of respondents want information included on Leisure Opportunities, Parent/Carer events and Parent Support Groups
- The number of respondents who have accessed services and attended events as a result of finding out about them from the bulletins and newsletters highlight their value and importance to local families and professionals working with families

- A wider range of areas in the North East and Cumbria region need to be included to ensure as many families as possible have the opportunity to access leisure opportunities and relevant events
- It is apparent from a number of respondents who work with families that they pass on information from within the email bulletins and newsletters to a wider audience through their networks which hopefully benefits more families in the region and not just those in direct receipt of the newsletters and bulletins

Next Steps

It is really helpful that so many people completed the open text questions with some helpful suggestions, ideas and comments on the information they receive. Contact a Family North East will implement as many of these ideas as we can to ensure our bulletins and newsletters continue to prove as useful to families and workers as they appear to be so far.

Ideas/Suggestions for Improvements:

- Stop attaching flyers and documents to the email bulletins as respondents said that attachments can often be difficult to open and are too large for their email boxes – ***this has already been implemented and we now include more information in the body of the email and/or links to the website where people can obtain more detail if needed***
- Increase the geographical range of events and activities included in bulletins and newsletters as many people pointed out that they lived too far away to be able to attend these
- Some respondents mentioned the fact that they felt there were no activities and services specifically for some conditions including ADHD and Down Syndrome so we will try and source more details of local information about what is available for children and young people with a wider range of conditions
- There was a mix of responses as some people feel there isn't enough information for families of younger children and others said there wasn't enough for older children so we will try and ensure we include a good mix of activities for as many age ranges as possible
- As a number of people asked for more information on legal issues, rights of families and children, Special Educational Needs etc we will use the News section to try and link people to information available on issues affecting disabled children and their families available on both the Contact a Family website and those of relevant external organisations
- Other suggestions for contents included grant giving organisations and holiday information so again, we will seek to include more details on these within the bulletins and newsletters as appropriate

Detailed Analysis

An analysis of each question follows:

Q1 – Where in the North East & Cumbria do you live?

Area	Number	%
County Durham	22	24
Cumbria	1	1
Darlington	3	3
Gateshead	13	14
Hartlepool	0	0
Middlesbrough	4	4
Newcastle	16	17
North Tyneside	5	5
Northumberland	11	12
Redcar & Cleveland	1	1
South Tyneside	7	8
Stockton-on-Tees	6	6
Sunderland	4	4

Q2 – Please tell us who you are

	Number	%
Parent/Carer	67	66
Family Member	4	4
Local Parent Support Group	4	4
Paid Worker	16	16
Other	10	10

The “other” respondents were:

- Disabled person
- PIP
- Foster-carer/special guardian
- And local parent support group
- And paid worker
- Also a parent as my son had a physical disability but sadly died at 16 years 4 1/2 years ago
- Police DSA Rep
- FIS Newcastle
- Carer Support Worker
- Voluntary

Q3 – If you are a parent/carer, please tell us the age of your child with a disability or additional need

	Number	%
0-5	9	16
6-12	39	71
13-19	5	9
20+	2	4

Parent/carers were also given the opportunity to say if they had more than one child with a disability/additional need. Responses received were:

- 13 and 16
- 7 and 10

Q4 – If you are a parent/carer, please tell us brief details about your child’s disability/additional need

- 44 respondents said their child had an Autistic Spectrum Disorder and/or Attention Deficit Hyperactivity Disorder
- Other conditions mentioned several times were Down Syndrome, Cerebral Palsy, Dyspraxia, Learning Disability, Global Developmental Delay
- A smaller number of children have Visual or Hearing Impairments, Chromosome Disorders, Speech and Language difficulties
- Rarer conditions mentioned were Nephrotic Syndrome, McCune-Albright Syndrome, Left Sided Hemiplegia, Rubinstein-Taybi Syndrome, Microcephaly and Noonan Syndrome.

(A full list of conditions is included as Appendix One to this report)

Q5 - What type of information do you receive from Contact a Family North East? (Tick all that apply)

	Number
In Contact - Quarterly Regional Newsletter (by post)	42
In Contact - Quarterly Regional Newsletter (by email)	41
E-mail Bulletins	62

Q6 - How would you best describe the information you receive?

	Extremely Useful	%	Quite Useful	%	Not Really Useful	%
Newsletters	36	46	37	47	5	6
E-Mail Bulletins	31	48	32	49	2	3

Please add more details here if you would like to explain your choice

- It is mostly for children over 8, not a lot for younger kids
- E-mail is less costly and greener
- Not much for children in this area, we are the far west of Gateshead on the border of Northumberland
- I do wish we could see the relevant part of the region to us. I don't really want to see the rest of the North East's news
- Very informative; local information and events
- There is not much going on in the Stockton area, lots at Newcastle
- I have only just started to receive this information
- Keeps me informed of events that I can attend, either with my child or for me to gain information relating to his condition
- Regarding information sent out on funding released by the government for disabled children, there were not specifications about who may be entitled to this. Could you kindly list and specify all categories of people that may be entitled to claim this funding. Example - Adults who are normal and under full time care as a result of having mental capability of a child. Etc
- It provides our group SNAPS to pass in information to our families
- Like to keep up to date with current matters and changes
- We keep this information should a parent call and require activities for children with disability. It helps us refer your organisation to them
- There's nothing of any relevance to children with Down syndrome or families with a member who has Down syndrome. I suppose this is driven by demand, but there are several groups in the North East so I am surprised there is no representation at all in your information
- It's a great way of finding out about things that I otherwise would not be aware of
- I want more activities across the patch and not just around the Newcastle area
- Great information of what's happening local, and regionally. You do an excellent job!!!
- Information is normally in relation to other areas
- Keeps me up to date with activities and helps me with funding when newsletter puts in companies that will fund you for holidays or items I need and can't afford being a single parent
- Am interested in what is available in area, even if not directly relevant to us

- No Information - unaware service existed
- It is a central source of information. Not only have I accessed more leisure and play opportunities for my child in my immediate area, I have accessed other events which I would not have known of a bit further afield. Good source of information available to fit your circumstances it also give me a lot of reassurance that there is so much going on around us and that support is out there. The bulletins are timely
- I also work for the local PCT and manage a database of health related support groups and find the bulletins are a good source of information on support groups that may benefit our patients and carers. I also use the information for my own benefit
- It is good to see what is on in the region although some activities are too far from where we live to attend
- I realise it has a big area to cover Contact a Family and a lot of disabilities. However, there are only a few sections that are particularly relevant to our family. Also, a lot of the events/activities are for usually nearer the Newcastle area and not at all local to us
- I find the news letter brilliant, a great source of information
- Because it covers such a large area some of the groups are not relevant to me, but I like knowing what's happening around the region even if it may not be suitable for my own child

Q7 - Please can you give us an example of how you have used information you have received within the bulletin/newsletter e.g. have you attended an event/leisure opportunity as a result of seeing it advertised within the bulletin/newsletter?

- Attended cinema with my child
- Attended Cinema screenings previously
- I've attended a Wills & Trusts Seminar which was very useful, and Contact a Family were very helpful in assisting with local contacts to assist with our DLA claim. I've also just recently found the info on the last email bulletin about I CAN, the children's communication charity, very interesting and intend to follow this up as local SLA support is almost non-existent
- Attended events
- Information has been passed to parents/carers who do not receive their own copies of bulletins/newsletters. Parents/carers have subsequently attended events
- Not in two years used to get good ones for us nothing applies much especially for working families
- Normally I contact or email some body to take part in some events
- Bulletins have been useful for local events my son can go to
- Help with increasing my knowledge which I have passed onto colleagues
- We have used the information we received in the news letters to attend different venues and to go to places suitable for our daughter in the holidays
- The bulletins keep me in touch with what's happening both in my area and in other areas within the North East region

- Due to not driving I can't access the activities I wish there were more near Hexham and Prudhoe
- County Durham short breaks
- I have attended a conference, I have taken my family to the free screenings in the past
- We have attended leisure events thanks to the newsletter
- I have attended a few events and it good to no what's going on
- I have sent information to be advertised within the bulletin
- N/A because I'm always working when the events are on, or they are for older children
- We attend Cumbria Wheelchair Sports club events in Carlisle, this was advertised in your newsletter
- Simply good to be informed & feel supported although very little goes on close to home
- I have attended many events as a result of the information received, Mainly conferences for me but also events for my son e.g. the Doctor Who exhibition at the Centre for Life
- They helped me to understand what was wrong with my son and that it WASN'T my fault
- I have sign posted colleagues who are affected to yourselves, as a result of limited information I had, I advised for them to find out from you if they might be eligible for your support
- Have attended events. Parent's conference
- Used personally and professionally very very useful
- This recent email provided me with a reminder to book up at the Open Day event in Middlesbrough for parents/carers to let people know more about SNAPS. So that's great big thanks as I had overlooked the date!! Also a massive thank you for including SNAPS information
- I share the info with other parents
- Yes
- Attend play schemes and events
- Attended an event
- To disseminate to parents & carers
- I have ordered information from Contact a Family (on how the budget affects benefits) after getting a bulletin
- I haven't been able to use it at all
- I forward to my professional contacts plus Local groups of families I also make use of the info for outreach opportunities which have been extremely useful and successful
- I have passed information on to parents and members of staff about events and activities
- Normally yes I contact or email and request a place for the event/leisure.
- Use to attend event but finding it very hard now to go anywhere as my little one wont go out of house and I have a baby to look after too and I find it hard to get babysitter for my baby
- Have followed up attending a seminar / event
- Training mostly, the activities are toooooo far away to access
- Most in my area, but hopefully branch out to other areas

- I would love to attend more events etc but I don't have access to transport
- I have attended parent conferences in the past
- Attended outing to activity
- Used the information as a "springboard" to showcase our own group's activities
- I have not been able to attend any of the events as yet as most require a diagnosis first but I have found the information provided useful and it has made me more aware of the kind of things that are available once we have diagnosis
- I have attended cinemas play schemes got funding from different charities
- I attended a "Making Changes Together" conference at Ramside Hall Hotel. I also attend many events with the children in school holidays
- I pass on all information to the parents that I work with. I also like to read the information as it helps me in my role and keeps me up to date
- Event dates
- I have passed information on about events to colleagues and other professionals
- Yes, but can't give specific examples
- I take the newsletter to Team Meetings to share with colleagues and to show parents information who do not know about CAF
- Useful to know what is going on around the area for children with disabilities
- Have attended leisure and play events as a result of doing so, have then made more contacts with other people for other events/play opportunities have attended a Wills and Trusts seminar There are loads of training events that I would like to go to but as I study at University full time and am a single parent with limited child care I do not - when I finish University I will be able to follow these up
- Passed information to Information, Guidance and Support Workers to pass to their client base for use
- I have attended an event advertised in the bulletin and also add new groups to the database I manage at work
- Yes - have attended an event at the Alan Shearer Centre and cinema events
- Attended events; kept up to date with what's going on: passed information on to other parents
- Occasionally attended the subtitled cinema showings that used to be on
- I have attended the cinema screenings when they were in Darlington - however, Newcastle is too far to travel for us for the cinema. I have been to some of the courses/conferences which I have found useful and informative
- I have been able to attend a few events because of the newsletter
- I have booked for workshops and I ordered the fact sheet on how the budget affects families with a disabled child which was really helpful
- Looked up information on website or attended event that did not know about previously

Q8 – What types of information would you like to see included in the newsletter/bulletin?

	Number	%
Leisure Opportunities	72	85.3
Parent/Carer Events	69	82.7
Parent Support Groups	62	73.3
Resources & Publications	47	54.7
National News	32	34.7
Other	12	13.3

The “other” suggestions were:

- Education issues
- Parent support groups that are not on mornings only, as this presumes parents do not work, which I must admit most of the parents in my son’s school with the same condition, do not, but it is not fair on working parents who cannot attend day groups, to get help and advice
- Praise for voluntary groups of parents who try to make a difference, like MCT in County Durham
- Holiday clubs
- Please clearly specify the groups and ages of people you can support
- details of disabled friendly holidays
- The more information passed on the better
- Legal; disabled person’s rights and the law and what they should be allowed to access i.e. further education. Needs to be more on what legal standing a person has
- I would like to see parent support groups that are not condition specific as I feel unable to attend any that have been previously advertised and run
- Stories about how families cope
- Volunteering opportunities
- Information about disabled children's rights, and educational supports, like websites etc
- More county focussed as opposed to Newcastle focussed
- Places that help you with funding
- However, you do all this already!!
- Training for paid workers and volunteers
- Basically, all of the above. Also, advice/support on Tribunal Issues etc
- Places to apply for grants etc
- Events for siblings (or which include siblings)

Q9 - Please let us know more about what you think about the bulletin/newsletter. We need your views to help us improve the way we send information to you and the kind of information you receive

- Find the newsletter very useful, things happening in local area which may be of interest
- Very worthwhile
- I find the email bulletins very useful although the events etc do tend to be Newcastle based, while we live in Teesside
- Your recent change of format has been useful - made the information easier to scan. National information is useful but only when translated as local impact
- I would like to receive information for days out etc or what's on in Tyne and Wear for children with ADHD/ODD
- It would be better if you added more information about the rights that children with disabilities have in this country
- More localized activities for children with ADHD and there families
- The bulletins give me just enough info so that I can find out more if its of interest to me The newsletters are informative for national and regional information
- Informative
- Should be more info about the various conditions that exist. More info about SEN statements, how to get a CAF, more info on Lead professional, the Lamb Inquiry, the Green Paper from the CON-DEM government, help parents can get from children's services
- I think you have got it right. You can only send out what you know about. I think people really appreciate information on accessible leisure activities, conferences, seminars and local support groups. Anything specific to the disability affecting their family is useful. Sometimes we get repeat information from different sources; this is good too
- I think the newsletters have lots of information
- I am happy with the current format
- I think the bulletin/newsletter is fine the way it is; it is easy to read and understand
- I find the regional information a little too broad and would like to see a more local "county version" with more local news and events as unable to drive and use public transport
- Gives people a good choice and the bulletins are quiet frequent, which I think is good
- Very informative
- Well done CAF on your quick and easy to read guides and info Also CAF NE your local staff are a credit to you and I always enjoy working with them!
- I think it is extremely useful. Well done
- Its fine the way it is. The only thing I would say is that when including information about events, please ensure that any restrictions are mentioned e.g. if an event is only for Newcastle residents, please say so
- It's excellent! Especially like the Contents button to skip to relevant section, thank you for all your hard work

- I like it, I just find the information and events tooooooo far away to be practical
- The newsletter is perfect it gives all accounts of what is going on in different areas
- I think its good, not complicated
- I think the emails are really helpful as we have the information to hand straight away. There are lots of things happening in the region such as cinema screenings and days out that I would never have been aware of before I started receiving the emails
- I think it is very informative and I am pleased with how it runs would like to see more stories from families competitions the kids can enter and more cinema trips if it can be funded
- I find the e-mail bulletins very useful, however would like to see more County Durham information included if possible. The national newsletter is very helpful for keeping up to date with national changes
- Quite happy with current newsletter. It gives all required information succinctly and clearly
- I make sure that I read the bulletins and the newsletter as I rely on it for local information. I don't know where else I can get this kind info that is specific to our area. I really like the Cerebra magazine for information but local events are far more important to me because limited opportunities to play and socialise can be very isolating
- It's fine it seems that a lot of the leisure things are always in Newcastle and Sunderland not Teesside so much however I do remember seeing a lot more recently that has been Teesside based
- Sometimes the addition of attachments to the e-bulletin, which is contained in the body of the newsletter, is confusing and time-consuming to read. It should all be either in the e-bulletin or attachments as opposed to a mismatch of both. Some of the attachments, which have been sent recently, have been illegible. Perhaps more care before dispatching is needed?
- Not all information I receive is relevant to me but I have made some useful contacts over the year
- I think it is valuable information which is convenient to read on an email
- Newsletter is full of interesting articles. Keep up the good work
- Really useful and informative. Keep up the good work
- I think in the main it is a good newsletter and I know that Kathy and Sarah are at the end of the phone/computer should I need them
- I'd like more pictures please. It would be nice if they were in colour, but I understand that the costs would be prohibitive
- Useful although not always clear whether can attend events not in your home area

Appendix – Full List of All Responses

Full list of conditions listed for Question 4:

- Cystic Fibrosis and Diabetes
- Down Syndrome
- Autism
- ADHD
- ADHD
- Down syndrome
- My son has Down's Syndrome with learning difficulties and speech/communication problems, leading to frustration and behavioural issues
- Timor behind left eye which is regularly monitored. Nf1 and learning disability. Mobility problems.
- ADHD/ODD gets very very angry and aggressive, has global learning problems
- She has Down Syndrome and is going to mainstream school with a support.
- ADHD
- My child has Cerebral Palsy and severe mental learning disabilities.
- Cerebral palsy, epilepsy and associated learning difficulties
- Nephrotic syndrome, diabetes and coeliacs
- Autism, Absence Seizures and severe Learning Delay plus non verbal
- Our child has global delay, severe learning disability & social/emotional problems. Getting assessed for ADHD & autism.
- ASD, ADHD, Dyslexia
- Undiagnosed! However for us to gain some help my child has been placed under the Cerebral Palsy umbrella. Physical disability proving more difficult now that my child is growing. Bi-lateral hearing aids and poor vision are just two of the other problems my child copes with on a daily basis. We get no help however have a near future appointment with social services to hopefully get some sorted.
- Autism, ADHD, Asthma and Arthritis
- ADHD
- 12 has mobility problems the other has learning difficulties
- Asperger's Syndrome
- The eldest has a McCune Albright syndrome with Polystotic Fibrous Dysplasia. The younger one has Aspergers syndrome
- ASD plus many associated difficulties.
- Autistic
- Left sided hemiplegia and cerebral palsy
- ADHD/ASD/Dyspraxia
- Issues surrounding adoption, Reactive Attachment Disorder, Dyspraxia, Learning Difficulties, Behavioural Issues
- ADHD Language processing
- Autism and ADHD
- Autism

- Rubinstein Taybi, ASD and non verbal
- Autism, ADHD, Dyslexia, Anxiety, Dyspraxia, PDD and Depression
- Microcephaly, Dyspraxia, Global Developmental Delay, Speech problems
- Dyspraxia, ADHD, ASD
- My child has Global developmental Delay and requires help across all areas of physical, emotional, cognitive and social development
- Chronic physical needs.
- Emotional and behavioural problems. Diagnoses of Attachment Disorder, ADHD, XYY Syndrome
- Chromosomal abnormality (not linked to any known condition) causing learning disability, motor skills problems, speech & language problems, dyslexia and dyspraxia
- She has Down Syndrome
- ADHD and ASD
- Daughter has ADHD and ASD, son is ADHD
- ASD, ADHD, migraine at the moment she wishes she was dead as her class mates say she has no life and will never have a life as she isn't normal
- Aspergers and recent diagnosis of ADHD
- ASD, ADHD, learning difficulties, dyspraxia
- ADJD and odd
- ADHD, Dyslexia, Dyspraxia
- My daughter has communication and language problems and is being investigated for possible autistic spectrum disorder.
- Autistic and behaviour problems
- ASD
- My son has severe DCD, Aspergers, traits of ADD and PDA, Challenging behaviour, anxiety and sensory issues along with sleep issues.
- Downs syndrome
- Noonan Syndrome and Autism
- ASD, Dyspraxia, Speech delay, motor coordination problems.
- Autism & learning disabilities
- ADHD, ODD, ASD
- Cerebral palsy
- One child with autism, one child hearing impaired
- Autism and ADHD
- Autism, LD, sensory dysfunction (I mention this aspect as it dominates all areas of function)
- Alex (7) has ADHD and receives DLA Clayton (10) has growth hormone deficiency
- My son has an under developed corpus callosum which means he has global developmental delay.
- Cerebral palsy and Hearing impairment
- Profoundly deaf
- Autistic & Learning Difficulties/no language
- Autism spectrum disorder, bowel condition, migraine, panic attacks

- Rare chromosome disorder causing leaning disability, motor skills problems, developmental delay, speech & language problems, dyslexia, dyspraxia
- 8 yr old has quadriplegic cerebral palsy and is non verbal and Gastrostomy fed. Full time wheelchair user. 13 year old has severe learning difficulties and occasional wheelchair user
- Autistic
- Aspergers Syndrome