

Members Feedback Questionnaire 2011 – Results



Positive Change for our Children and Young People
with Disabilities and Special Educational Needs

1. Membership

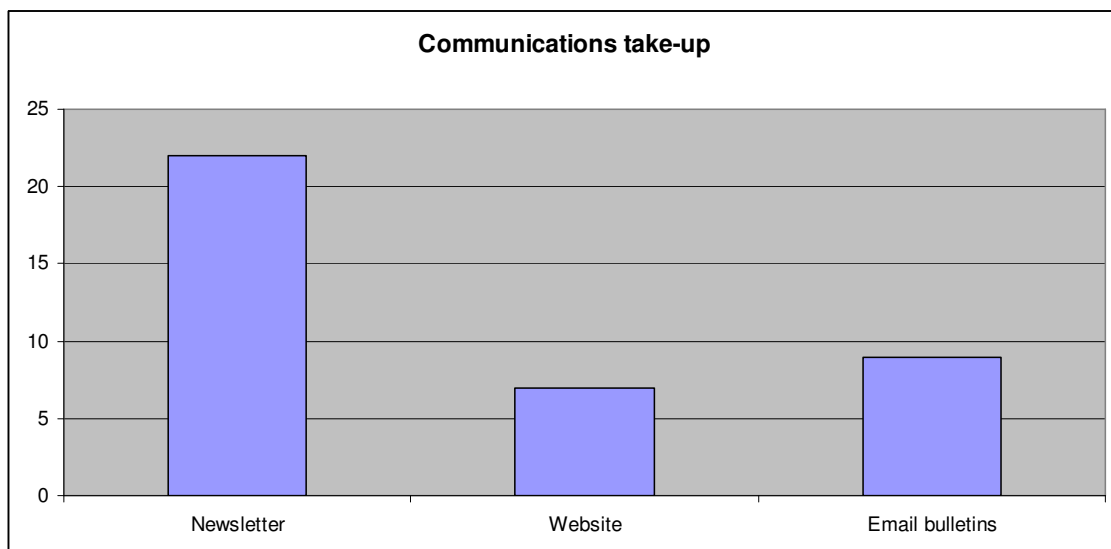
22 people responded, 21 of whom were members (1 did not say whether they were).

2. Where did you hear about us?

- Friends x3
- SIGN x3
- Support group
- School SENCO
- Beighton Clinic
- Sheffield Deaf Children's Society (SDCS)
- Asperger's Children and Carers Together (ACCT)
- INDEX & parent
- By chance in a magazine
- Sheffield Autistic Society

3. Communications

- **100%** of respondents read the **newsletter**.
- **32%** access the **website**.
- **41%** read **email bulletins**.



Most useful/interesting: *(Most respondents named several things.)*

- “Did you know” information, e.g. on benefits and discounts x7
- All of it x 5
- Local news x4
- Changes to local policy and provision x4
- Personal stories, tips and advice x3
- Education issues/SEN x2
- National news x2
- Facts and figures
- Allowances (updates)
- Interesting web pages
- Seeing how parents together can bring about change
- Opportunities to meet other parents
- Support and access to groups / supported breaks
- Email bulletin & web forums

Least useful/interesting:

- Website, facebook page and email (no computer access)
- Duplicate information I may have read in other newsletters

What would make you more likely to read our newsletters, emails and website?

- Nothing, I do anyway
- Being up to date, like the new layout, as a booklet, likely to keep it rather than sheet which would get recycled
- I want to read and know about what is going on in Sheffield about disabled children
- More targeted to my concerns
- A day in the life of – children living with different conditions, example junior school day for boy with autism

4. Fun day, conferences, workshops and meetings

- 32% had attended events, 68% had not.

Best things about events: *(Most respondents named several things.)*

- Opportunity to enjoy time as a family x3
- Meeting other parents / families with children who have special needs x3
- People are approachable / understanding x2

- Finding out what is going locally x2
- Speaking to professionals / feedback x2

“There is something for us that is relevant to our family needs. Good to have fun together. Feel as if something can be done and others feel the same. Not on your own.”

Things to change:

- “Fun day – organise catering so that families go at different times. i.e. half at 12.00, half at 12.30. Children found queue difficult, also would have been able to find somewhere to sit.”
- “Workshop at St Mary's church – didn't find clear signs or welcoming directions, when we signed in we were directed to two rooms with other organisation and yourselves, not to workshop.”

Next time, respondents would like to see:

- More people being involved
- Electronic note taker
- A “how do we?” info stall with simple answers to questions like “How do we apply for direct payments”, “How do we fill out a DLA form?”, “what is SA, SA+ A statement?”, “How do we get a PA for our child”
- 4 to 6 weeks' notice
- Some times outside of normal working hours

Reasons why respondents haven't attended events:

- **36%** said lack of time
- **18%** said they were not relevant/interesting
- **27%** said it was another reason. (This was 6 respondents.) Of these, 3 specified a reason:
 - Childcare
 - Fed up discussing my child's condition. It's nice to do normal things instead.
 - Didn't know about it

Preferred session times: *(Some respondents stated more than one preference.)*

- **41%** said during school hours
- **41%** said evenings
- **27%** said weekends

5. Benefits of member involvement

Respondents gave the following reasons for and benefits from their involvement with the Forum:

- “Useful information about SEN & council”
- “Found out about local / national policies and provision. Helps to understand and navigate the system. Support from other parents, a chance to help SEN parents’ voice be heard”
- “We have already fought most of our battles and just want to use our experiences to help others. Being involved also keeps us up to date with developments”
- “Attended a focus group on short breaks, found it interesting to find out other peoples views”
- “I like to be informed but will still support something I feel important like respite care at Rushey. It was good to work together to achieve something.”

Reasons why respondents have not got involved (*Several respondents gave more than one reason.*)

- **64%** said no time
- **32%** said no energy
- **Nobody** thought it was pointless
- **18%** said they did not feel confident
- **32%** (7 respondents) said it was another reason, of which one person specified:
 - Something has to have an outcome and a timescale for it to be worthwhile to me.

6. Interest in future involvement

- Being on our Management Committee – **1 person**
- Representing parents’ views at strategic groups (meetings with officers) – **2 people**
- Delivering disability awareness training for schools, professionals etc. – **6 people**
- Joining parents’ groups on specific topics, e.g. special educational needs – **5 people**
- Attending one-off meetings about specific issues – **5 people**
- Taking part in consultations – **4 people**
- Supporting other parents – **7 people**
- Helping with general admin – **4 people**
- Other – **1 person**: Translator – Lithuanian , Russian

7. What has been the best thing that we have done for you?

This was scored from 1-5, with 5 being the highest. The following scores are averages from all responses:

- Getting information about services – **4.77**
- Learning about your family's rights – **4.36**
- Getting training – **2.23**
- Meeting other parents at events – **2.36**
- Developing friendships and support networks – **2.50**
- Having fun at family events – **2.55**
- Feeling like your family belongs – **2.82**
- Getting emotional support – **2.59**
- Being able to flag up problems and have someone pursue them with decision-makers – **2.82**
- Being able to influence policy – **2.86**
- Something else – One respondent added "Having input".

8. Using Forum information to change things for your child

10 people listed the following information they had received from the Forum and used to benefit their child:

- "Passes for cinema, busses, Slice card"
- "Able to get cinema card, didn't know about Merlin tickets"
- "Family Fund, Plus One card, cinema card"
- "I have got up to speed on SEN"
- "Has enabled us to navigate the transition process with much clearer understanding of the issues and professional bodies involved. i.e. how the system works, and make it work better for you"
- "Applied for one off grant payment – short break grant which benefited family"
- "Cinema card / meeting magic wand / support for completing DLA claim form"
- "No but it has given us ideas for the future"
- "Not sure of publication but blue badge, radar key, short breaks, cinema pass, travel insurance"
- "Knowledge and up to date information has helped me feel more confident when speaking to professionals - school, SELT, doctors etc. The confidence in my own ability helps my boy in his everyday life"

9. Examples of good services

Sheffield Parent Carer Forum

- “You let us know about “with carer” travel permit. This is very good.”
- “Got a SEN booklet from Eva, very impressed & will help with casework.”

Short Breaks

- “Being contacted by letter by short break grant office, submitted a ball park figure for a two day break. Getting the grant and a follow up phone call to say they were increasing the amount to the maximum allowed. Brilliant and much appreciated.”

Advice services

- “Parent Partnership group tailored advice service – really helped me in putting together an appeal for assessment & statement. V informative & very helpful & interested me as an individual.”
- “Support from Langsett Citizens Advice re appeal over DLA motability. First point re blue badge / radar key.”
- “Carers Centre – legal advice. Parent Partnership – advice re review.”

Respite services

- “Good service from Mulberry Lodge, for my older child who is now 21. Good social worker.”

Health services

- “Dietician at Children’s hospital. Spent a lot of time going through our concerns, and were very supportive and reassuring.”

Education services

- “Service given by Autism teachers at Ryegate, we have been involved with the same contact since my boy was 3 years old and is now 9. she is supportive when needed with advice that’s practical and really works.”

Leisure services

- “Bents Green after school club is great as it’s a continuation of the kids’ learning & a vital chance to socialise (our child is very isolated). We dread our child leaving school as we don’t know how & where to meet other young people with LD / ASD.”
- “SIBS”

Other services

- “Help programme with the National Autistic Society.”

10. Passing on information

12 respondents (55%) said they had passed on information they had received through the Forum. They had passed information on:

- To other parents of disabled children x3
- To mums at school in the playground
- Through the SDCS (Sheffield Deaf Children's Society?) website, facebook & twitter
- About short breaks

11. What should the Forum concentrate on next year? *(Several respondents named more than one topic.)*

- Education x3
- Mainstream schools – staff training, awareness among pupils, help and support x4
- Statementing
- Post-16
- Transition 14+ to adult
- Childcare for disabled children
- Funding for trips/activities, what's available for families x2
- Respite / holiday clubs
- Every child matters
- Speech & language therapy x2
- Supporting parents in DLA claims
- Assessing funding for mental health and physical health needs
- Autistic spectrum disorder
- Organise more family events and meetings
- Do what you do now

"My main concern for the future is post 16 for my child. What is for him after school?"

"Helping to change schools' attitudes to SEN from being a problem that they have to deal with. Often the designated SENCO has to continue teaching duties while learning SEN on the hoof on a part time basis."

"SEND is never discussed and rarely addressed as an important everyday issue within schools. Disability Awareness Training is a priority. We must get more professional members or get consultants."

12. Comments, complaints and suggestions

- “Love the leaflet.”
- “Any information on ADD, dyspraxia and Asperger’s or how to get info would be great, so I can look at my own leisure”
- “I get 2 newsletters, one addressed to my son. Just one would be better.”
- “More information on any workshops / days to do with Autism or out of school help for autistic children.”
- “Very interesting speech & language article – my son has no language and felt had little support over years (now 12). Great campaign.”