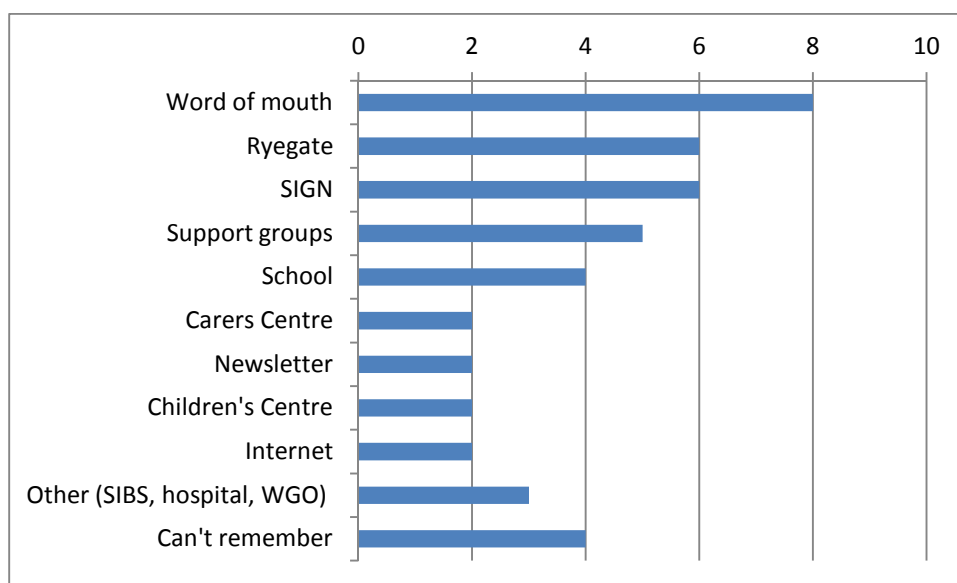


# Members' survey 2013

## 1. Participants

At March 2013, we had 682 full members (families) and 96 associate members (professionals and practitioners). The questionnaire was circulated to our postal mailing list and email list. We received 49 responses; 35 of these were paper responses and 14 were online responses. All but one respondent were full members (parents).

## 2. Where did you hear about us?

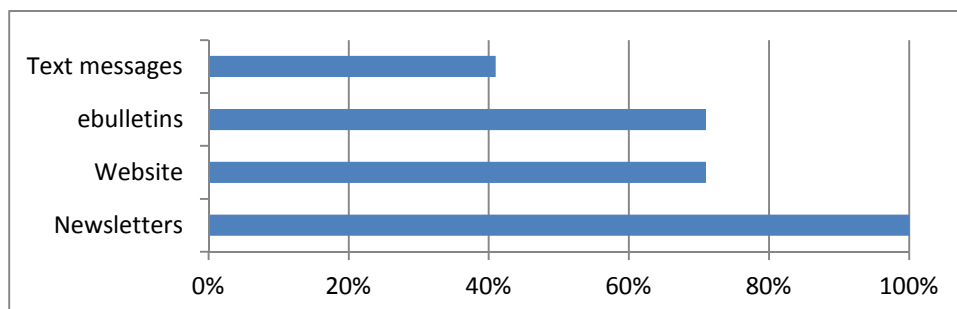


## Communications

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## 3. Do you read our communications?

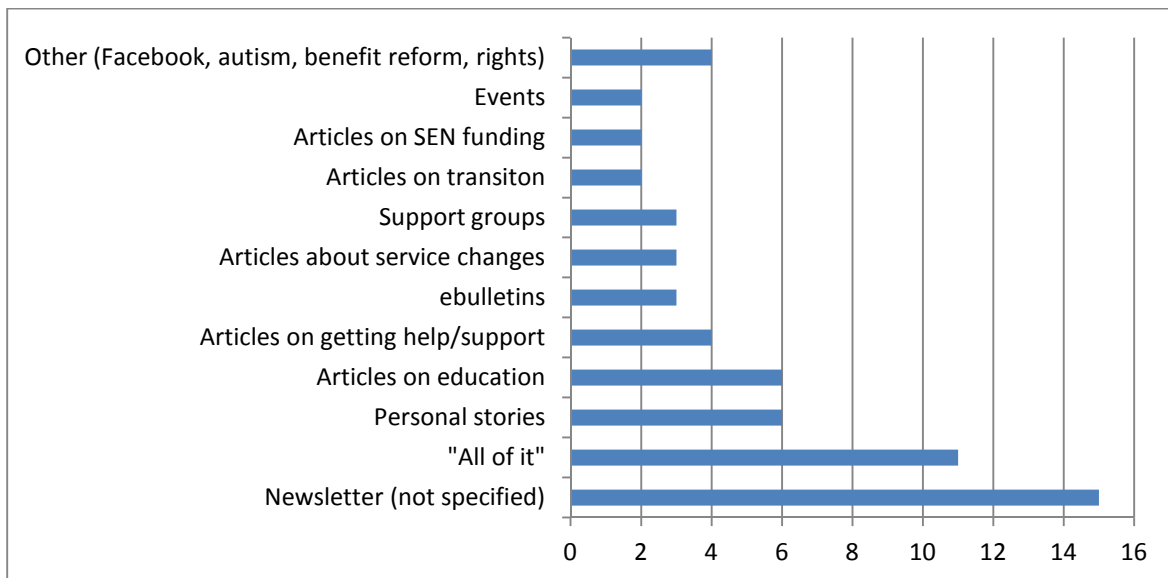
The newsletter was by far the most popular medium of communication, and was read by 100% of respondents. Unfortunately it was not possible to ascertain whether those who said they did not read the ebulletins/text messages did not do so because they did not find them interesting, or because they had opted not to receive emails/text messages.



#### 4. Which bits of our communications do you find most useful and/or interesting?

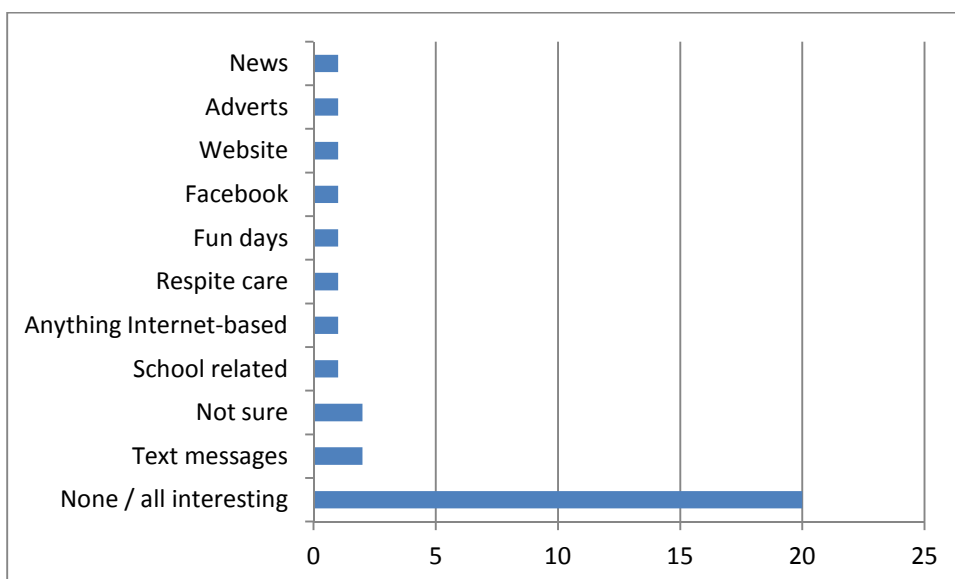
15 respondents mentioned the newsletter, without specifying particular topics, and 11 respondents said they liked “all of it”. The most popular topics were personal stories, articles on education, and articles about the help and support available.

*“I enjoy reading all the information in the newsletter, education updates, parents’ stories, what’s happening. All these features help and give you the feeling you’ve got support.”*



#### 5. Which bits of our communications do you find least useful and/or interesting?

Respondents mentioned a range of things, e.g. advertisements, Facebook, text messages. However, most of these were only mentioned once. 20 respondents said they found everything interesting.



## 6. If you don't read our communications, could you tell us why?

3 respondents selected "No time". Nobody selected "Too long" or "Not interesting".

## 7. What would make you more likely to read our communications?

There were eight responses to this question, of which four contained concrete suggestions. These were:

- more information about services
- more practical advice
- more personal experiences
- more positive stories, e.g. how well a child fits into mainstream school
- more professional's articles, e.g. speech and language therapy
- less political issues

### What we will do:

- Continue to publish the newsletter as a hardcopy version with a large circulation
- Include more personal stories in the newsletter, focusing particularly on "good news" stories
- Continue to report on education topics and particularly the SEN reforms which will come into force in September 2014
- Continue to provide information about the range of support available
- Include practical advice from professionals and parents

## Events

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### 8. Have you been to our fun days, conferences, training/information workshops or other events?

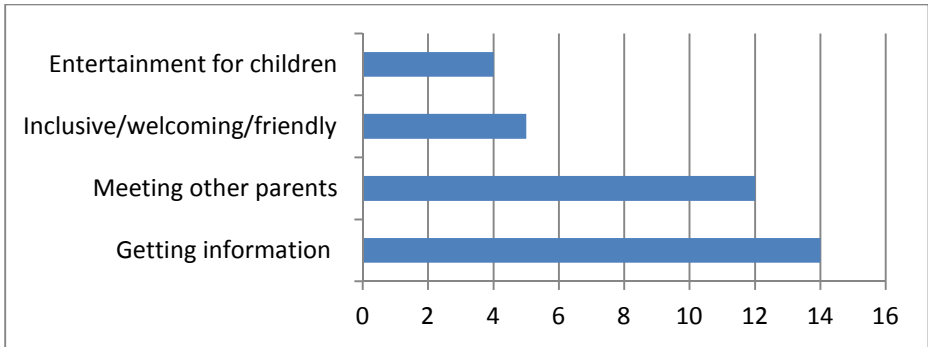
59% said "Yes", 41% said "No".

### 9. What are the best things about our events?

Getting information and meeting other parents in a similar situation clearly topped the list. Several parents also commented on how inclusive and welcoming they found our events:

*"Find out new up to date information. Everybody is friendly and welcoming."*

*"Meeting people who really understand and are not judgemental"*

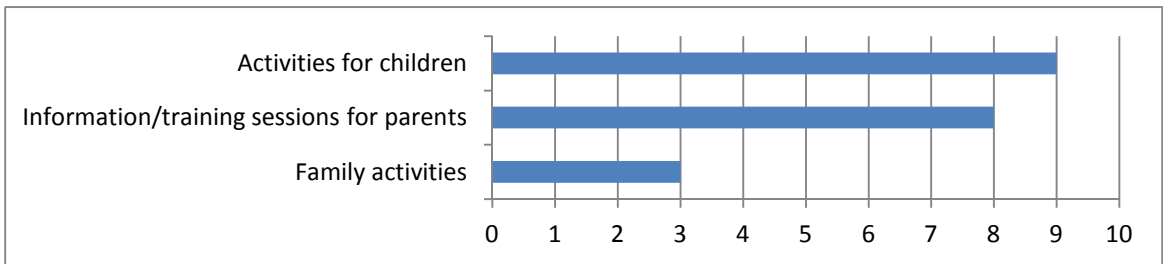


**10. What would you have changed about our events?**

- 4 respondents said they wouldn't have changed anything.
- 4 people said timings were an issue because events clashed with their work commitments
- 2 parents were unhappy with the pantomime (not at the right level for the children, poor production)
- Other suggestions included: provide BSL interpreter, warn parents if they are expected to speak in a room with total strangers, more time (especially to ask questions), more heating in venue, more leadership at meetings (not allowing individual participants to dominate discussions)

**11. What would you like to see next time?**

- 9 respondents mentioned activities for children; 3 specifically requested activities for older children/teenagers, and 2 requested holiday activities. Some parents wanted activities for children to run alongside information/training sessions for parents.
- 8 respondents requested information/training sessions for parents, and 2 of these suggested specific topics:
  - behaviour management
  - SEN reforms (single plan, local offer)
  - communication training (especially Makaton).
- 2 responses concerned location of events (requested closer to town / in Hillsborough area)
- 1 respondent suggested workshops for older children (post 14/16)
- 1 parent felt that training was mostly aimed at mainstream parents and therefore not relevant to her



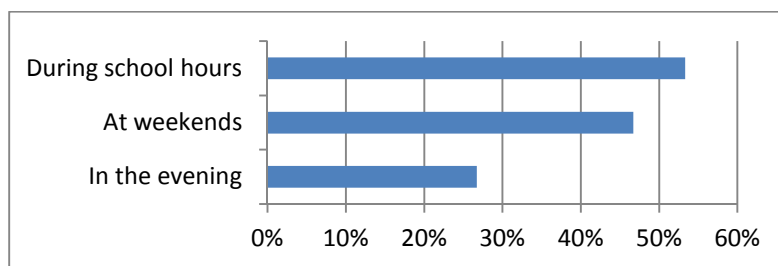
## 12. If you haven't been to any of our events, could you tell us why?

12 respondents said “No time”, and 2 respondents said “Not relevant/interesting”.

Other reasons given were:

- Only family knows of child's disability, so wouldn't want to see someone we know
- Timing of events (x2)
- Transport issues
- Attending events is very emotional and draining
- Child doesn't want to go to anything
- Childcare issues (children not in school)

## 13. When would you prefer to come to sessions?



### What we will do:

- Organise a family event during the summer holidays which will include activities for teenagers
- Bid for funding to enable us to provide more family events
- Include an article about activities/clubs for teenagers in the next newsletter (unfortunately we do not have the funding or the capacity to organise activities/clubs just for children)
- Try to find an amateur drama group which is able to work with us to produce a high-quality Christmas pantomime tailored to the needs of our children; unfortunately this is proving difficult. We do not have the funding to pay for a professional theatre company.
- Organise an information event about the upcoming SEN reforms in March 2014
- Bid for funding to enable us to provide parent training sessions on behaviour management and other topics requested by our members. At the moment we are limited to organisations/speakers who can provide their services free of charge.
- Continue to publicise relevant training sessions provided by other organisations
- Aim to run sessions at a range of venues and times. However, we are limited by funding (we get preferential room hire rates at St Mary's because we have our office there) and the availability of our staff and volunteers (not normally available in the evening and on weekends due to their caring responsibilities). We will offer to send notes, handouts etc. to parents who can't attend sessions due to work commitments.

## Participation and representation

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**14. Some of our members just want to be kept informed, others like to get actively involved by attending focus groups, representing parents at meetings with council officers, etc. If you have done so, please say why and what benefit you got from the experience:**

There were 14 responses to this question.

- 8 parents said that being involved in parent participation had helped to improve their knowledge and understanding.
- 4 parents mentioned opportunities to influence decisions and make a difference for all children
- Other benefits mentioned were support received from other parents, and improved confidence

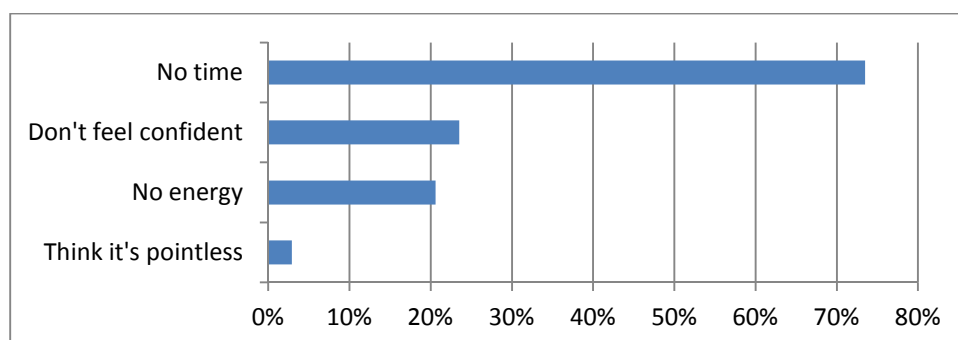
*"I was involved for a brief period before getting work. It really helped being close to people who have a good understanding of the issues and also working with service providers - it helps to see the 'whites of their eyes' and for them to see the realities faced by families!!"*

**15. If you haven't got further involved, could you tell us why?**

18 respondents cited a lack of time, 7 parents said they didn't feel confident, 7 said they had no energy, and only one person felt it was pointless.

Most of the freetext comments referred to a lack of time due to caring responsibilities and/or work commitments. Other reasons given:

- Too focussed on severe disability /statements
- Other people more able/skilled
- Don't like to listen to negative experiences



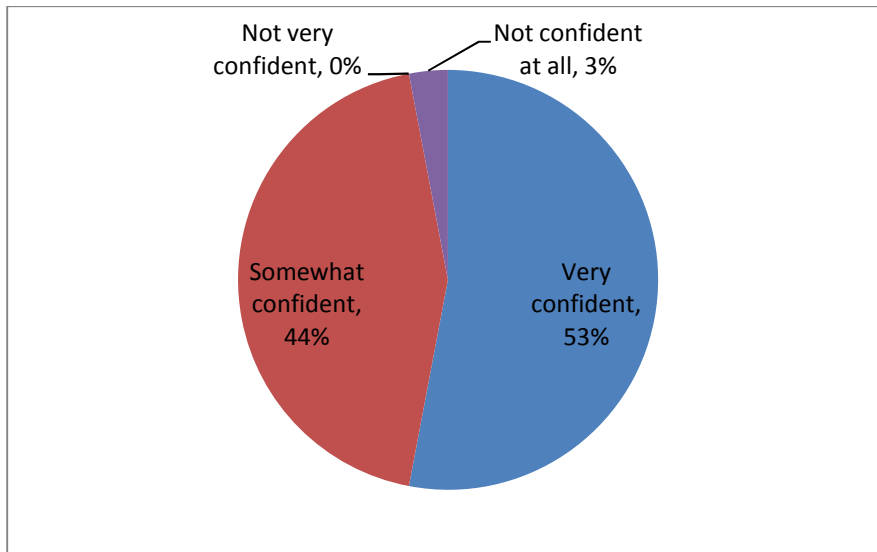
**16. How confident are you that the Sheffield Parent Carer Forum can accurately represent parents' views?**

An overwhelming majority (97%) of respondents said they were either “Very confident” or “Somewhat confident” that the Forum could accurately represent parents’ views. Only one person stated they were “Not confident at all”. This response is identical to the 2012 survey.

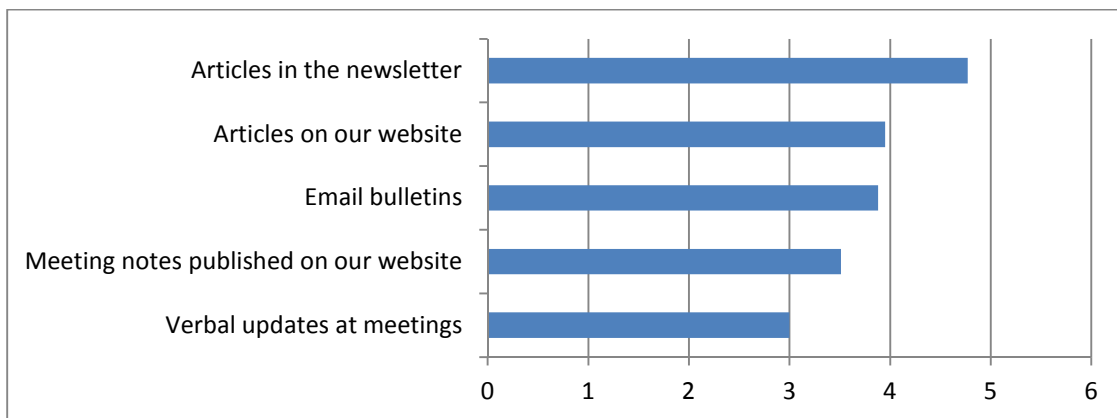
There were two comments:

*“There is a good cross section, high number families have a child with autism, physical disabilities not so well represented”*

*“More able kids with dyslexia and ASD less represented”*



**17. How should our parent representatives provide feedback to you from meetings with the local authority and the health service? Please say which methods you find most useful, by giving a score from 1 (least useful) to 5 (most useful).**



## What we will do:

- Use buddying, mentoring and training to help more parents to feel confident to get involved in participation/representation activities
- Map our membership against city-wide data and target any underrepresented groups through outreach
- Stop providing feedback from meetings by writing our own meeting notes for the website. (These notes get very few hits, but take a lot of time to write up. We will still publish official minutes where available.) Instead, we will spend more time reporting on specific topics via articles in the newsletter and on the website (signposted via email bulletins).

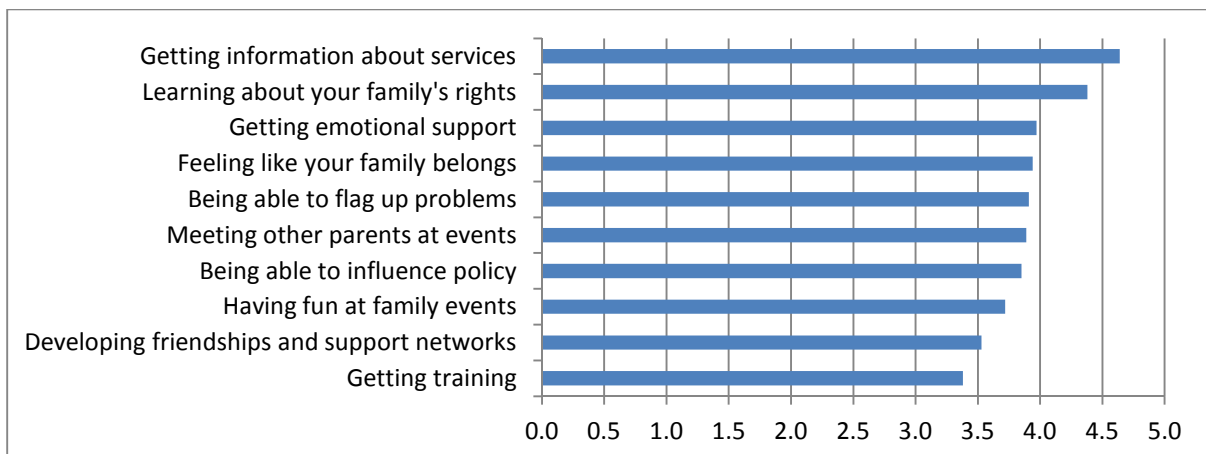
## Service evaluation and impact

**18. What has been the best thing that we have done for you? Please give a score of 1 to 5, or select n/a if you haven't used the service.**

As in previous surveys, “Getting information about services” and “Learning about your family’s rights” topped the list.

There were a few freetext responses describing services members would like to see; these related to:

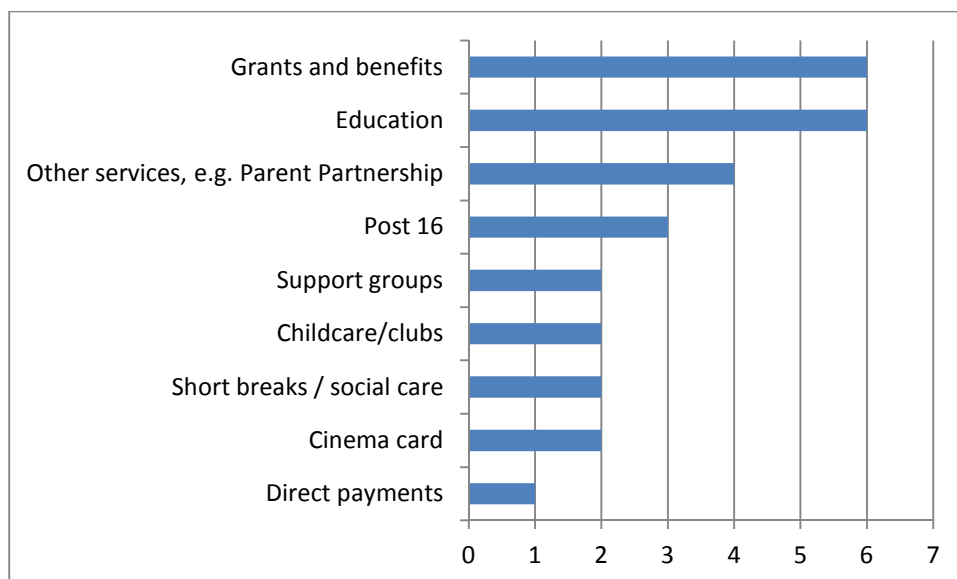
- Emotional support, particularly around the time of diagnosis
- Help with grant/benefit applications
- Information about child’s condition, their entitlements and future possibilities



**19. Have you used any of the information we have given you to change things for your child?**

64% said “Yes”, 36% said “No”. There were 28 freetext responses to this question which mentioned:





Several parents described how being well-informed helped them to stand up for their child's rights:

*"Nothing specific, but being well informed of developments really helps in meetings for our daughter. If the professionals see you are confident & up-to-speed, they treat you with respect."*

*"Used the information to get a statement and then to argue my child's case during review meetings"*

## 20. Please give an example of a good service - who was it from and what made it good?

### Ryegate

- Rygate - very supportive paediatrician who got us best professionals realising we had been mis- reassured?? for years
- Dr Desurkar, Consultant Paed Neurologist at Ryegate. Our daughter's condition is severe & (as she approaches adult services) we sometimes felt the doctors had given up trying to look for solutions. Dr Desurkar is very positive and a 'woman of action' ! She is looking for new ways to improve our child's health/well-being and doesn't take any nonsense from other services - THANK YOU DR DESURKAR!
- "Ryegate Centre when L was initially diagnosed

### Parent Partnership

- Parent Partnership Service - supported us at meetings, putting a case together
- Parent Partnership have always been helpful with my queries and advice and helping by going to school meetings with me.
- I once had a visit from a gentleman from Parent Partnership who helped me in finding a new school for my son. He was very helpful and his name was Derek Ainslow. He no longer works for the Parent Partnership. It is a pity, he was brilliant, he sorted things out and got a RESULT.

## Sheffield Parent Carer Forum

- Post 16 event
- The Transition Day
- SPCF
- I love the newsletter. I really enjoy having a read when the boys have gone to bed and I think oh I didn't know that!

## Family Fund

- Family fund has helped us lots
- Family Fund
- Family Fund, Cinema Card
- Family Fund, it has enhanced my child's speech, communication and learning level. The company granted my child technology equipment e.g. laptop and game equipment.

## Other

- Local GP nurse - patient and didn't make a fuss
- Pippa Murray (ibk initiatives): providing help with finding a PA; really took time to work out type of support i.e. personality/age of worker which would work with our child; unlike SNIPS who send anyone and hope it works
- CAMHs - superb support and ?? once obtained. Sorted our problem within 5 weeks with ongoing SNIPS accessed too.
- Transport admin team - very efficient paperwork
- Childcare
- Short breaks grant
- Person who came with me to a meeting at primary school, ensured my child's needs were uppermost in the minds of the teachers and that she was put on School Action Plus - something I'd never heard of!!
- Being kept informed on relevant matters - Jan
- Legal advice -> Carer Centre Forum/Workshop - Parent Carer Forum talks - ACCT
- SENCO at Abbey Lane Primary School and Meadowhad Secondary School - helpful, friendly, supportive and provided a good service for my children.
- At parent carer lunch we discussed problems with changing my daughters' school and also transition to secondary school and listened to others' views on different schools and paperwork and groundwork etc. My girls are now in specialist schools after a fight.
- Portage services in Sheffield are amazing and have been a fantastic help to us.
- Skools Out is very good. Individualised and flexible.

## 21. Have you passed on information you have picked up through us to anyone else?

74% said "Yes", 26% said "No".

6 respondents said they had passed information on to other parents, and 2 respondents said they passed information on to school. Others mentioned passing information on to Ryegate, Sheffield Autistic Society, ACCT, Carers and Young Carers Board and FLASh.

## 22. If you had to choose, what ONE issue would you feel the Parent Carer Forum should concentrate on this year?

There were 33 responses to this question. Many parents were concerned about the impact of the cuts:

- 6 parents mentioned concerns about changes to **welfare benefits**, particularly the change from DLA to PIP
- 7 parents highlighted issues around **education** (legislative reform, banded funding system, refusal to statement, lack of support in mainstream settings, primary to secondary transition)

Respondents suggested the Forum could provide **advocacy**, **training** and **meet-ups** and help with **form-filling**.

Other issues mentioned included:

- Speech and Language Therapy
- Activities for teenagers
- Support around diagnosis
- Finding the right school
- Transport
- Healthcare services (access and quality)
- Bullying via Facebook
- Autism Service
- Nursery provision/cuts to SureStart centres
- Information on short breaks.

The response about Facebook bullying was very worrying: *"I recently experienced parents at my child's school (an IR school) bully my child via their Facebook accounts. I did not know who they were and I could not defend him. Social networking sites are terrible and it creates bullies."*

## 23. Do you have any comments/complaints/suggestions about how we can work with you?

There were lots of positive comments, e.g.:

*"What you do is extremely useful. You provide a valuable support, which is greatly needed."*

*“Keep up the good work guys”*

*“Carry on and keep up the good work. You have a mammoth task with amount of information that there is out there and with the diverse needs of your members.”*

*“Well done for the good work you are all doing to uphold and uplift carers, children, siblings, relatives and families with people with disabilities of any form.”*

Suggestions included:

- Regular communication
- Send out information from Post 16 event as hardcopy
- Whole-family events and days out
- Support for parents who find using the telephone and social situations difficult
- Suggestions on how to obtain a Blue Badge (application turned down)
- Information about kids in mainstream secondary school, e.g. “a day in the life” article

**What we will do:**

- Continue to provide information about services, rights, grants and benefits via events and meetings, website, ebulletins, Facebook and newsletters
- Co-produce an information event for family carers about rights and benefits (“Knowing Your Rights” event on 13<sup>th</sup> June)
- Include a new “Ask the Lawyer” column in our newsletter
- Gather information about the support needs of parent carers (Support Services consultation on behalf of Sheffield City Council) and lobby for these needs to be met
- Continue to signpost parents to organisations which can provide practical support, e.g. with form-filling, appeals etc.
- Carry out an independent survey of the experiences of parent carers (“State of the City” survey)
- Respond to local and national consultations, e.g. Health and Wellbeing Strategy, revised SEN Code of Practice
- Continue to represent the views of parent carers at meetings of strategic groups
- Continue to collate information about issues reported to us by parents and inform service managers about any common themes/trends
- Continue to run focus groups to enable service managers to get direct feedback from parents
- Work with the local authority to co-produce the Local Offer, which should provide better information for families with disabled children from September 2014
- Bid for funding to run a 3-year project around improving disabled children’s access to, and experience of, healthcare services
- Continue to meet with the Autism Service through a parents’ reference group
- Post out a report from our Post 16 event