



Information, advice and support for parent carers

Consultation report

September 2013

1. Background

This report summarises work carried out by the Sheffield Parent Carer Forum in April/May 2013 as commissioned by Sheffield City Council. It forms part of a needs analysis in relation to the support requirements of families with disabled children in Sheffield.

Sheffield City Council will use the information gathered to decide whether current information, advice and support services for parent carers are meeting local need, or whether different or additional services are required.

2. Method

Parents' views were sought through a combination of questionnaires and consultation workshops. Hardcopies of the questionnaire (see Appendix C) were circulated to the postal mailing lists of the Sheffield Parent Carer Forum (514 families), the Sheffield Parent Partnership Service (180 families) and the Sheffield Carers' Centre (25 families). Both the Sheffield Parent Carer Forum and the Sheffield Parent Partnership Service included their annual satisfaction questionnaire in the same mailing, which may have affected response rates.

Response rates to questionnaires from BME communities are often low. In order to boost responses from BME parents and parents of younger children, we targeted specific nurseries and children's centres in Burngreave, Darnall, Sharrow, Broomhall and Tinsley. In addition, hardcopies were handed out at drop-in sessions of the Parents as Carers advice service. A link to the online version of the questionnaire was circulated to the email list of the Sheffield Parent Carer Forum (520 members) and advertised on the Forum's website. Due to duplication across these distribution lists, a definitive response rate is difficult to ascertain.

A total of **139 responses** (95 paper responses and 44 online responses) were received.

In order to obtain more detailed feedback and address the complexity of the issues raised, three consultation workshops were held during the week commencing 22nd April 2013. The workshops were held in different locations (Quaker Meeting House, St Mary's) and at

different times of the day (morning, lunchtime and evening) to enable a wide range of parent carers to attend. Participants received a £15 shopping voucher to offset any travel/childcare expenses.

The workshops were attended by **21 parent carers** who represented a good mix of children's age groups and impairments, school types, postcodes and ethnic groups (see Appendix A).

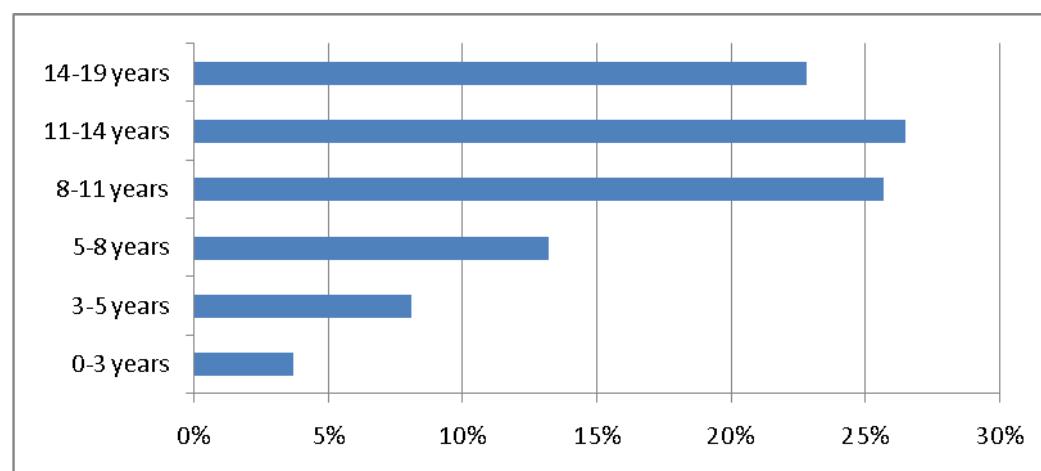
The workshops all followed the same format, which consisted of two sets of activities; the first focused on gaps in the range of services currently offered, while the second aimed to define the characteristics of a good support service (see Appendix B).

This report will focus on the remit of the commission, which was to identify if there are any gaps in the current range of services available. However, we recognise that families with disabled children can face a range of complex issues, which are often inextricably linked. As part of this work, families inevitably shared with us experiences, concerns and observations in relation to specific services. Whilst these are outside the remit of this specific piece of work, they are nevertheless of equal importance, and have been documented in a separate document (see www.sheffieldparentcarerforum.org.uk/page/consultations). We will feed this information back to senior staff in the local authority and in the health service, in order to ensure that the voices of parent carers can influence the design and delivery of services accessed by disabled children and their families.

Please note: Where percentage results are given, these are based on the total number of respondents to each question.

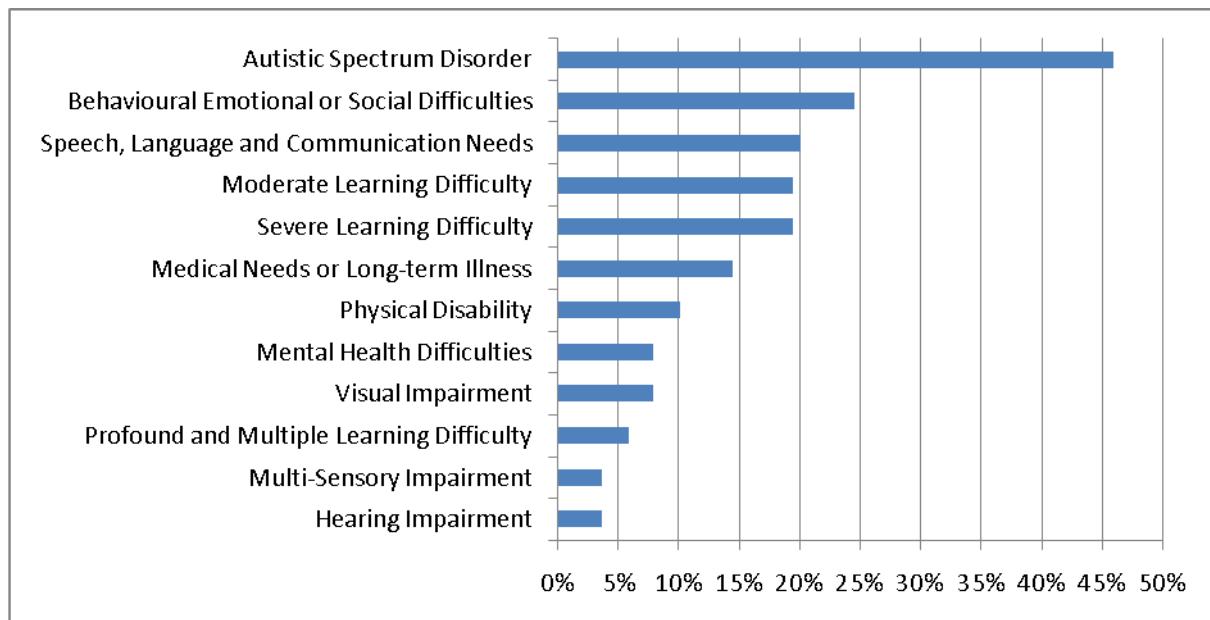
3. Demographic breakdown of respondents to questionnaire

3.1 Children's age groups



3.2 Children's impairment groups

Despite instructions to select only *one* main impairment, 48 respondents selected more than one option in this field. A further 45 respondents listed additional impairments under "Other". The breakdown below includes **all** impairments listed as **main** impairments:



Although autism is the largest impairment group among pupils with statements of SEN both nationally and in Sheffield, the percentage of parents of autistic children in our sample is higher than one would expect (46% in the sample vs. 32% of statemented pupils in Sheffield).

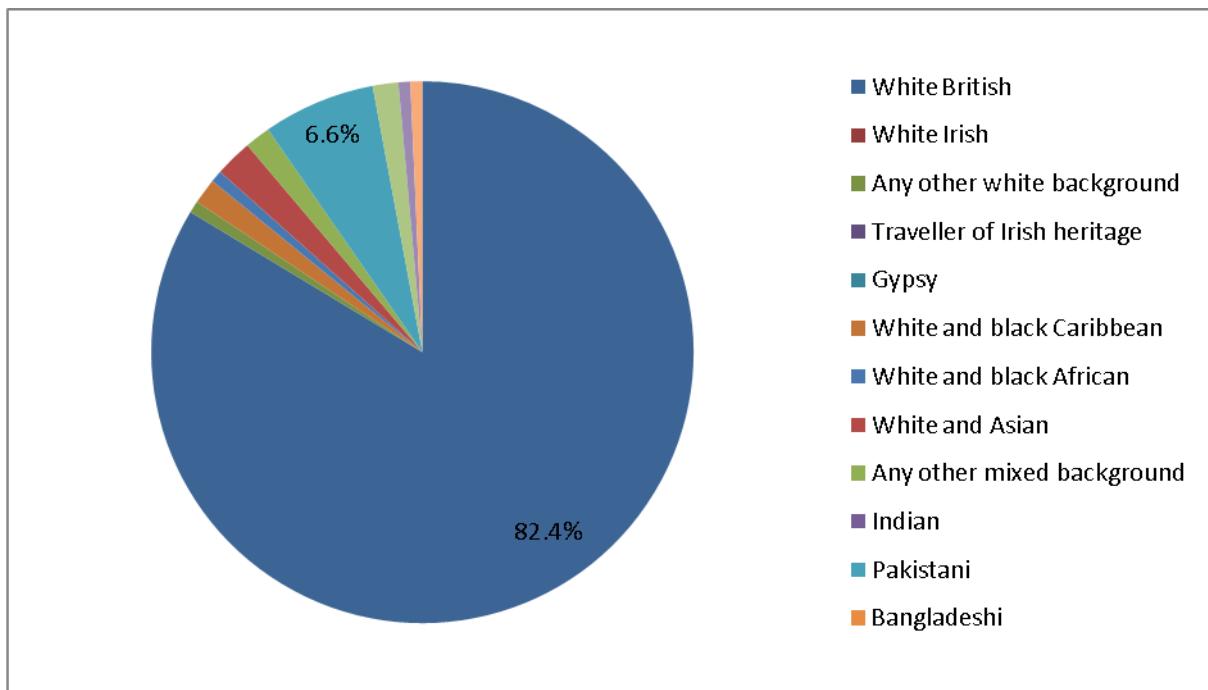
This overrepresentation of parents of autistic children in consultation/participation activities is a national phenomenon.¹ We hypothesize that this may be due to a particular lack of support for this group of children. For example, one questionnaire respondent wrote:

"Provision for our son with Diabetes is good with most needs met and an improving service. However, it is the opposite for our son on the autistic spectrum. The system doesn't meet his speech and language needs. We regularly meet with a lack of understanding about his condition and needs. The state secondary school, although good, struggle to support sufficiently at times as they aren't sufficiently funded or trained for individual children's needs. Trying to support our son on the autistic spectrum is our biggest challenge and worry. Note - we met with a Psychologist in October 2011 at Ryegate to discuss issues and they suggested that intervention was required and we are still waiting to hear from them. Obviously we have had to deal with the issue without the support that we were told was appropriate."

¹ In a survey conducted by Contact a Family, 68% of parent carer forums in England said that autism was represented by a significantly greater number of members of their forum. (Strengthening Parent Carer Participation: The National Picture 2011-12)

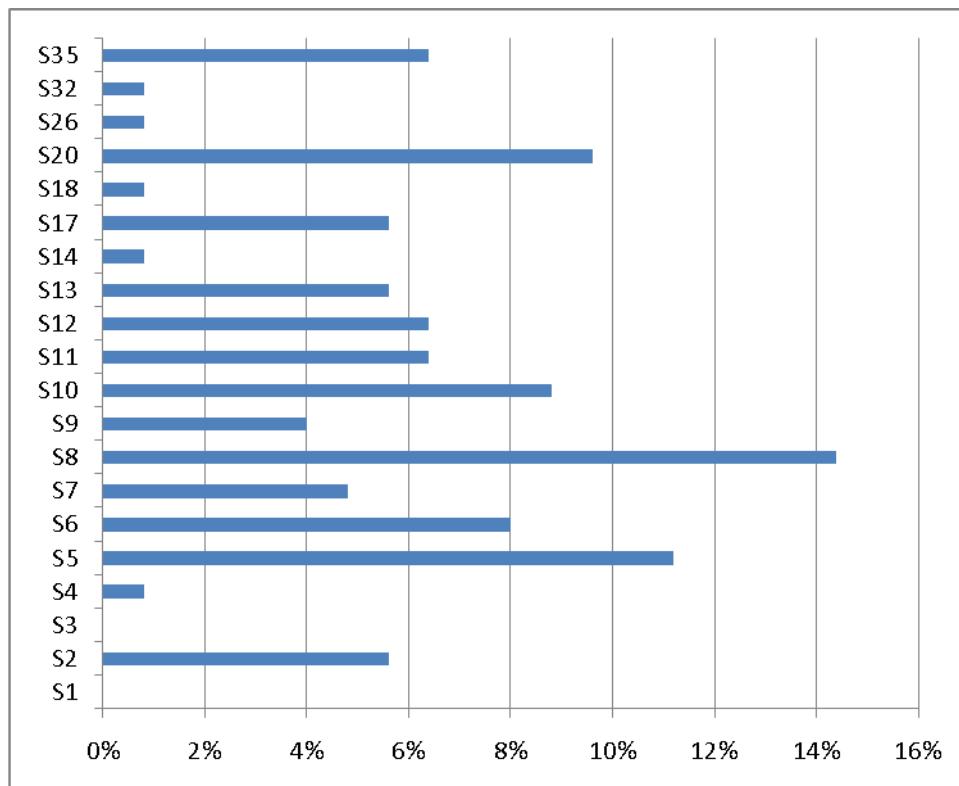
3.3 Ethnicity

Of those who stated an ethnicity, 82.4% were White British, and 16.5% said they belonged to a BME (Black Minority Ethnic) community. Of these, the largest group was Pakistani with 6.6%.



3.4 First part of postcode

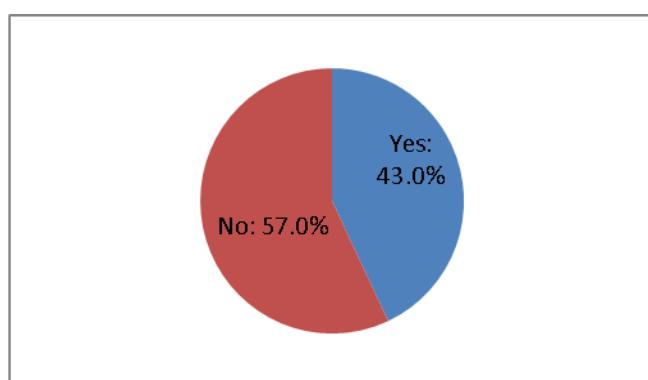
There was a good spread across the city with most post codes showing a level of representation, with a fairly even split between areas of high and low levels of economic deprivation:



4. Gaps in service

4.1 Questionnaire responses

Questionnaire respondents were asked if they had ever sought information, advice or support in relation to caring for their disabled child, but had been unable to find a service that offered what they were looking for. 43% answered “Yes”, 57% answered “No”:



We analysed the demographic data of those who responded “Yes” to the question to see if any groups were overrepresented in this sample. We found no significant variation in terms of ethnic groups, postcodes or impairment types, and only a slight overrepresentation of parents of children in the 11-19 age group.

However, more parents in the “Yes” group stated in response to question 6 that they had asked a social worker for help (40% in this group vs. 28% in the total sample). In response to question 7, these parents also indicated a significantly higher need for information, advice and support in relation to understanding and accessing the following services: social care services (49% vs. 33% in the total sample), home-to-school transport (42% vs. 31%), childcare (38% vs. 20%) and leisure services for their child (60% vs. 48%). These parents also faced more barriers to accessing support services, particularly in terms of caring for a disabled adult, or having a disability or long-term illness themselves.

Respondents were asked to provide more information if they had answered “Yes”. There were a range of responses in relation to experiences of existing services, both in terms of service availability, delivery and access. This information has been included in an accompanying document and will be fed back to the local authority and the health service in order to help improve service design and delivery. The predominant themes from the questionnaires in terms of gaps were in relation to:

- The ability of services to meet the needs of disabled children
- The availability of suitable local provision, particularly with regard to childcare and leisure activities
- Access to services, both in terms of information about the support available, and in terms of meeting the eligibility criteria for services
- Availability of parenting support, particularly around challenging behaviour, sleep and toileting, and support around the time of diagnosis
- Help for parents to understand and navigate the “system”

In the workshops, participants were asked to describe an instance when they had looked for advice or support in relation to caring for their disabled child, but had been unable to find it. Working in small groups, participants identified three key areas:

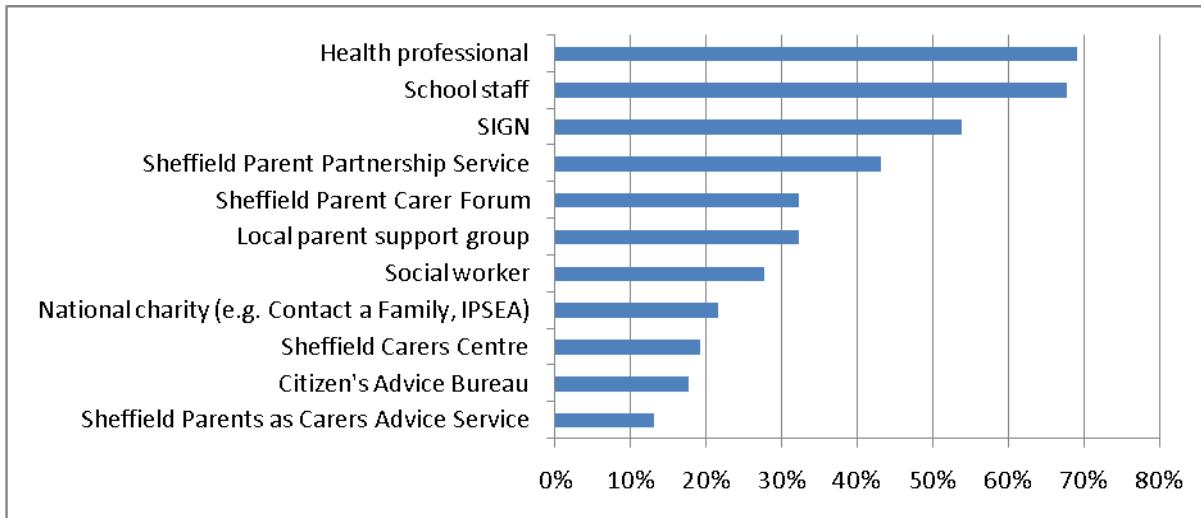
- Access to the right information, from the right person, at the right time
- Support in relation to accessing or using services
- Crisis support

Detailed feedback is included in our accompanying document, available from:

www.sheffieldparentcarerforum.org.uk/docs/uploaded/spcf_doc_248_260913149pm38.pdf

Existing sources of information, advice and support

Questionnaire respondents were asked to indicate which people or organisations they had asked for information, advice or support in relation to their disabled child:



Respondents listed a number of other services, including MAST, SNIPS, Deaf Advice Service, national and local government departments, local support groups (ACCT, Ray of Hope, Sheffield Autistic Society), national charities (SHINE, St Vincent, National Autism Line, Family Fund) and the Sheffield HelpYourself database. Workshop participants also cited other parents as a key source of information and support.

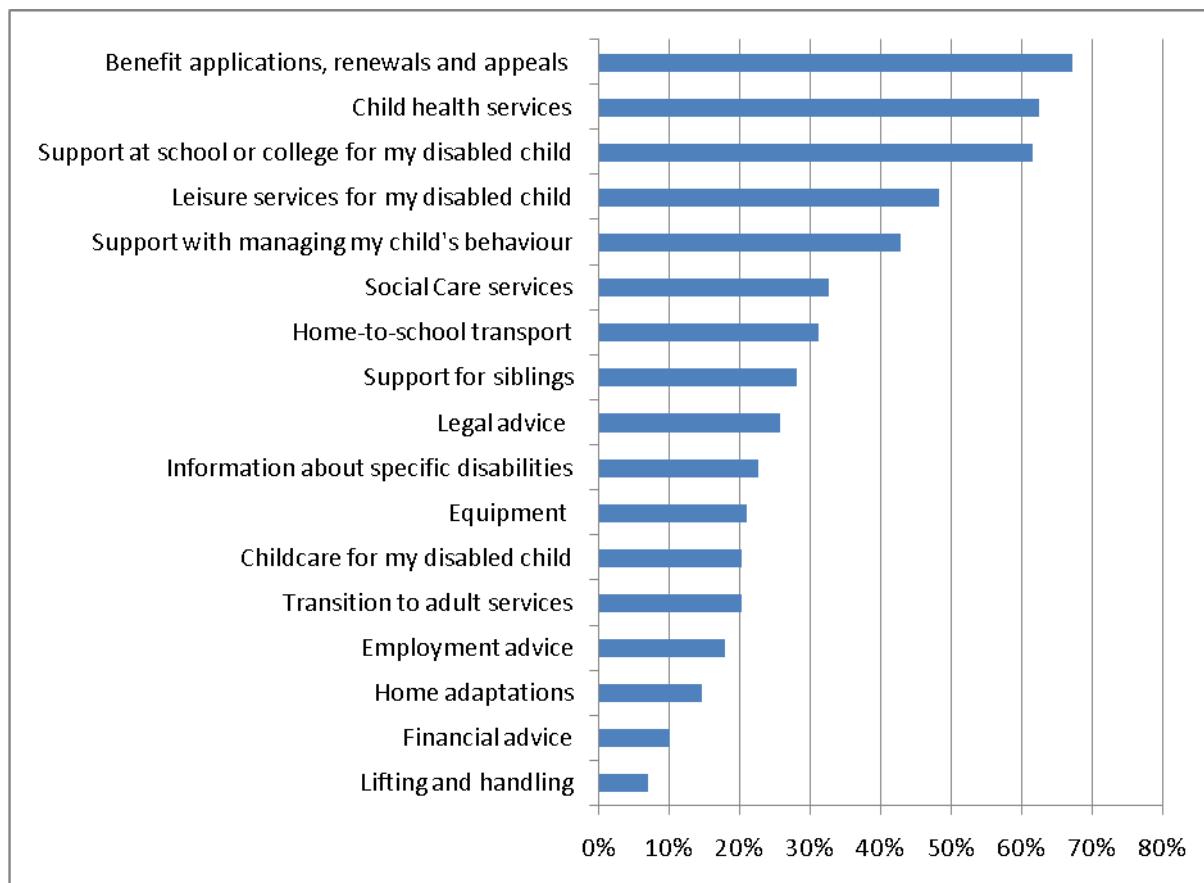
These responses highlight parents' reliance on frontline staff for the provision of information, advice and support, and consequently the need to ensure that these workers have a good knowledge of local support services and are able to refer/signpost families to the right services. However, responses also indicate that sometimes families require something additional to signposting.

Evidence from the questionnaire and the workshops suggests that despite efforts from services to publicise their offer, there are still sections of the parent carer community who are not aware of key services available for their support:

"I wasn't aware that the other groups exist. This actually highlights how big the problem is, because having been seen by CAMHS, Ryegate, MAST, local GP and hospital, I have not been advised about these services to support me."

5. Areas of need

Questionnaire respondents were asked to indicate IN WHICH AREAS they currently needed, or had needed, information, advice and support in relation to their disabled child (to include help understanding the "system" and the options available, and help accessing the services listed):



Given the recent significant welfare reforms, it is perhaps not surprising that "support with benefit applications, renewals and appeals" tops the list.

Almost two thirds of respondents stated that they needed help to access educational support and health services for their child. These results reflect the findings of our subgroups on Health and Education.

We analysed the demographics of the respondents who stated that they needed support around child health services but found no significant overrepresentation of any impairment group. More research is needed in order to fully understand the barriers families face in this area.

Several parents commented on the need for more joined-up working between services. At the consultation workshops, participants debated and explored the need for a

keyworker/co-ordination role when there are a number of services required to work together.

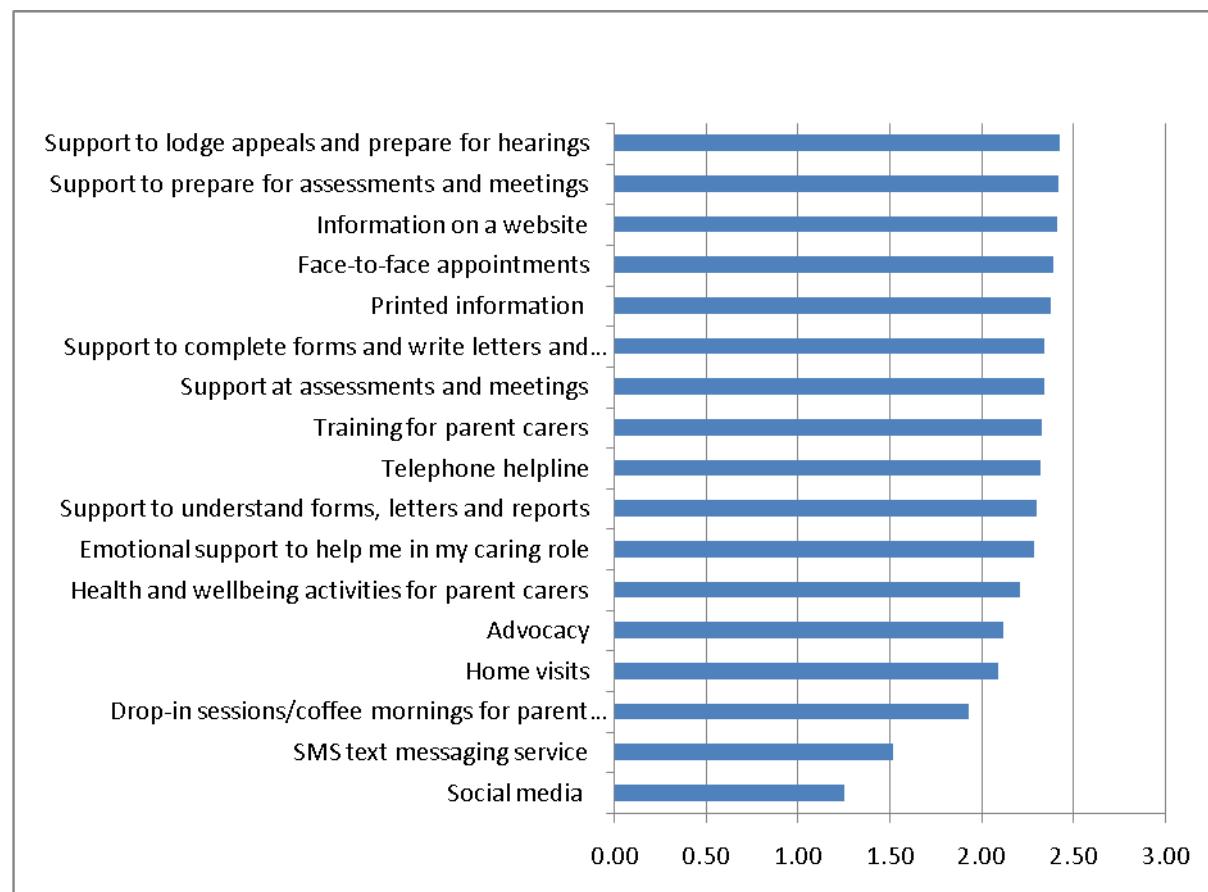
"From birth to present (he is now 14 years old) I've needed and still need the [services] above and it's up to me bring them together and to provide information or find information etc. - extremely exhausting, frustrating and demoralising."

"Very confusing with too many agencies who do not communicate with each other. MAST team are unable to obtain any information from Ryegate."

A number of questionnaire responses conveyed an urgent need for support with behaviour management. 72% of respondents with children in the 14-19 age group said they needed help with the transition to adult services. In relation to leisure services, several respondents highlighted a lack of local small-group provision.

6. Ranking of support activities

Questionnaire respondents were asked to indicate HOW they would prefer to receive information, advice and support, by ranking activities as "Very important" (3), "Quite important" (2), "Slightly important" (1) and "Not at all important" (0):



Most of the service activities listed received an average rating between “Very important” (rating 3) and “Quite important” (rating 2), with only drop-in sessions, SMS text messaging and social media being rated lower than 2. It is important to remember, however, that texting is a vital communication medium for hearing-impaired parents.

There is little differentiation between the various support mechanisms above. Without further exploration it is not possible to be categorical but this could be indicative of a number of reasons:

The high level of need is a result of the complexity of the issues and processes that families with disabled children encounter.

Many parent carers face additional challenges, such as having a disability or long-term illness themselves, having more than one disabled child, or also caring for an adult (see section 10).

The freetext comments emphasized the challenges parent carers face in relation to accessing information, support or services:

“Often we need to TALK things through. So information on its own in whatever format, is NOT enough.”

“I think it needs more qualified people to actually visit the homes of carers with a disabled child.”

“Face to face and parental support is vital. You cannot get emotional and personal interaction from a website or newsletter, they should be used to disseminate information.”

“[...] having two disabled children I struggle to get to meetings etc. as one may be at school the other won't be, so it's very difficult to guarantee that I can get to appointments and meetings. Leaflets, texts etc. I can get to look at during a spare second.”

Several parents stated that their work commitments and/or caring responsibilities prevented them from attending drop-in sessions, coffee mornings or support groups.

7. Key elements of a good support service

We asked workshop participants to look at a fictional case study (see Appendix B) to identify key elements of a good support service. They felt that practical and emotional support for Emma (the single mother) should have the highest priority, as the rest of the family depended on her. They pointed out that parents in crisis did not have the time or energy to chase things up; the family in the case study needed a key worker to provide stability and to support Emma to access the right services for each family member. Participants identified childcare as the most urgent issue, as without this, the mother was at risk of losing her job.

Participants warned that parents often downplay their issues because they worry that social services might take their children away if they think they are unable to cope. They felt there was a risk that any services a parent might ask for help were likely to focus on their particular subject area, and might not look at the family's situation holistically. Although a Carer's Assessment should identify all the needs of the family and address them, several parents felt that this did not happen in all cases. Parents within the workshop indicated they had never heard of a Carer's Assessment, others thought they were only for carers of adults.

There was a consensus among parents of older children that the role of social workers had changed considerably over the past decade. Several parents said that social workers used to be very helpful, but were nowadays thwarted by regulations and a system focussed on throughput.

Only two workshop participants had accessed Family Intervention Workers through MAST (Multi-Agency Support Team); one of them reported high levels of satisfaction, while the other one said that they did not get the level of support they felt they needed.

Participants at the workshops stated that a good support service should provide:

- **Keyworker type support.** The need for a key worker system was identified as a top priority in all three workshops. Discussions centred around the idea of co-ordination and practical support: "*At the moment, the parents are the keyworkers.*"
- **Face-to-face consultations and home visits** (if required/preferred by the parents), especially for initial contact. This is particularly important for those parents who have more than one disabled child, who also care for an adult, or who have a disability or long-term illness themselves (see question 10).
- **Emotional support** (particularly around the time of diagnosis, and during a crisis)
- **A central place for parents to get all their information from**, which provides *proactive* signposting. Parents felt that, although a lot of information existed in different places, the distinguishing factor in terms of good support was the provision of time-relevant information in manageable chunks.
- **Regular, long-term support** (someone to have regular contact with, who will get to know the parents and the child, and who will check up on the parent and get them back on track)
- **Practical support**, e.g. someone to accompany parents to meetings, look around prospective schools, do research, make phone calls, help with form-filling etc.
- **Someone to troubleshoot and move things on** when they get stuck. This role would also need to include the provision of feedback to service managers so that service performance could be improved.
- **Independent advocacy**

- **Advice on parents' / children's rights.** Parents felt there was a tendency for parents to accept services that are not really suitable because they feel there is no other option.
- **Access to peer support**, e.g. through coffee mornings, buddying/befriending schemes
- **Counselling**

Workshop participants identified the following characteristics of a good support service:

- **Responsive** (able to respond quickly to families in crisis, and provide a wraparound service – 24/7 support)
- **Accessible** (parents should be given a direct phone number / email address for their worker; if staff are working part-time or are on annual leave, an emergency phone number / email address should be provided)
- **Empowering** (must be able to tailor the level of support to the personality of the parent, and help parents to understand and navigate the system, e.g. by clearly explaining the significance of assessments and forms. Parents should have ownership of the case file.)
- Able to provide **continuity and dependability**
- **“Can do” attitude / ability to think outside the box**
- **Independent** of Health, Education and Social Services
- **Competent and professional**
- Good **listener**: need to listen to the parents and the child, able to draw out detailed information
- Able to **empathise** (rather than just sympathise) and who BELIEVES what parents say: “Someone who is on our side”
- Excellent **knowledge of the system and the range of local provision**, and not afraid to say “I don’t know, but I will find out” – and then deliver!
- **Good knowledge of disability and how it can impact on the child and the family**
- Excellent **communicator** (able to tailor their communication to different groups of parents)

One workshop group suggested that there needed to be two levels of service:

- 1) a crisis service which can respond quickly to advise and chase things up;
- 2) a lower-level service which can facilitate peer support.

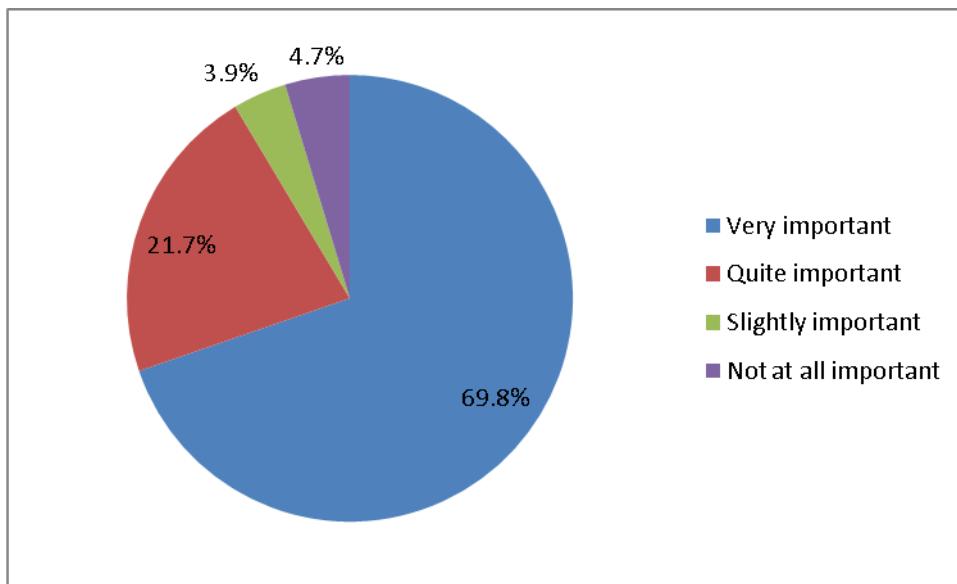
Good practice examples

We asked workshop participants to provide examples of good support they had received. Most of these referred to individuals rather than a particular service:

- A parent said that a social worker she had had 14 years ago was “like a fairy godmother”. This worker came to her house, helped her to fill in DLA forms, and was well informed and always available. *“She knew what I needed, and told me what I needed to do.”*
- A parent praised ibk initiatives for being child-led and holistic: *“I even called them when my child was stuck in a lift, and they helped me with that.”*
- A parent described how a specialist teacher had gone above and beyond the call of duty and taken on a key worker role, accompanying the parents to look at schools for their child.
- A parent described how a Family Intervention Worker met with her once a week and got to know her and her child. The worker was very supportive; she provided some vital signposting to St Vincent’s furniture store, and sorted out toys for the child.
- A parent described a good experience with the Portage service. She felt that it was very beneficial to have weekly sessions over a longer period, as the Portage worker was able to go away and find the information the parent had requested, and then bring it along to the next session.
- Parents praised the service they had received from the Ryegate Centre; they particularly liked the fact that everything was provided under one roof.
- One parent described a very positive experience with CAMHS workers, who had educated the parents about the child’s needs and introduced medication.

8. Sources of information, advice and support

Questionnaire respondents were asked to indicate how important it was for them to be able to get all their information, advice and support in relation to caring for their disabled child from a single source:



The majority of respondents (91.5%) felt it was either “Quite important” or “Very important” to be able to access a one-stop shop for information, advice and support.

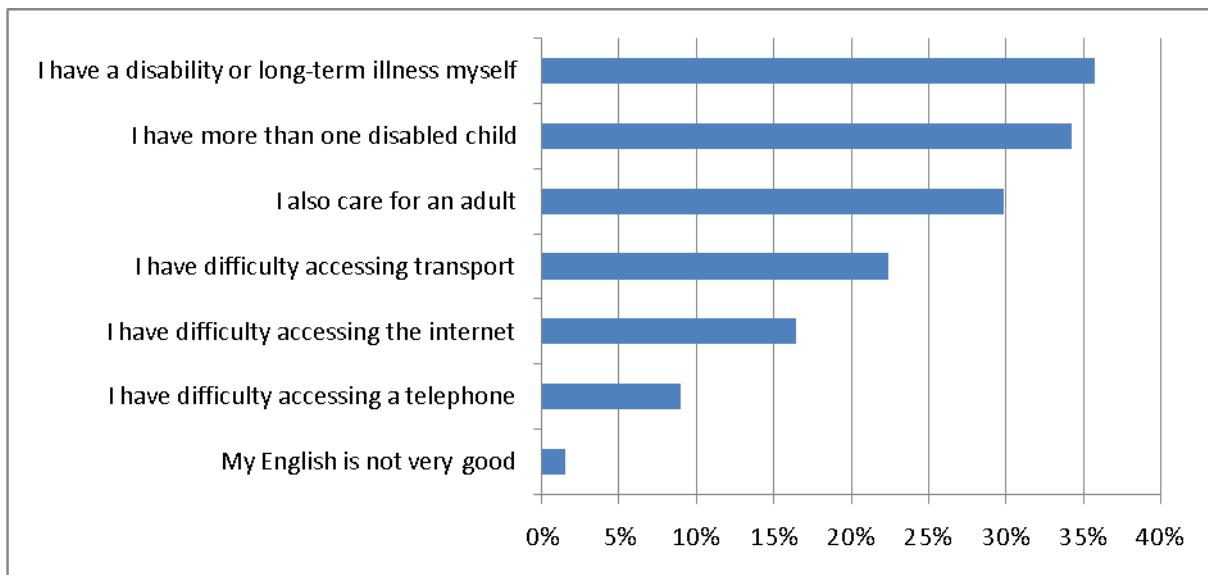
“Because you have to get info from all over the place not just one stop does it all, it's very confusing and time-consuming for parents who don't have much time to go round and are constantly shattered.”

“I wish there was ONE place that did everything and knew everything, that had flexible times to contact them. Also if you are told what help you can get, not parents having to find out what help is available. Like benefits, you claim one but you're not told what else you can claim. You have to fight for everything.”

9. Barriers to accessing support services

Questionnaire respondents were asked to identify additional challenges which might make it more difficult for them to access a support service.

49.3% of respondents said they faced at least one of the following barriers to accessing support services:



Respondents identified a number of additional barriers:

- **Time constraints due to combining work and caring (8 respondents)**

"I work to support my family. Sometimes feel either working or looking after kids. No other time to help others! Or self! Everything seems to assure you can't work and have disabled kid - all daytime meetings. Enough with school and health appointments!"

- **Exhaustion/lack of sleep (5 respondents)**

"Overwhelmed by things to do in relation to my child - filling in forms, making appointments/attending appointments, looking for solutions to issues, fighting for resources, challenging professionals"

"You need to understand that having ONE disabled child is incredibly difficult for families. Many parents are anxious, depressed, isolated, frightened. Many relationships are collapsing under the strain."

- **Caring for siblings, particularly if very young (5 respondents)**

"Having another child under 3, it's quite difficult to get childcare to attend meetings alongside working."

- **Being a single parent (3 respondents)**

"Being a single parent with no social support network is hard."

A parent pointed out that it is not just the most disadvantaged parent carers who need support: *"There is also an assumption that if you have a job and an income that you must be managing and don't need any input or support from services - very frustrating!"*

10. Additional comments

Questionnaire respondents were asked to write down any additional comments.

There was a wide variety of responses to in this section, many of which were very similar to responses given to other questions, e.g. school issues (particularly for pupils without statements), access to oversubscribed health services (particularly speech and language therapy), support for working parents, support for disabled parents (particularly in terms of communication barriers faced by deaf parents), and disabled children's access to leisure services. Other comments included help with making a will, counselling for parent and child, social housing, and a request for SIGN to expand and move back to Ryegate.

Several parents commented how difficult it is to access services when "you don't know what you don't know":

"Information comes at you in bits. Quite often you find out about something you could have used years after it was needed simply because you didn't know it existed."

There were several comments about how hard it is for parents to keep up with services when their names, premises, providers etc. keep changing.

11. Conclusions/Themes

The following conclusions/themes have been drawn from the information and responses provided by parent carers in the questionnaires and workshops.

Information

Workshop participants discussed at length the complexity and the challenges of understanding the range of services and options available to them as parents of disabled children. Understanding and navigating the "system" was a recurring theme.

Parents expressed confusion and uncertainty regarding access points/routes into services. For some parents, this appeared to be the case even when they were aware that a service existed.

The questionnaire responses clearly indicated that families rely on frontline workers for information, advice and guidance. Workshop participants also cited other parent carers as a key source of information and support.

Support

Throughout the responses there were consistent references to a requirement for support for parent carers. When asked which areas they needed help with, parents listed benefit applications renewals and appeals, child health services, support at school or college for

their disabled child, leisure services for their disabled child, and support with managing their child's behaviour as their highest priorities.

Questionnaire respondents were asked to rank a variety of support mechanisms (e.g. face-to-face appointments, information on a website, telephone helpline), but this was inconclusive as parents attributed a high importance to most of these activities.

When discussed and explored in the workshops, parent carers had a clear view on good practice aspects:

- There was a consistent message from all three consultation workshops that families would like to be supported via a key worker system.
- Participants emphasized the need for support to be dependable, long-term, hands-on / face to face, independent, professional, empowering and tailored to needs of the family.
- Parents said that workers must have an excellent knowledge of the system and the range of local provision, and be excellent listeners and communicators who are able to empathise with parents and be “on their side”.
- Parents highlighted the importance of emotional support and peer support.

Parents identified issues with several services that form part of the wider support structure for parent carers, such as childcare, direct payments and behaviour support. A detailed account of these issues can be found in the **accompanying document**; see www.sheffieldparentcarerforum.org.uk/docs/uploaded/spcf_doc_248_260913149pm38.pdf

The Sheffield Parent Carer Forum's Management Committee has responded to the findings outlined in this report. To read their **comments and recommendations**, please go to: www.sheffieldparentcarerforum.org.uk/docs/uploaded/spcf_doc_247_260913149pm14.pdf

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