

Information Requirements of Parent Carers with Regard to Childcare for Disabled Children

Consultation report

Background

Sheffield City Council is working to improve the range and quality of childcare available to parents of disabled children. Providing better information for parents about childcare for disabled children is part of this work.

In order to meet parents' information needs as effectively as possible, Sheffield City Council commissioned the Sheffield Parent Carer Forum to consult with parents and carers of disabled children and young people about their information needs.

The consultation aimed to establish:

- what parents/carers of disabled children want to know about childcare;
- what format they would like to receive this information in;
- where they would go to get this information.

The consultation targeted parents of children and young people who require an element of additionality in order to have their needs met in a childcare setting. A formal diagnosis was not required.

The consultation ran from 6 to 31 January 2011. A link to an online questionnaire was advertised to the Forum's email list (228 members) and forwarded on to the email lists of a number of disability-specific parent support groups. Paper questionnaires were posted to those Forum members who had joined the postal mailing list but not the email list (81 members). A further 120+ paper questionnaires were handed out at a number of parents' meetings in Sheffield. A total of 102 responses were received, of which 55 came via the online questionnaire and 47 were paper responses.

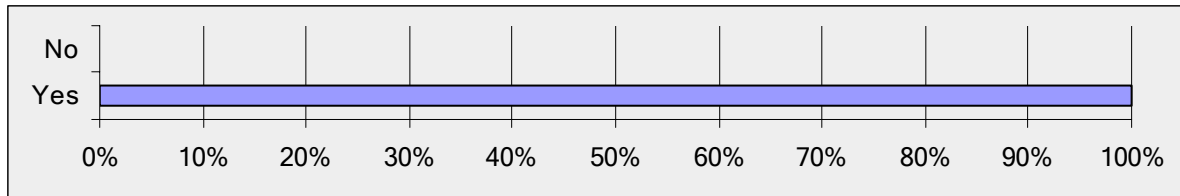
The information gathered through the questionnaires was supplemented by a focus group meeting attended by eight parents/carers of disabled children (see Appendix A).

This report summarises the outcomes of the consultation. It will inform the development of a brochure providing information about childcare for disabled children in Sheffield.

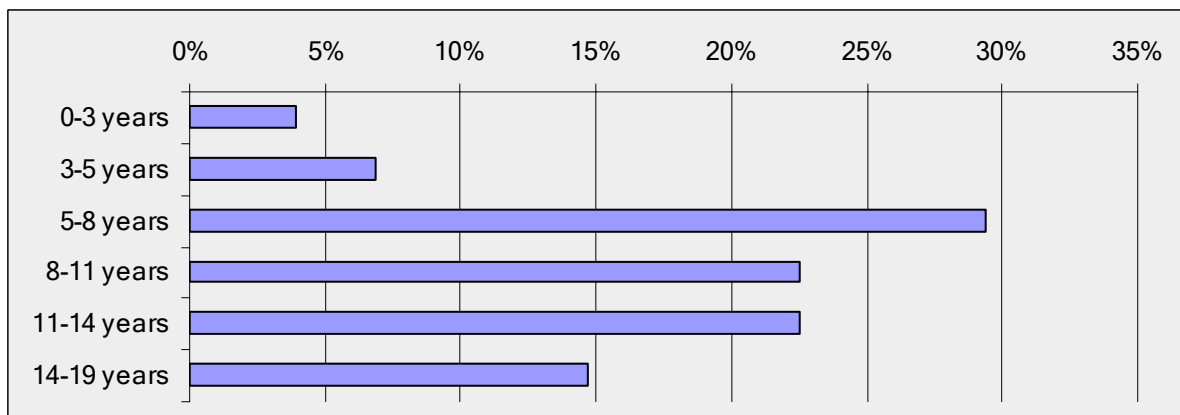
Analysis of responses

1. Statistical information

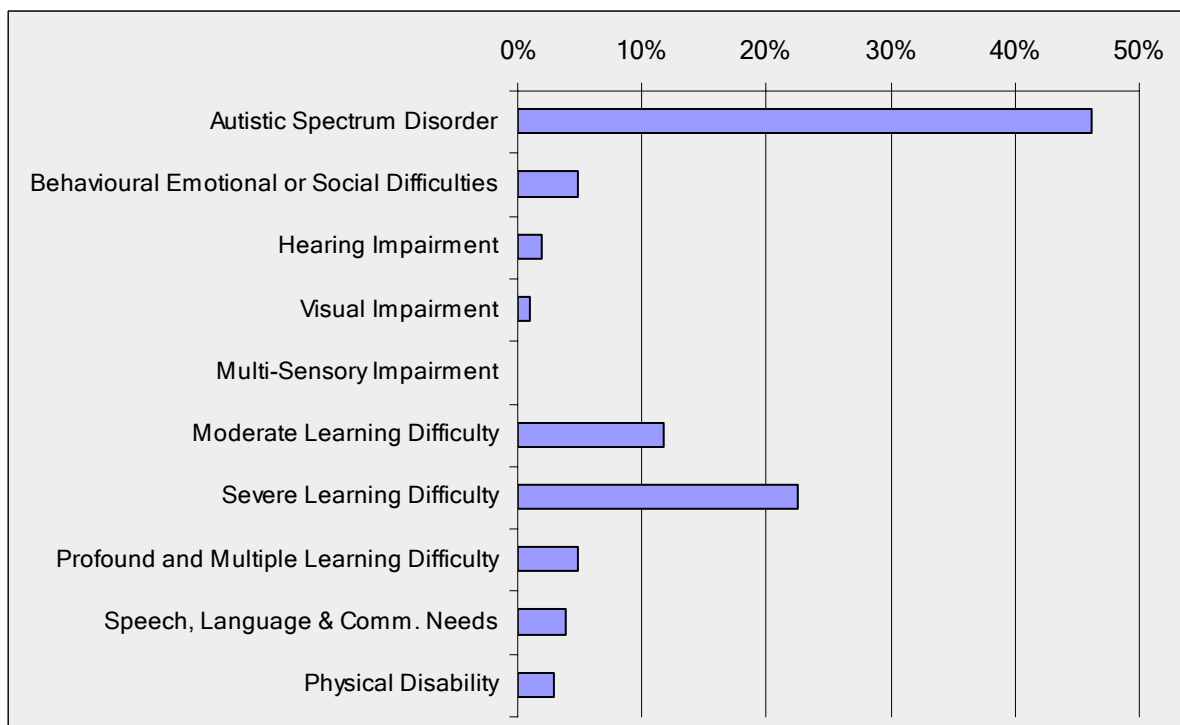
Question 1: Are you a parent or carer of a child with additional needs?



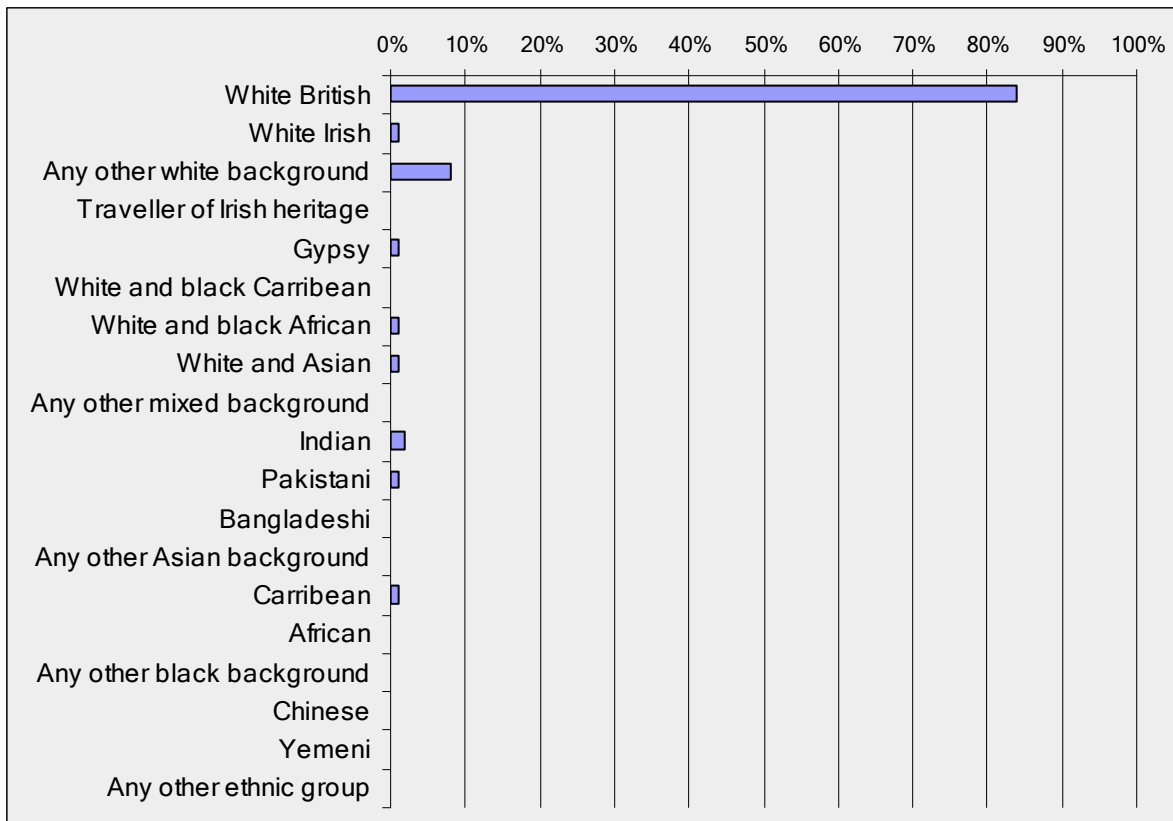
Question 2: How old is your child with additional needs?



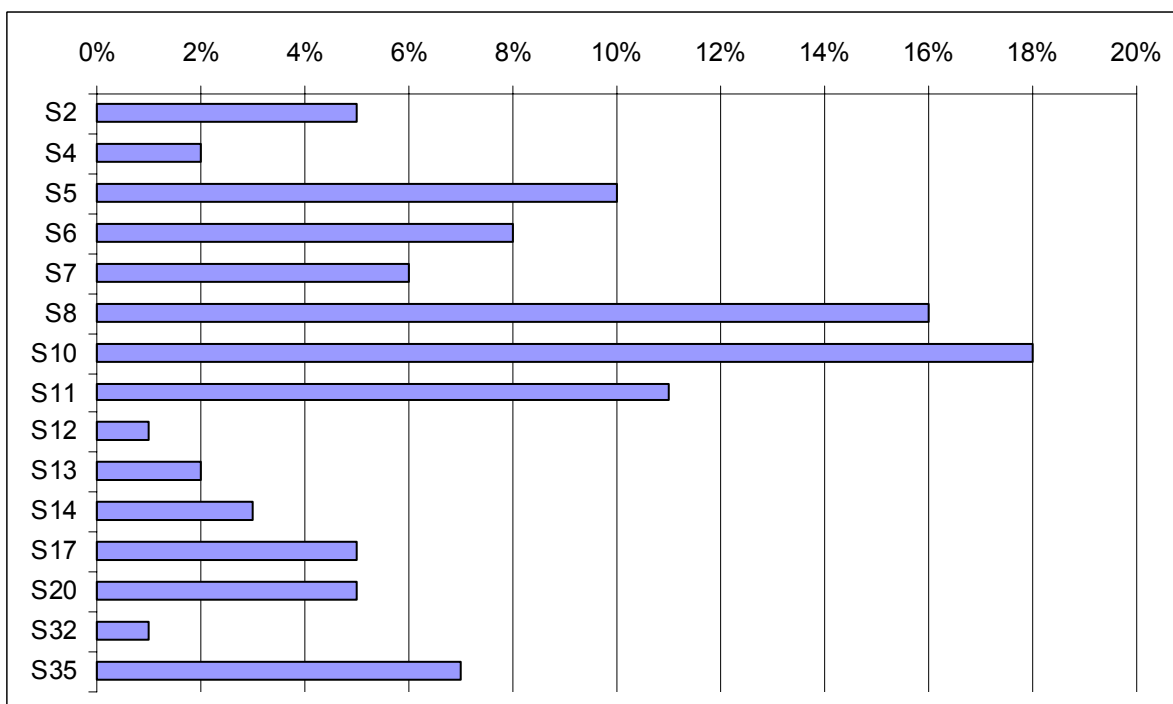
Question 3: How would you describe your child's MAIN impairment?



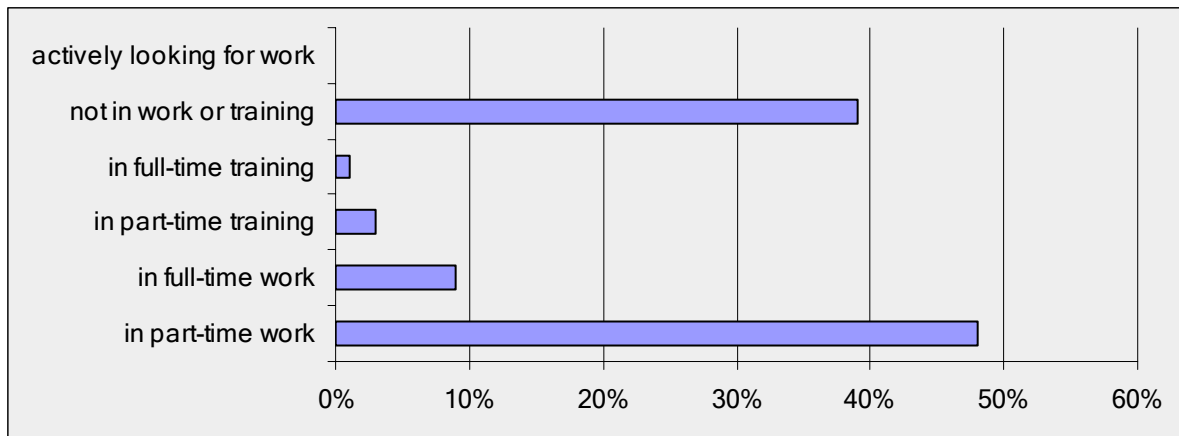
Question 4: Your ethnic group (optional):



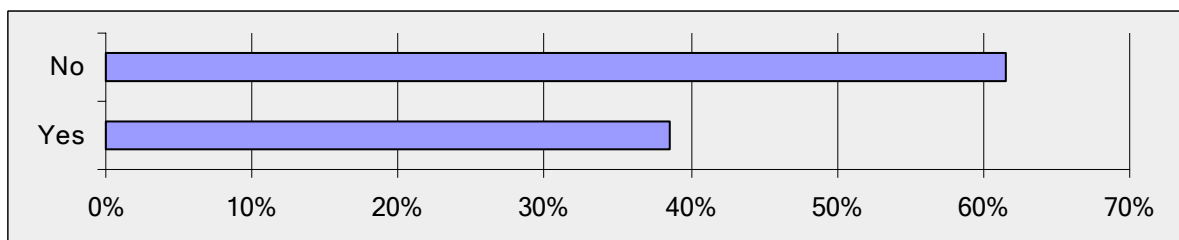
Question 5: The first part of your postcode (e.g. S35):



Question 6: Your work situation:



Question 7: Are you currently using, or looking for, childcare for your child/children with additional needs?



Note: The sample studied was not entirely representative of Sheffield's parent carer population. There was a notable underrepresentation of parents of pre-school children, which may be due to the fact that many children do not receive a formal diagnosis until they enter the school system. This can prevent their parents from accessing relevant support networks. Parents of teenagers and parents from the BME communities were also underrepresented.

Efforts to increase responses from these groups were hampered by the tight timescale of the consultation, and failed to have a significant impact.

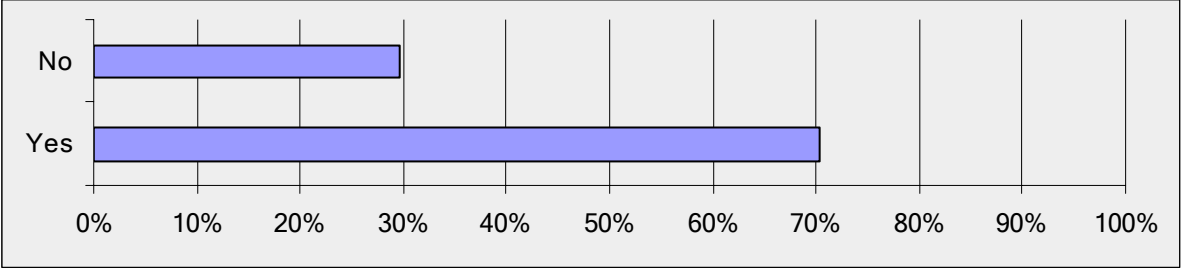
The overrepresentation of parents of children with autistic spectrum disorders is a phenomenon that we see across many areas of parent participation. It may be that autistic children struggle more than children with other types of disabilities to access mainstream provision, making their parents more inclined to participate in consultations. It should also be noted that 40% of the children in the sample had more than one impairment. Where children have several diagnoses including autism, parents tend to list autism as the primary impairment.

The responses to questions 6 and 7 show that there were more parents in work or training than parents using or looking for childcare. This suggests many parents either fit their work hours around the school day, thus avoiding the need for childcare, or rely on family members to care for their children whilst they work. It would be interesting to see what kind of childcare arrangements these families use during the long school holidays.

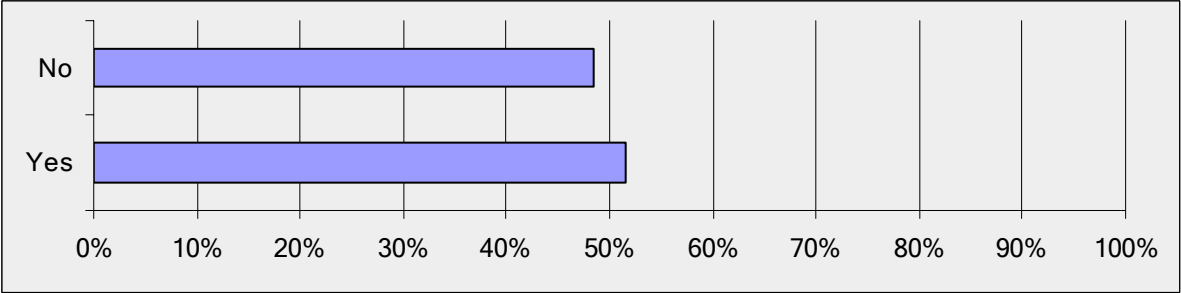
2. Difference between childcare and short breaks

We wanted to find out if parents were aware of the difference between short breaks and childcare. We explained this difference in a few sentences and then asked:

Question 8: Were you aware of the difference between childcare and short breaks?



Question 9: Would you like more information about short breaks?

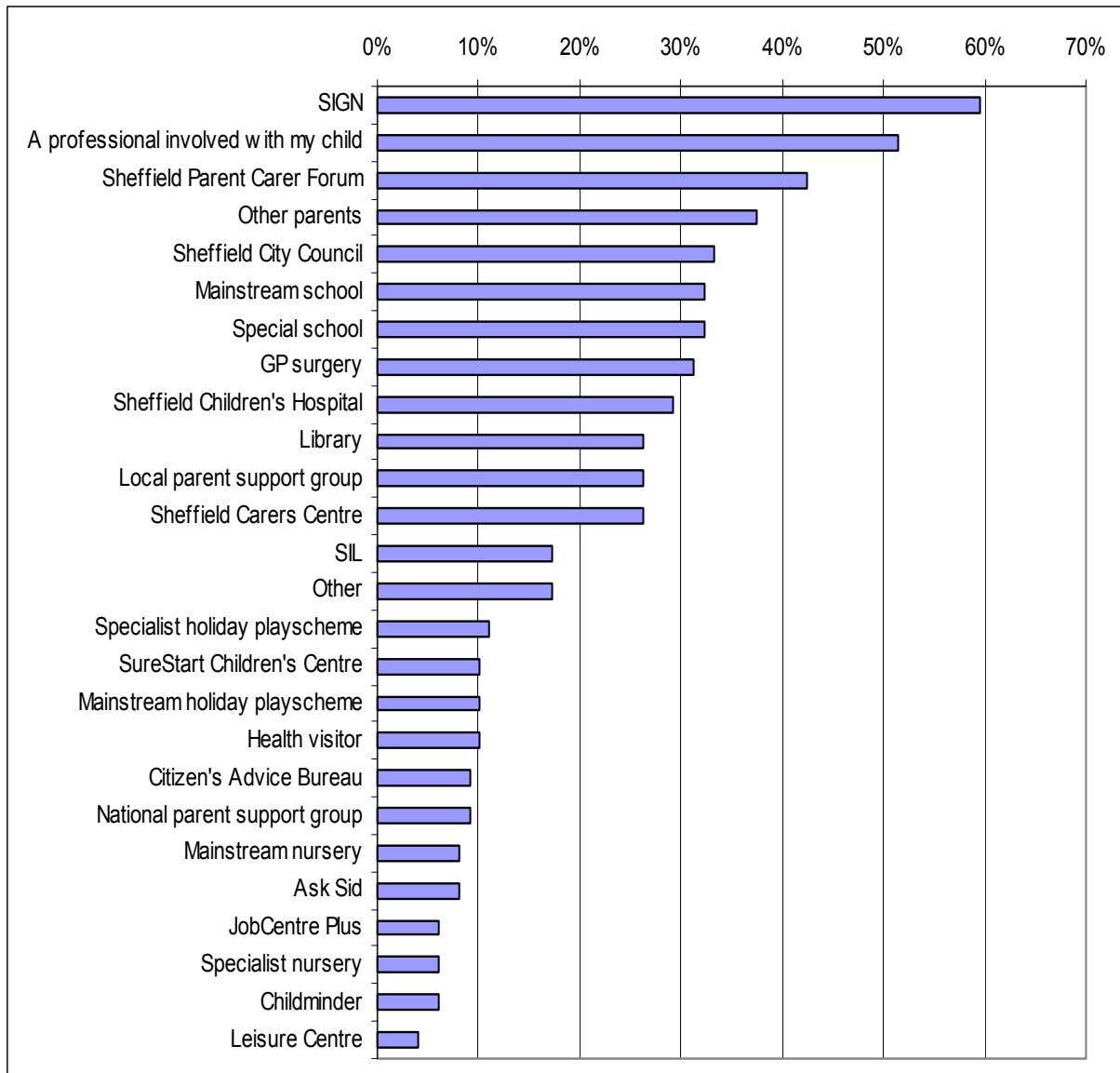


Note: These responses suggest that a booklet about childcare should at least include some basic information about short breaks, as well as signposting to sources of further information.

Where services have differing policies for childcare and short breaks (e.g. home-school transport, SNIPS, direct payments), these should be explained clearly in the relevant sections.

3. Information access points and formats

Question 10: Where would you go to get information about childcare for disabled children? (please select all that apply)



Other information providers suggested:

- Relevant charities e.g. NDCS (National Deaf Children's Society)*
- SNIPS (Special Needs Inclusion Playcare Service)
- ACCT: Asperger's Children & Carers Together*
- Grandparents' groups*
- I think that the more places this information is available the better and then can be accessed by more people
- Ryegate
- Not applicable, use family
- The closure of the SIGN office on Pinstone St by Sheffield City Council makes finding information more difficult
- Portage worker*
- Anyone who can give support for my child's needs*
- Social worker*
- Mostly by word of mouth/ chatting to other mothers/users of childcare/childminders*

- Parents are not consistent / ad hoc etc*
- Internet x3
- Mumsnet website

* Respondents who gave these answers also ticked the corresponding options in the list above

Note: The low ranking of Health Visitors, SureStart Children's Centres and Nurseries as information providers may be due to the underrepresentation of parents of pre-school children in the sample studied.

The relatively high ranking of special and mainstream schools suggests that information provision should be a key element of any SENCO training.

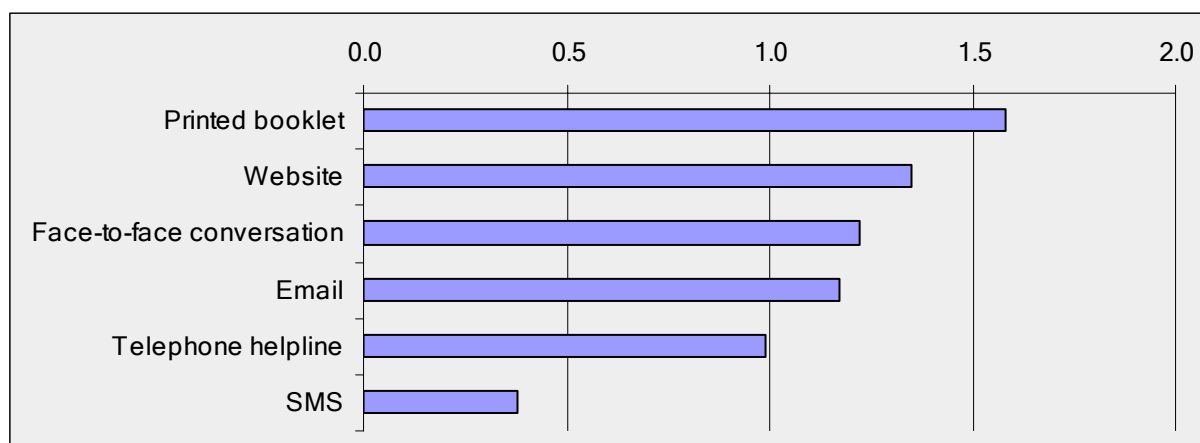
The high ranking of "other parents" as sources of information underlines the need to foster peer-to-peer networks.

Question 11. We would like to know in which format you would prefer to receive information about childcare. Please tell us how interested you are in the formats suggested.

0 = Not interested

1 = Moderately interested

2 = Very interested



Other information formats suggested:

- Maybe you could put a video on the website which can be easily updated when information changes - for people who prefer to watch rather than read information
- A one-stop shop for enquiries regarding all SEN/disability issues - whether this is education, health, child care or short breaks.

Note: It is important to note that 15% of the parents who answered this question said that they were "Not interested" in websites. This suggests that a significant proportion of Sheffield's parent carer community may not have access to the internet, and would be disadvantaged if information was only provided in electronic format. This is borne out by the fact that over a quarter of the Parent Carer Forum's members have not provided an email address.

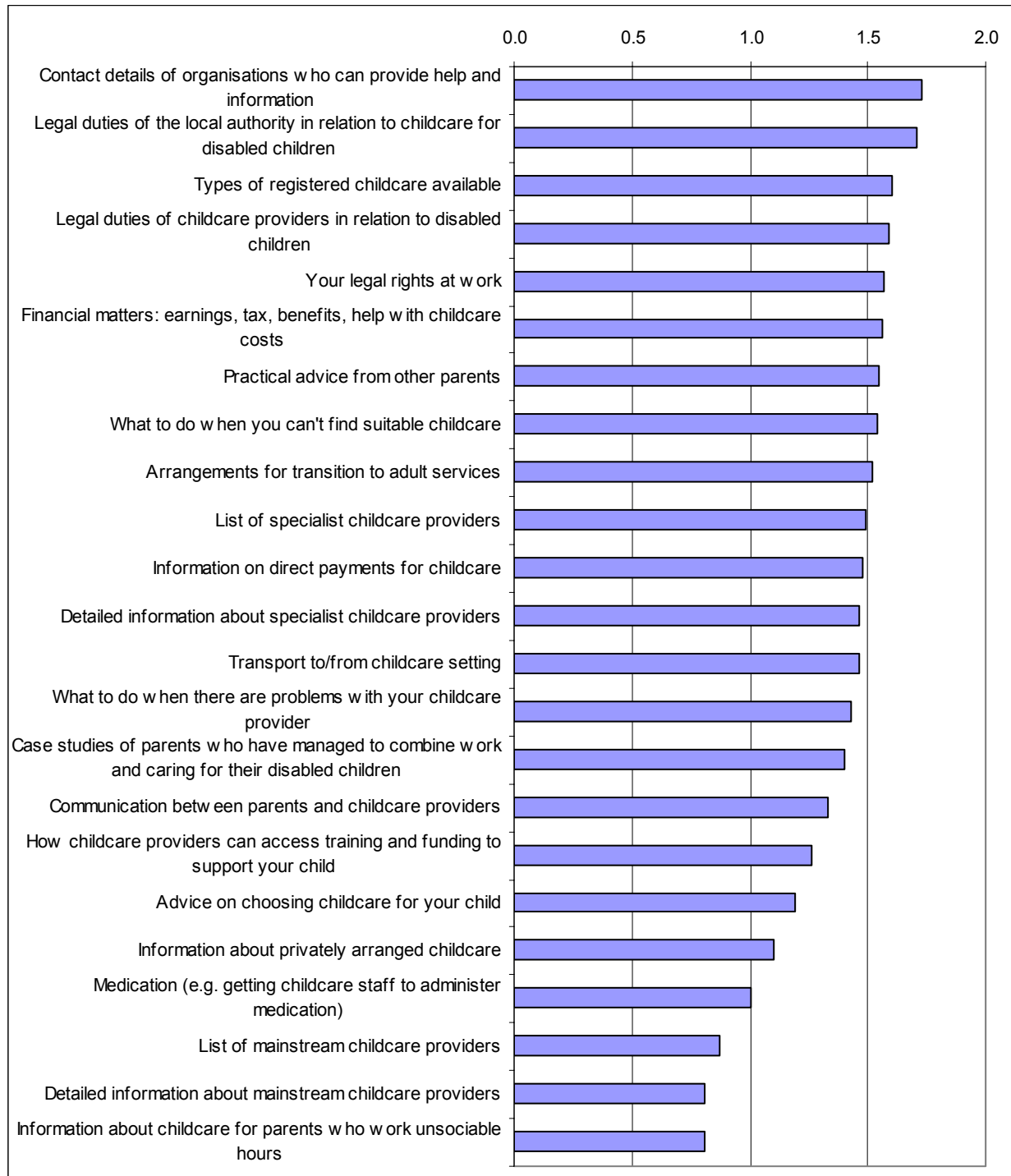
4. Information content

Question 12. What do you want to know about childcare for disabled children? Please tell us how interested you are in the topics suggested. You can also suggest additional topics.

0 = Not interested

1= Moderately interested

2= Very interested



Note: It is possible that the low ranking of the topic "Medication" may be due to respondents erroneously selecting "Not interested" instead of "Not applicable". This would have distorted the rating, as ticks under "Not interested" were rated 0, whilst ticks under "Not applicable" were excluded from the response count. The same may apply to "Childcare for parents who work unsociable hours";

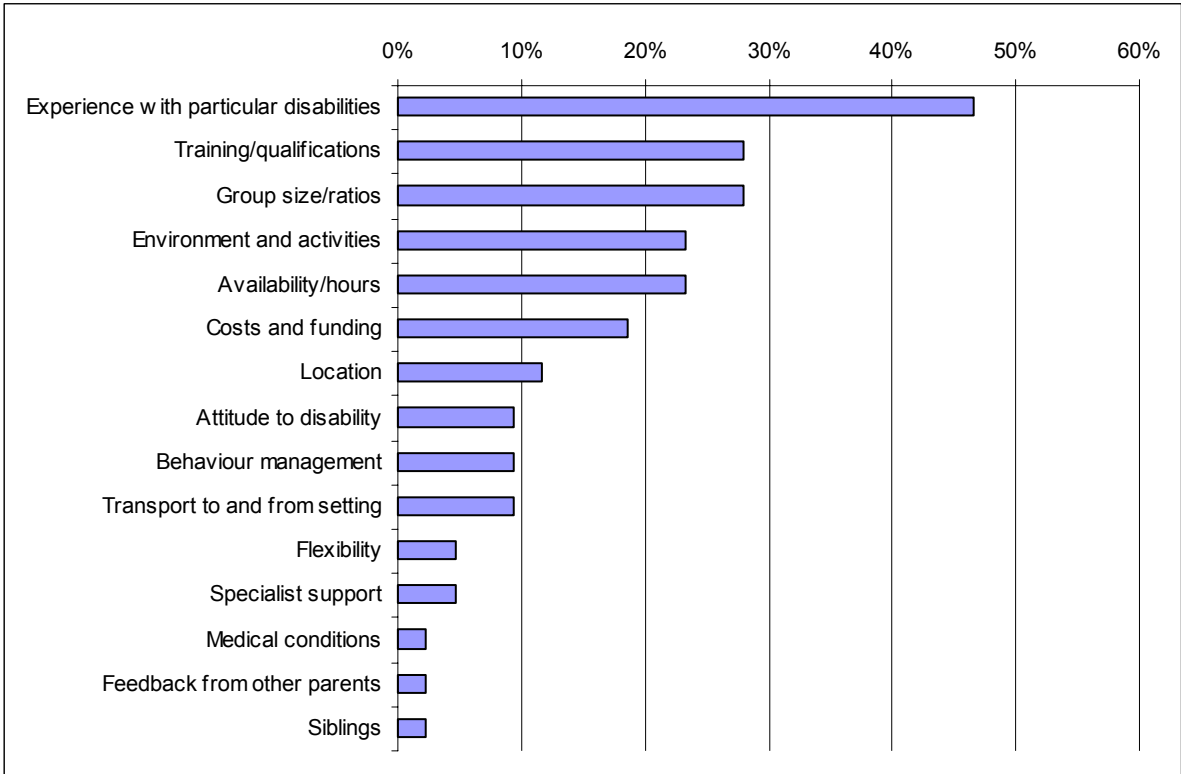
however, the lack of interest in this topic could also be due to a widespread reliance on family members to provide childcare during such hours.

Other topics suggested:

- List of all information for parents with disabled child in one place
- How to recruit a personal assistant for a disabled teenager when we probably don't qualify for direct payments. Is there a list, how do we know they are CRB checked & have relevant training/expertise?
- 1 to 1 carers are great. Provides continuity for child. Carers get to know child and issues
- My child attends an integrated resource unit but only mainstream after-school care is provided - who can support him if I am NOT at work, SNIPS only provide care for when parents are working.
- Information on travelling to and from childcare which is not local.
- Childcare for older disabled children. I have a 12 year old daughter who does not want to do what a 5/6 year old does.
- Age related childcare/playschemes for 11+
- What help and advice is available to the older carer. I am a grandmother with parental responsibility for an autistic boy of 7 years. I worry as I get older and my grandson gets bigger. What help can I get when I start to struggle with him?
- Management of therapy support when you have more than one childcare provider in place i.e. who coordinates visits to different venues etc.
- I would particularly like to have a childminder who was prepared to have a child on an odd/rare overnight stay should there be an emergency with other disabled sibling or own parental disability/illness. This has proved invaluable for children with ASD.
- Holiday schemes for disabled children. Private tutors specialising e.g. in dyslexia

Question 13: What sort of information about childcare providers do you need when choosing childcare for your disabled child?

Mentions per topic as percentage of all responses received for this question:



Question 14. Do you have any unanswered questions regarding childcare for disabled children?

Specialist childcare

- Why are there no holiday clubs specifically for special needs children?
- Why is the provision of childcare specifically for disabled children so limited? My daughter does not attend a mainstream school during term-time but is expected to cope with a mainstream environment during the holidays.
- Is specialist childcare available?
- Why are special schools not encouraged to offer holiday schemes for working parents during the holidays as part of their extended school provision? They have the facilities to care for disabled children and the environment would be familiar to the children.

Complex needs

- No. It appears to me at the moment that childcare is not really possible for my child because of the nature of his difficulties.
- I must admit that I've never used childcare. I changed my career to suit my child's needs. I know not everyone can do this but it was because I never knew where to go when my child needed childcare and due to her needs I wouldn't leave her with anyone.

Emergency care

- My child's epilepsy is un-predictable and so far I have not been able to look for work as I'm needed to care for her at any moment. Just as there are supply teachers/TAs, is there such a thing as a "supply" service for care? I'm training at the moment (P/T) and would dearly love to work but worry about applying for jobs knowing that I may need irregular/significant time off to care for my child.

After-school activities

- I don't specifically need childcare at this moment in time as such but would like a system in place that I could access for assisting my son in after school activities. SNIPS is available but not consistent in providing support.
- Are there any childcare after school clubs for kids over 11?
- Afterschool clubs.
- Schools - why do they think they are exempt from providing for children with disabilities? And why do they make it an issue? My son's school claimed that they didn't have the facilities and asked who was going to pay!

Transport

- When are you going to change the transport from school policy? We have had to have one parent give up work because there was NO childcare provision that the transport services would allow us to use. Strict home to school, school to home policy. Unless you change this my husband will never be able to work more hours than he currently does.

Childcare for working vs. non-working parents

- How can my child access childcare if I am NOT at work, to encourage his independence?
- Why is childcare for working parents considered secondary to "short breaks" for non-working parents? I'm not looking for "free" childcare but a secure, supported environment for my daughter whilst I work.

Grandparents

- Is there any help out there for grandparents? Is there any help with respite? Is there any help at all. More and more grandparents are looking after children. Once you get a Residency Order social services don't want to know and won't support you.
- With reference to section 12 - help with financial costs of childcare. Again the older carer. How do you afford childcare costs when you are drawing your pension and your child is under 19?

Information

- Where do I find out about providers?
- What is available?
How do we access it?
Is it affordable?

Quality standards

- What are the minimum standards, checks and qualifications childminders are expected to have/undertake to be included in a register published by Sheffield Local Authority?
- How do we know that the childcare provider is trustworthy and capable?

Help towards childcare costs

- If there is any additional funding available to help towards the cost of childcare for disabled children?

Legal responsibilities

- Their legal responsibilities to a child with disabilities.

Other

- Yes, about how I can get more one to one in speech. In a mainstream school my little girl is getting left behind. They just keep not asking or saying nothing to me.
- Information and help for transition from primary to secondary school
- All answers are not answered! It is just reports and rhetoric that never deliver anything.

Note: Many of the issues raised here would lend themselves to a Question & Answer section. It will be important for the integrity of this project that questions for which there is currently no clear or no satisfactory answer (e.g. questions regarding the lack of specialist childcare, inflexible transport policy, emergency care, etc.) are not "brushed under the carpet".

Question 15. Do you have any advice on childcare you would like to pass on to other parents? (your comments may be included in the booklet)

- Always go with your gut instincts!
Ensure your child visits the placement before and see how they react
Ensure you can spend a little time with your child in their new placement at the beginning for YOU to get a feel of how the staff handle children
Ask questions and keep asking, don't be afraid to question situations that have arisen
Get other parents to help you in your choices and for feedback, if you can
- Both me and my partner work, so we have childcare provided at home. This has helped us enormously in being able to continue work when our child was of an age when no after school club would have him. Thank you to our social worker and the Council.
- Don't think that you are alone with a disabled kid and always search for more information and advice!
- Make use of direct payments if your child does not like to be with other children.
- I received a list of childminders in my area which was quite comprehensive and very helpful.
- The main thing is that your child is happy and settled with the childcare provided. We are lucky that our childminder is very caring and nurturing and has been really happy to be fully involved in Portage exercises and advice given from the Early Years team on how to improve our son's learning ability. We felt happier knowing that our son was being looked after alongside children with normal needs, as we hope he will be able to access mainstream education and so didn't really want him in a specialist setting.
- 1. Maintain patience - difficult!
2. Discuss matters honestly and openly with the child
3. Remember to ensure that the child's siblings who do not have any special needs or learning difficulties get enough attention and assistance

4. Try not to overcompensate for the child's special needs - they need to develop into an independent adult and not be/become selfish or over protected.

- Looking for afterschool care - good students around that can pick up your child from school and feed them. Can advertise this local to universities or sixth forms/colleges. Paying for mothers help first aid, insurance, training and registration with Ofsted can be helpful to recruit and retain staff.
Providing a sheet with what your child is like, top tips for what they like, do not like and how to handle tricky situations perhaps is helpful.
- As I am fighting to get my child out of mainstream school and into special, transport is not supplied. I have been given an extra 5 hours a week direct payment to get him to and from school using a childminder. As I have other children and my child needs one to one support outside this has been a fantastic help.
- No childcare will be perfect, expect to need to work with the childcare provider and attempt to build positive relationships based on what is going well and then tackle the hard issues. Ask for help in working with the childcare provider from professionals in your child's life. Decide what's really important and what you can live without or just accept as good enough. Do look at lots of settings and options before you make a decision.
- 1. Start looking as early as you can - visit holiday schemes in the previous holiday period when they are active.
 2. Look at the activities and facilities from your child's view point: what would they actually be doing during the day, what activities would be particularly suited to your child.
 3. Make sure that you are confident that staff could handle any medical emergencies - have they had the necessary training.
 4. Give providers a realistic estimate of extra support that will be needed and find out how they will provide it before you book a place on the scheme.
 5. Make sure you work out the true cost of childcare - including travelling costs (I had a round trip of over 30 miles between home, childcare and work - not particularly good for the environment or my wallet). Seriously consider whether other options (including unpaid parental leave) would be more appropriate.
- My daughter has access to SNIPS in the school holidays; she is entitled to 1 day a week free. You can also pay extra for other days. If you are on Working Families Tax Credit you may be eligible to have extra days paid for. I think you also have to be claiming DLA. She attends a nursery that is open in the school holidays. You can visit nurseries to see which is suitable for your child. I find this very useful as my daughter enjoys herself and it gives me and my son time on our own to do something together.
- If you don't understand, ask again. Ask what help is around. You are your child's voice and ears, so speak up for your child. You have to be your child's voice. Never give in. And most of all enjoy your special children they are very rewarding.
- Keep it simple. Do whatever works for you and your child. Keep a sense of humour and if your child is happy then you will be happy. Applaud every small achievement and progression and accept your child as he is, not what you hoped he would be.
- Be determined for your child. If you find obstacles in the way you have to push through, not give up.
- A very good open and flexible relationship with a childminder is excellent. They should be valued appreciated and trusted with as much helpful information as possible. Firm boundaries and agreements need to be made both verbally and written (signed by both parties). They should be encouraged to be members of their local and national Childminder networks and Children's Centres, if they are not already. Longstanding, excellent childminders may become friends but remember it is a business arrangement.
- Seek help as unless you know a childminder who is a friend then there isn't anything immediately suitable. Most out of school clubs are for early years and to get more than a 1:8 ratio they need SNIPS extra funding which for me took months. The service I believe has improved since.

Appendix A - Notes from Focus Group

Focus Group Meeting on Information about Childcare for Disabled Children

21st January 2011, 12-2pm, Sheffield Carers Centre

The meeting was attended by eight parents/carers of disabled children, aged between seven and fourteen years, with diagnoses of Autism, Asperger's Syndrome, Downs Syndrome and Tuberculous Sclerosis. Four of the children attended special schools, two attended Integrated Resources, and one was in mainstream. Five parents were not currently using any childcare services for their disabled children, two were employing privately-recruited carers, and one relied regularly on extended family for childcare.

To provide a backdrop for the meeting, parents were given an update on the DCATCH work in Sheffield and a quick summary of responses to the consultation questionnaire received so far.

Parents picked up on the fact that over 60% of parents had said that they were "very interested" in financial matters such as benefits, help with childcare costs, etc. All parents were in agreement that information about benefits is not readily available. All except one parent reported that it had been other parents (rather than information services or professionals) who had told them about benefits like Disability Living Allowance, Carers Allowance, free driving lessons etc. One parent reported that a worker at JobCentre Plus whom she had asked about DLA for her child had been unaware that this benefit was available for children as well as adults.

One parent commented on information about additional needs funding for childcare providers. She described a situation that she had found herself in a few years ago, when her child's disability had just been diagnosed. Her child's nursery had refused to take her child for 5 days per week as initially agreed, citing a "lack of resources" required to meet her child's needs as the reason. The parent then had to find a second nursery to care for her child for the remainder of the time. This had a negative impact on her child, who finds it hard to cope with uncertainty and change.

With regard to information about transport, several parents raised the issue that the transport service will only drop children off at their homes and not at alternative sites, such as a childminder's house or a sibling's school. One parent commented that it was the rigidity of the transport policy which made it impossible for her to find a childminder for her children. Other parents confirmed that having children at different schools - i.e. disabled child at a special school who can only be dropped off at home, and sibling(s) at local mainstream school who need to be collected from their school - is a major barrier to accessing a childminder.

Parents confirmed that it would be useful to have more information about specialist childcare providers. However, they also pointed out that it was the lack of specialist childcare, rather than lack of information about it, that was the real problem. Nobody knew of any special schools in Sheffield that offered breakfast clubs. After-school provision at special schools is patchy; many do not offer any after-school care, and those that do so tend to provide it solely as a short break service, rather than paid-for childcare. This disadvantages working parents. Special schools wishing to set up after-school clubs find that transport is a major obstacle. The transport service will not take pupils from an after-school club to their homes. Instead, they can only be dropped off at a central point, where they would need to be picked up by their parents. For this reason, the Rowan School abandoned plans to set up an after-school club. Heritage Park special school is currently negotiating with the Council about organising their own transport, in order to be able to offer an extended school day in the future.

Parents advised that there is a general shortage of childminders in some areas of Sheffield. Many childminders do not offer holiday care, which is a major obstacle for parents of children who cannot access mainstream holiday playschemes.

Two of the parents in the group said that they received Direct Payments in lieu of a social care service. They commented that they felt restricted by the fact that they were not allowed to undertake paid work whilst their child was being looked after by a carer. They also felt that regulations that prevent their child's carer from looking after siblings were an unnecessary interference in their lives. Sending siblings to childcare settings or using a second carer in the home while the disabled child is being looked after by "their" carer was regarded as both impractical and divisive.