

Parent Carer Support Services Consultation

Workshop 1

Monday 22nd April 2013, 7-9pm, Quaker Meeting House

Six parent carers in attendance. Not conflicts of interest declared.

Exercise 1: Gaps in Service

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 the following gaps:

1. Help to access information and advice

Parents commented that information is **not provided proactively**. For example, some parents only learnt about Transition reviews and S139a Learning Difficulty Assessments at the Post 16 Information Day organised by the Parent Carer Forum; they could not understand why schools were not volunteering this information.

Parents felt that the knowledge base and experience of the professionals they had approached for information and advice was patchy:

"It's a lottery."

"I only found out about Direct Payments by accident."

It can be particularly difficult for parents of **children without a diagnosis** to access information and support. A parent reported that she had only started on the route to diagnosis only after watching a television programme which featured a person with Asperger's. She eventually secured a diagnosis of Asperger's, OCD, Dyslexia and Dyspraxia for her son when he was 16. She said, *"Our life was hell for 16 years, and we didn't know why."*

Parents felt that more effort was needed to make information and services **accessible to minority groups**. For example, a deaf parent reported that many deaf people find it difficult to communicate by telephone due to the limitations of the TypeTalk service (a service which allows telephone users and deaf textphone users to communicate with each other using a third-party operator to relay voice and text communication). The parent felt that a Council service had deliberately ignored his emails, hoping he would "go away". It was only with the help of the Parent Partnership Service that the parent was able to resolve his issue.

All parents agreed that **published service standards** requiring Council employees to respond to emails and voicemail message within a specific timeframe would be very helpful. Some services now publish response targets in their email signatures.

A parent from a minority ethnic group commented that parents may need to access to information in their **home language**. Services providers need **cultural awareness training**; they must understand that one negative experience may be enough to make a family withdraw from a service and rely on family networks instead.

Most parents had experienced being passed “from pillar to post”. All felt that getting information and support had been an uphill struggle, and that access to services depended largely on the parent’s ability to push for them.

“It’s survival of the fittest.”

While some parents were quite happy to spend hours surfing the web in search of information, others felt **overwhelmed by the information** available. One parent said, *“I was looking for a service on the Help Yourself database, and making notes as I clicked through the search results. By the time I got to the letter ‘I’, I had run out of steam and broke off the search. I tend to put things off when I feel overwhelmed, and then nothing gets done.”*

Parents said that they **struggled to filter the vast amount of information** available because they didn’t know what they were looking for, or what to expect. They pointed out that having a range of options was only helpful if they were able to weigh up their relative merits. A parent described searching for a support planner for her son:

“There was nothing to go on, I didn’t know what to expect or which questions to ask, so I just rang the first person on the list. She sounded nice on the phone, so I decided to go with her.”

Parents felt that it would be useful to have some kind of user rating system, or a checklist of things to look for.

Parents commented that information tends to be **scattered across different sites**. For example, a parent reported great satisfaction with youth clubs run by Sheffield Futures, but said she only stumbled across this information during an internet search.

2. Emotional support

A parent described how the personal statement for her child’s social care assessment had affected her for weeks afterwards, as it had forced her to think about how much her disabled child’s younger sibling had missed out on, and how she had missed out on time with her younger child.

Parents highlighted the long-term effects of being a carer on their mental and physical health. They did not think that health and wellbeing activities for carers would help to alleviate their stress (*“half an hour of hand massage won’t do it for me”*), but felt that having good peer support networks made a big difference. One parent described her get-togethers with another mother of a disabled child as her “weekly therapy session”.

Parents said they particularly needed emotional support just after diagnosis.

3. Help to access support groups

Parents had different views about the usefulness of support groups. Some felt that it made them more stressed to listen to other people's problems, while others felt they benefited greatly from the chance to exchange information and provide mutual support.

The parent of an 18-year-old with a rare neurodevelopmental disorder was only aware of condition-specific support groups, and had assumed that there were no suitable groups for her. She was not aware that pan-disability groups existed, nor that SIGN holds a register of support groups.

4. Help to access short breaks / respite

A parent reported that she had lost her entitlement to weekly overnight respite when her child moved to secondary school, and was awarded 3 hours per week of short breaks instead. She was told that her family didn't "fit the criteria", but it was never told what those criteria were. About a year later, the parent made another attempt of getting respite, and submitted a supporting statement from Ryegate. The request for respite was turned down, but the short breaks entitlement was increased from 3 to 6 hours. After a few false starts, the family accessed Crossroads for a few years. The parent then received a letter 5 weeks before Crossroads was due to close. This was a few weeks before her child's 18th birthday. When she rang adult social care to ask about respite, she was passed from pillar to post.

Another parent felt that people tended to "put children in boxes". For example, the respite care home attended by her child would insist on her son following the same routines as the other children, even though his needs were quite different and the routines not suitable for him. It was only through the intervention of a social worker that a more flexible approach was adopted.

Parents also reported issues around accessing Direct Payments, and several said they needed support with finding a PA for their child.

5. Help finding Childcare

Parents reported that many families with disabled children rely on relatives for childcare, but can find that ageing grandparents eventually get too frail. It can be difficult to find someone they feel they can trust.

One parent had accessed the brokerage service for student practitioners via SIGN and found this very useful.

6. Support to manage child's behaviour

Several parents had attended Triple P / Stepping Stones parenting courses. Although they felt that the eight-week course was quite generic, they did report that it provided validation and gave them

useful strategies to try. The biggest benefit, however, seems to have been the opportunity to meet other parents in a similar situation and provide mutual support.

Other parents said that they needed help managing their child's sleep problems and toileting issues.

7. Education

Parents said they needed support with choosing a school and getting a place, and with school reviews.

8. Other

Other areas which were mentioned briefly included medication, aids and equipment, transition to adult services, and SEN transport.

Why did you need this help?

Parents needed help because:

- They were unable to find the information they needed
- They "got lost in the system" and needed someone to move things on
- They were in crisis
- They were experiencing severe stress at home

Where did you look for help?

- Online
- Support groups
- Doctors
- Asked around
- Children with Disabilities Team
- Ryegate support group
- Sheffield Carers Centre

How did you find out about services/people who might be able to help?

- Other parents
- Support groups
- Online
- Some professionals (only forthcoming with information when asked)

- Sheffield Help Yourself database
- Leaflets provided by SIGN

Why were they unable to help you?

- **Lack of joint-up working:** Parents said that the support they received was very fragmented; they said they had to repeat their story over and over again to different people. They felt that there should be one central record of the child's and the family's needs, which should be accessible to all the agencies/professionals involved. Parents were concerned that important information can get watered down or forgotten. When asked whether their child had a CAF, several parents said they didn't think so, and were unaware of the term. On further questioning, however, it transpired that their children were accessing short breaks services which require a CAF to be completed, so it would seem that that CAFs were completed but not explained to the parents.
- **Lack of time to provide individualised support:** Parents felt that, because of cuts to social care budgets, social workers no longer had the time to really get to know the family. They also felt that social workers were constrained by regulations (e.g. no longer allowed to help families fill in benefit forms). Once a family is deemed to be no longer at risk, they are handed over to the duty social worker. One parent said, *"I don't want any more to do with social workers, they just add to the pressure."*
- **Getting lost in the system:** A parent spoke of her experience with a social worker who did not show up for a second visit at the agreed time, and did not call later to apologise. She only knew the worker's first name and had no contact details, so felt unable to pursue the matter.
- **Lack of information:** Parents said professionals were not well informed, or did not volunteer relevant information
- **Suitability of information provided:** a parent said that the leaflets provided by SIGN were too simple, and didn't really help her with a complex disability (child severely autistic). Some contact numbers were out of date.

How did NOT being able to get support impact on your family?

Parents described how struggling on their own had taken a toll on their physical and mental health:

- *"I've been at breaking point several times"*
- *"It's put a strain on my mental health – I'm more quick tempered, fearful and stressed."*
- *"I've had a lot of stress and worry, and I'm now very ill myself."*
- *"I feel a lot of frustration and anger – it makes you negative about all services."*
- *"Our family life is very disjointed; we are a split family as one parent has to do activities with disabled child and the other parent with the other children."*

Exercise 2: What should a good support service look like?

The group looked at the case study, but mostly discussed their own experiences.

Parents said a good support service should provide:

- Keyworker type support
"At the moment, we parents are the keyworkers."
- Face-to-face consultations and home visits if required, especially for initial contact
- A central place to get all your information from, which provides *proactive* signposting, and gives parents time-relevant information in manageable chunks
- Long-term support (someone to have regular contact with, who will check up on the parent and get them back on track)
- Practical support, e.g. someone to accompany parents to look at schools, who can find things out, do trouble-shooting
- 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.
- Peer support
- Counselling

Parents described the characteristics of a good support service:

- Independent of health, education and social services
- Competent, professional and on our side
- Listens to the parents **and** the child
- Able to empathise (rather than just sympathise) and who BELIEVES what you say: "Someone who is on our side"
- Excellent knowledge of the system and the range of local provision
- Good knowledge of disability and how it can impact on the child and the family
- Able to respond quickly
- Able to tailor their communication to specific groups of parents, e.g. texting for deaf parents

Examples of good support

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."* The parent felt that this was because the person who runs the service is a former parent carer herself.

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 her child.

Parent Carer Support Services Consultation

Workshop 2

24th April 2013, 12-2pm, Quaker Meeting House

The workshop was attended by eight parent carers and Liz Roe (Service Manager – Strategy and Partnership, Sheffield City Council). No conflicts of interest declared. Liz Roe offered to step outside if parents felt this would help them to speak more openly.

Exercise 1: Gaps in service

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 the following gaps:

1. Support for parents who get “lost in the system”.

Example: A parent reported that it took her 9 months to set up a direct payment. A CRB check for a PA, which would normally take 6 weeks, took 6 months to complete as the direct payments worker had not filled in the correct forms. The parent was battling with a serious illness at the time and did not have the energy to keep chasing things up.

Parents identified a number of reasons why families can get “lost in the system”:

- lack of communication between different services
- too many people involved (e.g. social worker, Direct Payments worker, payroll provider, CRB service)
- lack of staff training (e.g. staff not completing the correct forms, giving parents incorrect information)
- human error (e.g. forms getting lost)
- unresponsiveness (e.g. staff not returning phone calls, not responding to emails)
- lack of continuity (e.g. no handover to another member of the team when staff are on long-term sick leave or annual leave)

Suggestions: Families should be able to contact someone to troubleshoot and move things on when they get stuck. This person would also need to provide feedback to service managers so that service performance could be improved. Parents felt that the need for third party intervention could be reduced if services had clearly articulated service standards (e.g. timescales, target response times), an effective complaints procedure, and easy access to senior managers.

2. Lack of signposting

Example: A parent of a child with Down Syndrome was looking for someone with Makaton training to do regular 1:1 work with her child at home. As her child also has a hearing impairment, she approached the Hearing and Speech Service at the Audio Department of Sheffield Children's Hospital. A member of staff carried out a home visit and arranged a follow-up appointment, but failed to attend. The parent made a complaint but received no response, and felt too deflated to pursue the matter further. Other parents advised that, if the Hearing and Speech Service was unable to help, the parent could contact SIGN to enquire if they had details of any Makaton-trained student practitioners looking for work. Failing that, the parent could try to recruit a student and send them on a Makaton course.

Not all parents were aware of SIGN, or knew what their role was. They felt that SIGN differed from other services (e.g. Short Breaks Grant scheme) in that it did not offer a tangible benefit to parents. Parents commented that many support services for parent carers have very similar names, and it is easy to get confused as to who does what.

Suggestions: Services need to articulate clearly what they can and cannot offer. When a service is unable to help, staff should refer or signpost parents to the correct service, and follow this up with a phone call a couple of weeks later. Professionals need to know who they can contact for information – a signposting directory would be helpful.

3. Emergency childcare

A grandparent carer needed someone to take care of her grandson while she had to go into hospital for an operation. She approached the child's school, which referred her to MAST. MAST were unable to help as much as she needed, which added to her stress.

4. Information and support around diagnosis

A parent reported that she did not know where to look for information and support when she had concerns about her child's development. The GP said there was nothing wrong. Eventually the school referred the family to MAST, and they now have a MAST intervention worker.

Exercise 2: What should a good service look like?

Parents said that the family in the case study faced multiple challenges, which Emma would not be able to deal with on her own. They said that someone needed to go in and support Emma to access the right services for each family member. The highest priority would be support for Emma, as the rest of the family depended on her.

Parents identified childcare as the most urgent issue, as without this, Emma was at risk of losing her job. In addition to the financial implications, losing her job could make Emma feel isolated and depressed.

Parents said that Emma needed emotional support to deal with the trauma she was experiencing. In the first instance, this should be provided by a keyworker, but in the long term Emma was likely to benefit from some form of peer support, e.g. support groups or befriending.

In order to access the multitude of services required by the family, Emma would need to deal with many different people, and a key worker could provide some stability.

Parents were unsure whether there currently was a service in Sheffield which could provide this type of support. Liz Roe explained the role of Family Intervention Workers, who are located in area-based Multi-Agency Support Teams (MAST). These workers provide preventative and early intervention services to local families who are experiencing challenging situations/circumstances and take on some key worker functions.

Parents said a good support service should be:

- Responsive: should start within days of referral
- Face to face: parents should be given the choice between a home visit and seeing someone in an office – some parents find home visits stressful (may feel they need to clean the house), others may find it difficult to get around. The worker should get to know child as well as parent.
- Direct: parents should be given a direct phone number for worker (if working part time or on annual leave, an emergency phone number should be provided)
- Hands-on: the worker should accompany parents to meetings, help with form filling, make phone calls on Emma's behalf

Parents described the characteristics of a good support worker:

- Good listener, communicator, deliverer
- Able to tailor the level of support to the personality of parent
- Able to provide emotional support
- Able to build parents' confidence and empower them. Must help parents to understand and navigate the system, e.g. by clearly explaining the significance of assessments and forms. The parents should have ownership of the case file.
- Have a good knowledge of local services, and be prepared to go away and find out what they don't know
- Able to draw out detailed information
- Have a "can do" attitude
- A lot depends on personality – "the value is in the person"
- Able to filter information and present it in manageable chunks that are relevant to the family, so that parents don't get overwhelmed by too much information
- Facilitate peer support – could be more than just signposting parents to support groups, e.g. could buddy parents up, run a befriending scheme
- Provide a wraparound service – 24/7 support

Examples of good support

A parent described how a Family Intervention Worker met with her once a week and got to know her child. The worker was very supportive, provided some vital signposting to St Vincent's furniture store, and sorted out toys for child.

Another 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.

Parent Carer Support Services Consultation

Workshop 3

26th April 2013, 10-12, St Mary's

The workshop was attended by seven parent carers and Liz Roe (Service Manager – Strategy and Partnership, Sheffield City Council). No conflicts of interest were declared. Liz Roe offered to step outside if parents felt this would help them to speak more openly.

Activity 1: Gaps in service

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 the following gaps:

1. Help with transport

A parent of a 4-year-old child with Cerebral Palsy said that lack of transport was a big issue for her. The parent doesn't drive, and cannot access public transport because of her child's disability. This affects transport to respite (SEN transport will not pick the child up from school as he currently only attends for half days due to his age) and to medical appointments.

2. Help to access home adaptations / equipment

A parent had applied for home adaptations / equipment to enable her to bath her physically disabled child, but this was declined. The reason given was that the family were living in rented accommodation. The child only has a bath once a week at respite.

Another parent had been told that the equipment services was means tested, but did not trust this information.

3. Help with referrals

A family had asked their GP to refer them to children's social care, and were still waiting for a referral to be made five months later. They were not aware that they could self-refer.

4. Help with benefits

A parent said she believed that she did not qualify for most disability benefits (e.g. DLA or Carer's Allowance) because of her immigration status.

Another parent felt that her child was on the wrong rate for DLA, and needed help appealing the decision.

5. Help with home-school transport

A parent said she had been waiting for 7 months for transport staff to receive training to manage her child's seizures.

6. Childcare/respice

Parents gave the following examples:

Problems finding respice for a 14-year-old with Cerebral Palsy, learning difficulties and autistic traits, who "doesn't fit into any boxes". SNIPS had tried to place the young person in a nursery. The parent felt that there was no suitable local provision, and no transport. The parent had applied for Direct Payments, but got "lost in the system" (paperwork was left with A4e when the contract with the Council ended).

Problems finding after-school childcare and holiday care. A parent said she did not know who offered this service or where to find information. She had asked a previous family placement carer, SIGN and a previous social worker, but found these only knew about one service. The lack of childcare caused a lot of stress for the family, and meant that the parents had to rely on 80-year-old grandparents to help out.

Lack of emergency childcare; a parent was unable to find someone to look after her disabled child when she was dealing with a family emergency.

Lack of holiday childcare for 16 to 18-year-olds.

7. Help with school issues

A parent of a 4-year-old child with a thyroid condition had concerns about her child's language development and behaviour, but felt she was being fobbed off by school and medical professionals whenever she mentioned these. She reported that her son struggled with understanding and was often tired, but received no extra help at school (despite being at School Action Plus). A social worker had briefly worked with her, but had now closed the case. A Health Visitor was coming in for occasional monitoring visits. The consultant at the hospital was mainly focussed on her son's medical needs. The parent felt that the school mostly saw her son as a trouble maker, and had called her parenting skills into question (e.g. staff had asked her when her son's bedtime was because he was often tired at school - which is a symptom of his medical condition). She reported that she had twice received a letter from school inviting her to an IEP review **after** the meeting had already happened.

The same parent also reported that one of her older children had been expelled from school and was now attending a PRU. She suspects that this child also has special needs, but when she took him to the GP, no referral was made.

A parent of an 8-year-old with a statement of SEN reported difficulties when changing schools. It took 3 months for the school to transfer her child's records, and during that time, her child received no extra help at school.

8. Help with housing issues

A single parent of seven children said that she struggles with housing conditions as her children share bedrooms and tend to wake each other up at night. The parent said she had no idea whom she could ask for help. She does not access the internet.

Another parent said their child was struggling to study for his exams as they had a younger sibling with learning difficulties and there was nowhere quiet for them to study.

9. Help making a will

A parent reported that she had been quoted £850 for making a will.

General discussion

Parents had varying levels of awareness of SIGN, short breaks, and the Parent Partnership Service. Some parents had not heard of any of them, some had heard the name but were not sure what the service offered and whether they were eligible. Nobody had heard of, or accessed, MAST or Family Intervention Workers.

Participants commented that different people had told them different things, and that it was very time-consuming to find the information they needed. For example, a family was told by Bents Green School that their son could not access their respite facility (Gibson House), but were subsequently offered Gibson House through Children's Social Care. Parents said that many professionals and services did not fully grasp how many demands there were on their time. Several parents gave examples of phone calls and emails being ignored.

Parents said that not being able to find the information, advice and support they needed made them feel frustrated, stressed, exhausted and mistrustful.

There was a general perception that it is harder to access services as children get older:

"Many services stop when the child starts school."

"It gets worse as children get older, and even worse when they get to 16."

Exercise 2: What should a good service look like?

Participants looked at the case study and discussed how Emma might access the support she needs. They said that parents will often downplay their issues because they worry that social services might take their children away if they think they are unable to cope. Several participants said that a visit to the GP was likely to result in Emma being prescribed antidepressants. They felt that any services Emma approached for help were likely to focus on their subject area, and might not look at Emma's situation holistically. Parents said that services don't communicate well with each other.

Although a Carer's Assessment should identify all the needs of the family and address them, several parents felt that this didn't happen in all cases. Many parents had never heard of a Carer's Assessment, others thought they were only for carers of adults.

Parents said that they sometimes spent time chasing people up to get an appointment, only to be given more things to do. Some parents felt that lengthy meetings with lots of people just increased their stress levels, as they were falling behind with all the other things they needed to do.

A parent of an older teenager described how the role of social worker had changed considerably over the past decade: *"They used to be really good, but now you ask a question, get an answer, and that's it."*

All agreed that Emma's wellbeing should be the first priority, particularly as there is no partner to take some of the stress. Several parents empathised with Emma's situation:

"Nothing can happen to me as otherwise everything collapses."

Childcare was identified as the priority issue, as without it, Emma was at risk of losing her job. Participants listed a range of other services required by the family, such as speech and language therapy and behavioural support for Alex, DLA advocacy, SNIPS, respite, leisure services, CAMHS referral for Lucy, school liaison, and support to liaise with hospital to sort out a social care package for Emma's parents. They pointed out that parents in crisis didn't have the time or energy to chase things up. Many felt that only the strongest and most determined parents were able to secure the services their child needed:

"It's survival of the fittest."

Parents said a good support service should:

- Be able to respond quickly to families in crisis
- Provide practical support, e.g. by making phone calls and chasing things up
- Get to know the family and have regular contact with them
- Be able to listen and empathise
"Many professionals would like to do that, but they are fighting a system focused on throughput."
- Be able to think outside the box
- Have a degree of objectivity – parents may be reluctant to speak freely about issues with Council services to someone who works for the Council

- Provide continuity and dependability. There is a risk that if workers are paid low wages, there could be a high turnover of staff.
- Have a good knowledge of local services, and not be afraid to say “I don’t know, but I will find out” – and then deliver!
- Explain things to parents in simple terms, and advise them where to go and what to do.
- Facilitate peer support. Parents had different views how this could be delivered – some preferred coffee mornings, others liked the idea of a befriending scheme. However, all agreed that the information they had received from other parent carers had been extremely helpful.

Parents felt there would need 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.

Examples of good support

Parents praised the service they had received from the Ryegate Centre; they particularly liked 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.