



Issues raised by parents

Background

In April/May 2013, Sheffield City Council commissioned the Sheffield Parent Carer Forum to find out whether the current range of services was meeting the support needs of parent carers in Sheffield. In particular, the Council wanted to establish whether there were any services which were required but were not currently being provided (i.e. gaps in the range of services).

As part of this work, families inevitably shared with us experiences, concerns and perceptions in relation to specific services. Whilst these are outside the remit of this specific piece of work, they are nevertheless of equal importance.

We have therefore compiled this document, which incorporates feedback from the questionnaires and consultation workshops, as well as feedback we have received from parents by telephone, email, Facebook and at meetings and outreach activities over the past 12 months. We have only included “common themes”, i.e. issues which have been raised several times and by several people.

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.

Updates will be published via our website (www.sheffieldparentcarerforum.org.uk).

Comments in relation to specific services

Childcare

- Lack of local holiday care and after-school care able to meet the needs of disabled children
- Finding suitable childcare is particularly difficult for parents of children who are older (secondary age), who have multiple impairments, who display challenging behaviour, who require medical interventions, who have specific communication needs, who require a high amount of supervision or who need a specific environment (e.g. enclosed outdoor space)

- Lack of emergency childcare
- Difficult to access childcare if child attends a special school and SEN Transport will not drop the child off at the childcare setting

Comment from questionnaire: *“Childcare and leisure services in Sheffield operate on normal behaviour management techniques. Poor behaviour results in child being excluded - this is acceptable according to OFSTED as long as it is stated in the behaviour policy.”*

Direct Payments

- Several parents have commented on the length of time taken to set up a Direct Payment (in one case this took 18 months)
- Communication and training issues (e.g. staff filling in the wrong forms)
- Parents would like help with finding a Personal Assistant (PA) for their child
- Information provided is too basic, particularly around parents’ responsibilities as employers
- Wrong information given out by social workers (parents were told they did not qualify for Direct Payments as their children attended mainstream schools)

Comment from questionnaire: *“Asked for social worker to help get support for Direct Payments but no outcome - passed from pillar to post - no one seems interested.”*

Education

- Parents said they needed help with the following issues: choosing a school and getting a school place, transitions between schools, school reviews, communication with school staff, getting the school to recognise the child’s needs, and getting the right level of support for their child.
- Many parents are unaware of the Parent Partnership Service
- Lack of support for families who have withdrawn their child from school because of mental health issues (e.g. anxiety, depression, suicidal ideation, often exacerbated by bullying). Families are not clear about the entitlement to support from the Home and Hospital Service and Social Care in these cases.
- Lack of support to help families find an appropriate school for a child with anxiety issues. Lack of flexibility in some schools to allow the child to have a phased return with extra support.
- Lack of flexibility of Integrated Resources (IR) to adjust the amount of time students can spend in the resource (e.g. to operate a staged integration into mainstream).

- Lack of appropriate specialist school placements for children with autism who are academically able, particularly for those who have significant additional needs (e.g. sensory issues, PDA, mental health issues, severe behavioural problems).
- Lack of information about processes, rights and responsibilities in relation to SEN
- Lack of information about specialist provision, e.g. admissions criteria, application process, transition timescales, special school open days

Comment from questionnaire: *“I've found help now but it's very difficult to find it. Having children in special school changes everything and everything is handed to me on a plate now.”*

Transition

- Concerns about the quality of Section 139a Learning Difficulty Assessments completed by schools, e.g. incomplete information about the young person's needs, assessments completed without involvement of parents
- Parents of young people about to enter post 16 education are worried about the prospect of a 3-day or 4-day week in education. They fear that they may need to give up their job to care for their child during the time they are not accessing education.

Short breaks / Social Care

- Parents often tell us that they don't understand the process for allocating short break services, and that there is not enough feedback from allocation panels when a request has been turned down (e.g. parents describe being “turned down” for respite without ever finding out what the criteria for this decision were; others said they were told very late in the process that they would lose some of their existing provision if another type provision was approved)
- The transition to adult social care services was identified as a particularly difficult time
- Concerns about the length of time taken by SNIPS to process referrals and place children, and about the appropriateness of SNIPS placements
- Complaints from parents whose SNIPS provision was stopped at short notice, with no alternative provision offered (except direct payments in some cases)

Health

- Parents have reported a lack of clarity among professionals (e.g. GPs) about referral pathways for accessing mental health support, which can result in lengthy waits

when re-referrals have to be made. We have had several reports of parents being asked to choose between Ryegate and CAMHS

- Parents often tell us that they feel their child is not getting enough input from Speech and Language Therapists. It is not uncommon for children to only see a therapist once a year. There can be issues around schools not referring children to the service for assessments, or not implementing therapy programmes
- Parents described how they had struggled to get their GP to take their concerns seriously and refer their child to a specialist
- Not enough post-diagnosis support

Home adaptations

- Confusion about the eligibility criteria for home adaptations (parents had been told that the service was means-tested and not available to families in rented accommodation)

SEN Transport

- Lack of information (or wrong information) for families about staff, vehicle and pick-up times, especially at start of new school year
- Transport making changes to travel arrangements without consulting with parents or school staff as to their suitability for individual children's needs
- Difficulty getting siblings into school on time because of pick-up and drop-off times
- Long journey times in excess of national guidance; up to two hours in some cases
- Staff not given information about children's needs and insufficient training to deal with them (e.g. one parent had waited 7 months for transport staff to receive training to manage her child's seizures)
- Children with behavioural problem being excluded from transport for having behavioural problem on the bus
- Poor communication between Transport office and bus crews, and between transport office and schools, especially during bad weather
- Lack of flexibility regarding alternative drop-off points is impacting on parents' ability to work, as they are unable to use after-school childcare

Behaviour support

- Parents often contact us to ask who they can approach for help with behavioural issues. This concerns not only challenging behaviour, but also problems with sleeping, feeding and toileting
- Lack of information about support available, e.g. most parents (and many professionals) don't know that Speech and Language Therapy Service can help with feeding issues, or that the Sheffield Children's Hospital has a Sleep Service
- Limited support from services such as Autism Service or Educational Psychology – although parents can ring these services directly, they are services to schools, not parents
- Long wait to access Ryegate Psychology “drop-in” clinic (currently 6 months)

Leisure activities

- Lack of suitable local provision
- Lack of small-group provision

Crisis support

- Lack of rapid intervention services to support families with disabled children at times of crisis, e.g. hospitalisation of child or main/sole carer, emergency childcare for working parents, severe family breakdown etc.

General comments

Provision of information and advice

Participants at all three workshops commented that getting information and advice had been an uphill struggle. They pointed out that the knowledge base of professionals is variable, and information is not always provided proactively. “I only found out about it by accident” was a recurring comment.

The main issue was not the availability of information per se, but getting the right kind of information, from the right person/service, at the right time. Some parents said that they struggled to filter the vast amount of information available on the internet because they did not know what to look for, or what to expect. Parents were clear that being presented with

lots of different options was not helpful if they were unable to weigh up their relative merits.

Parents with specific communication requirements (e.g. deaf parents, parents who speak English as an additional language) said they found it particularly difficult to engage with services.

A number of parents had never heard of key services like SIGN, short breaks or the Parent Partnership Service. Other parents had heard of them, but were unsure what their remit was and whether they were eligible; they commented that it was easy to get confused as some services had very similar names, and also because service names and providers kept changing.

Parents said that not being able to find the information, advice and support they needed made them feel frustrated, stressed, exhausted and mistrustful. They said that searching for information was extremely time-consuming, particularly as it tended to be scattered across different sites.

Difficulty accessing or using services

Workshop participants felt that access to services largely depended on parents' ability to push for them, and that only the strongest and most determined parents were able to secure the services their child needed:

"It's survival of the fittest."

Many parents described "getting stuck in the system" or being "passed from pillar to post". They identified a number of reasons why this happens:

- capacity issues due to low staffing levels
- too many people involved / lack of communication between different services
- lack of effective signposting / staff failing to take responsibility if a client falls outside their target group
- lack of staff training (e.g. staff not completing the correct forms, giving parents incorrect information)
- human error (e.g. forms getting lost)
- unresponsiveness (there were numerous accounts of staff failing to keep appointments, and ignoring emails and telephone calls)
- lack of continuity (e.g. no handover to another member of the team when staff are on long-term sick leave or annual leave)

There was general agreement that families needed support to chase things up when they got stuck. This is particularly important for families who face additional challenges, and families in crisis.

Parents were keen to point out, however, that third-party interventions could be avoided in many cases if services were held to account more effectively. For example, services could be required to publicise their performance targets more widely (e.g. target response times stated in email signatures and voicemail messages, timescales published in information leaflets). Clear eligibility criteria, effective complaints procedures, easy access to senior managers, and improved signposting would all help to reduce the need for third-party interventions.

Participants said that not being able to get the support they needed was putting a strain on their mental and physical health. They described feeling stressed, worried, frustrated and angry. Several parents mentioned the toll this was taking on their family life, particularly where the disabled child's needs were such that doing things together as a family was impossible.