



Comments and recommendations regarding information, advice and support for parent carers

14th September 2013

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. A summary of the findings can be [downloaded from our website](#).

This document sets out comments and recommendations from the Sheffield Parent Carer Forum's Management Committee.

We believe that, where parent carers experience difficulties accessing or using services to support them in their caring role, this is usually due to one of the following causes:

1. Issues around information
2. Issues around access to services
3. Gaps in the range of services, or services which don't meet needs effectively

1. Issues around information

Many of the parents who contact us are not aware of services like short breaks, direct payments, Parent Partnership, or SIGN. If parents don't know that a service exists, they are unlikely to ask for it. This makes it much harder for families to access support when it is most effective: early.

It can sometimes seem as if some of the services accessed by our children give a low priority to the provision of information to families. This, in turn, gives rise to a perception among some parents that information is being withheld deliberately as a way of rationing access to services; and that it is the most clued-up parents, rather than the neediest families, who get the services. Clear, easily accessible information would help to level the playing field.

Service areas where information is particularly scarce include:

- Transition (to post-16 education, and from children's to adult health and social care services)

- Special schools and Integrated Resources, including independent specialist providers (admissions criteria, cohorts, application process etc.)
- Eligibility criteria and access routes (e.g. for the different types of short breaks, for statutory assessments etc.)
- The range of short breaks providers

Attempts have been made to plug these information gaps, e.g. via the “Stepping Stones” booklet about primary-to-secondary transitions for children with statements, or the information folder about childcare for children with additional needs, both of which were developed with input from the Sheffield Parent Carer Forum. However, these publications have not been kept up to date. Information services like SIGN depend on service managers to provide them with up-to-date information which can be passed on to parents.

The requirement for local authorities to publish a local offer from September 2014 should help to improve information for families. By involving parents in the development of the local offer from the start, the local authority will be able ensure that the information is accessible and relevant to the people for whom it is intended. Since most parents access information via frontline workers, training for these workers to enable them to communicate the local offer to families must be an integral part of this work. A signposting/referral directory for professionals would be a great help.

2. Issues around access to services

There will always be parent carers who will need intensive support to access and coordinate services for their child and their family; this could be for a number of reasons, e.g. parental illness or disability, illiteracy or limited command of the English language, a crisis situation, or simply because the family has reached a point where it is all getting too much.

For many parents, however, the need for third-party interventions could be much reduced (and money saved) if services were more responsive to the needs of families. We heard far too many stories about phone calls which were never returned, emails which went unanswered, even appointments which were not kept. Parents told us they felt they had been “passed from pillar to post”, or that they had got “stuck” or “lost” in the system. It sometimes seems as if the system is forcing perfectly capable parents into a state of helplessness. When faced with what can sometimes seem like an overly complex or indifferent system, less resilient parents may simply give up.

In order to become more responsive, services must have adequate staffing levels, appropriate staff training, meaningful user involvement, and clear accountability structures. At a time of austerity measures, this may seem difficult to achieve. However, the transformation we feel is needed is not necessarily about investing more money, but about culture change – about working smarter. We have heard so many encouraging stories about

wonderful teaching assistants, social workers, teachers, Portage workers and other staff who “go the extra mile”. One parent even likened her social worker to a “fairy godmother”. We must do more to celebrate these people, and to encourage others to raise their game. Clearly, this kind of transformation cannot be achieved overnight - yet there are many families who need support **now**. So how should they be supported?

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.

Respondents to our questionnaire said they needed information, advice and support in relation to understanding and accessing a number of services, with the following areas ranked the highest: 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. However, evidence from both the workshops and the questionnaires shows that issues can and do arise with virtually all of the services accessed by families with disabled children.

3. Gaps in the range of services, or services which don’t meet needs effectively

Parents identified issues with, and possible gaps in, a number of services accessed by disabled children. Although many of these services are services to disabled *children* rather than to their *parents* and therefore fall outside the scope of the original commission, they nonetheless form part of the **wider support structure** for parent carers. For example, short breaks, childcare and leisure providers can all support parent carers by giving them a break from caring.

A detailed account of the issues raised can be found in the [accompanying document](#). Many of these issues are long-standing and have been raised by the Sheffield Parent Carer Forum on numerous occasions.

There is a perception among parents that there are services missing in the following areas:

- Childcare for specific groups of disabled children
- Support to help parents manage their child’s behaviour
- Crisis support

We recommend that Sheffield City Council:

- Map the areas which parent carers have said they would like help with against current support services, in order to establish whether there are any gaps
- Carry out further selective mapping in relation to areas where parents have reported gaps in the range of services (childcare, behaviour support and crisis support).
- Fund provision which addresses areas of unmet need and which supports parent carers in the way that they want to be supported
- Ensure that existing support services (e.g. Parent Partnership Service, SIGN, short breaks) are better publicised to parent carers and frontline staff
- Work with families to develop an effective key worker system (accessible to a wider group of families than those unable to engage in the EHC assessment process)ⁱ
- Work with families to co-produce a local offer that is tailored to their needs. The Children and Families Bill (which is currently passing through Parliament and which is expected to be enacted in September 2014) requires local authorities to consult children and young people with special educational needs (SEN) and their parents about the services these children and young people require, how the information in the local offer is to be set out, how it will be available to those without access to the internet, and how they can provide comments on the local offer. (*The Special Educational Needs (Local Offer) (England) Regulations 2014, section 5*)
- Ensure that training and information for frontline staff form an integral part of the local offer. This should be supported by a signposting/referral directory.
- Build an effective feedback mechanism into the local offer, e.g. via a web-based “rate and review” feature. Once more and more families start accessing personal budgets for education, health and social care support from 2014, this kind of feedback mechanism could help to ensure a degree of quality control and accountability.
- Work in partnership with the Health service and the Sheffield Parent Carer Forum to further explore the barriers faced by families with disabled children in relation to child health services, and develop and implement ways forward.
- Review and improve service procedures in relation to:
 - Handovers for holiday and sickness cover
 - Communication with minority groups (e.g. deaf parents, parents with English as an additional language)
 - Signposting (information and training for frontline staff, need for follow-up)
 - Publication and monitoring of performance targets (e.g. target response times stated in email signatures and voicemail messages, timescales published in information leaflets)

- Publication of complaints procedures and contact details of senior managers
- Publication of user feedback and actions taken to address any issues identified (e.g. via a “rate and review” feature in the local offer, see above)
- Continue to work with parents to review and improve the whole range of services accessed by disabled children and their families, including:
 - Advice and support around challenging behaviour
 - Direct Payments
 - Childcare for disabled children and young people
 - Leisure services for disabled children and young people
 - Short breaks
 - Transition support
 - Home adaptations/equipment
 - SEN transport

We would be very happy to discuss these recommendations in more detail with councillors, commissioners, service managers and other stakeholders. We remain committed to working with Sheffield City Council, the Health service and other partners to improve services for disabled children and their families.

The Sheffield Parent Carer Forum Management Committee

September 2013

ⁱ Although the proposals on key working outlined in the SEN Green Paper were almost universally well received, the concept is notably absent from the Children and Families Bill. The draft SEN Code of Practice only mentions key working in relation to the EHC assessment process: “Local authorities must consider providing additional practical support, such as key working support, to families who might not be able to take part in the [EHC assessment] process without such support”.