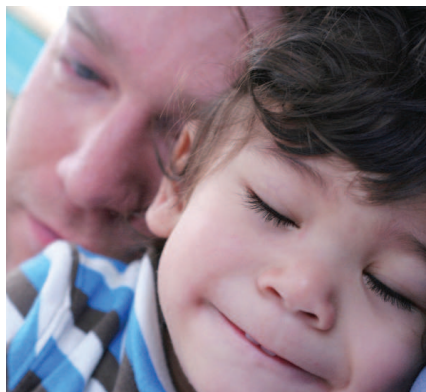




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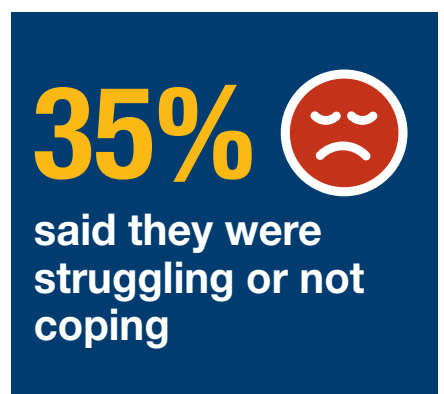
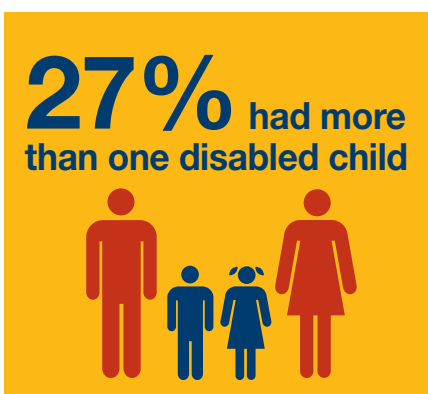


The views of
parents of children
and young people
(aged 0-25 years)
with disabilities
and /or additional
needs



Executive Summary

November 2014



Introduction

This report summarises a study of the views and experiences of parents of children and young people (aged 0-25 years) with disabilities and/or additional needs in Sheffield. It makes recommendations to commissioners and providers of education, health and social care services.

The study was carried out by the Sheffield Parent Carer Forum (SPCF) in March/April 2014 with funding from the Department for Education's Parent Participation Grant.

The study aimed to:

- **gather data on issues raised by parent carers;**
- **find out whether, and if so how, caring for a disabled child affects the whole family;**
- **establish a baseline of parental satisfaction with local services prior to the implementation of the Children and Families Act 2014 and the Care Act 2014.**

The findings and recommendations will be presented to Sheffield City Council, NHS Sheffield Clinical Commissioning Group and relevant providers of education, health and social care services. SPCF will work with them to address the key issues identified in this report.

Funding permitting, this study will be repeated periodically to monitor progress and assess the impact of the reforms under the Children and Families Act 2014 and Care Act 2014.

Method and sample

Parents' views were sought through a questionnaire. Hardcopies of the questionnaire were sent to SPCF's postal mailing list and handed out at events. A link to the online version of the questionnaire was circulated to the email lists of SPCF, Voluntary Action Sheffield, Sheffield Cubed and Sheffield Parents' Assembly. The study was also advertised via SPCF's newsletter and website, and the websites of Healthwatch Sheffield and Disability Sheffield.

A total of 320 responses were received. The response rate from SPCF members who were contacted by post or email was **31%**.

The questionnaire consisted of 67 open and closed questions, covering seven areas: family life, combining work and caring, education, social care, direct payments and personal budgets, health services, and general issues.

Most respondents took around 25 minutes to complete the online survey. Given the pressures described by the respondents, this may reflect their depth of feeling and need to be heard.

The sample covered the full range of children's impairment types, age groups (0-25 years), educational placements and family situations, and most postcode areas (including areas with high levels of economic deprivation). **57%** of respondents were in receipt of means-tested benefits. **15%** were non White British, and **9%** indicated that English was not their first language. **70%** of respondents were parents of children with statements of special educational needs (SEN), indicating that the sample reflected the more severe end of the spectrum of needs.

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Cumulative impact of disability

Key Findings

“With two children with disabilities and having to travel to the support our time is restricted. We get maybe 3 hours and still have to care for one disabled child and the travel can be very stressful.”

44% of the families in the study had more than one family member with a disability or long-term illness. 24% of parent carers had a disability or long-term illness themselves, 27% had more than one disabled child, and 16% also provided care for an adult over the age of 25. These parents were more likely to say they were “struggling” or “not coping” than parents without these additional pressures.

Parents repeatedly told us that services were not geared up to meet the needs of families with more than one disabled child. For example, the Short Breaks Grant is capped at £400 per family, regardless of the number of disabled children in that family.



44% had more than one family member with a disability or long-term illness



24% of parent carers had a disability or long-term illness themselves



27% had more than one disabled child



16% also provided care for an adult over the age of 25

Recommendations

We recommend that:

- Sheffield City Council and Sheffield CCG (Clinical Commissioning Group) systematically collect data on the number of children and adults with disabilities and/or long-term health conditions per household and use this information to design and commission services.
- Sheffield City Council ensures that social care assessments take account of the cumulative impact of providing care for more than one disabled person.
- Sheffield City Council awards the short breaks grant per disabled child instead of per family. Consideration should be given to lowering the threshold for accessing the grant for families with more than one disabled child.

High levels of isolation

Key Findings

“Going out as a family anywhere is now only possible if there are two capable adults. One adult going out with both children is a rarity as we usually end up in impossible situations.”

“Without other parents to share things with I would have had a breakdown.”

Families with disabled children experience high levels of isolation.

Over half of respondents told us that they found it “difficult”, “very difficult” or “impossible” to take part in everyday activities as a family, such as visiting friends or relatives, going out for a meal, going to the cinema, going shopping or taking part in sports.

This was mainly due to the disabled child feeling overwhelmed in noisy/crowded places, a lack of support for parents, and a lack of flexibility to adapt provision to meet the child’s needs. Respondents pointed out that the need for meticulous planning and constant supervision made participation in mainstream leisure activities a stressful rather than a relaxing experience for them.

Only 8% of parents felt fully included in wider Sheffield.

16% felt fully included in their local community.

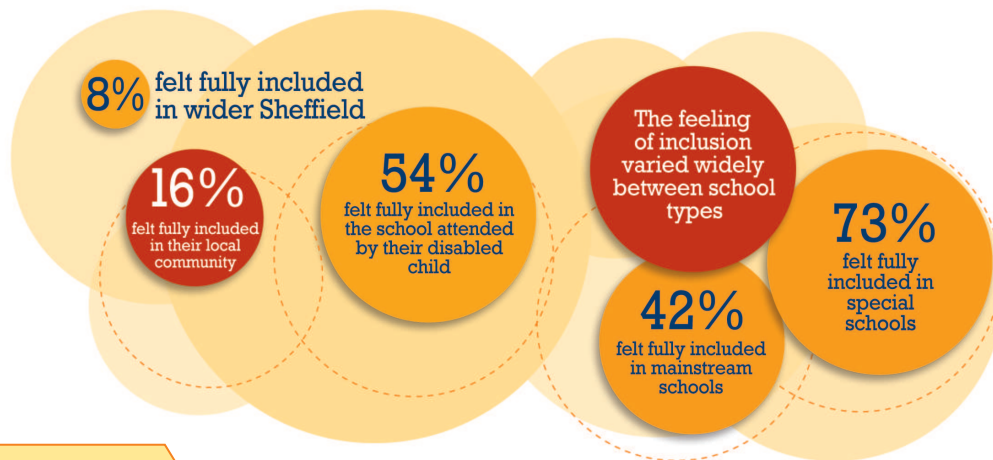
54% felt fully included in the school attended by their disabled child.

Schools play a vital role in enabling marginalised families to feel part of a community. The level of inclusion varied between school types, with more parents feeling included in special schools (73%) than in mainstream schools (42%).

40% of parents had given up work in order to cope with their caring responsibilities. These parents are doubly disadvantaged, as they miss out on social contacts with co-workers and have less money to participate in leisure activities.

When we asked parents what would make life better for them, many said they would like more clubs and social activities for their children to take part in, supported by a buddy or mentor, and more understanding and acceptance in the community.

They also told us that **making contact with other parent carers** helped them to feel less isolated and increased their resilience.



Recommendations

We recommend that:

- Mainstream leisure providers (e.g. leisure centres, cinemas, theatres, restaurants, sports clubs) invest in disability awareness training and work with disabled children, young people and their parents to identify and eliminate barriers to accessing services.
- Leisure providers put on disability-friendly events and/or provide additional support for families with disabled children (e.g. autism-friendly cinema screenings, “Access all Areas” project at Eureka).
- Sheffield City Council funds a range of peer support projects (e.g. parent support groups, befriending schemes).

Impact on parental wellbeing

Key Findings

“Both us as parents and the child that receives the overnight respite rely heavily on this, he needs the time out from the hustle and bustle of the busy family he is part of, he enjoys the peace, and we need the break from the responsibility of his health. The other children benefit from an undisturbed night.”

95% of parent carers reported that caring had affected their wellbeing, particularly their emotional wellbeing, their sleep and relationships. Around half also reported a negative impact on their physical and mental health.

Only 5% felt that they looked after themselves well.

26% said that they often neglected themselves.

35% said that they were “struggling” or “not coping”.

19% stated that they had never had a day or an evening off from caring.

We asked parents what would make life better for their family. The most common response by far was “time off” or “respite”. However, 38% of the parents who said they were “struggling” or “not coping” were not accessing a short breaks service. Most of them said this was due to a lack of information about these services.

Short breaks are a vital preventative service which can avoid the need for far more expensive crisis intervention: the cost of a disabled child being in long-term residential care is estimated to be £2,428 per week – more than £125,000 per year.ⁱ

Two thirds of parents who received a short breaks service said that a reduction in short breaks provision would have a “significant” or “devastating” impact on their family.

76% of respondents said they wanted training to help them cope with their caring role. Their top priorities were: understanding their rights as carers, coping with stress, managing challenging behaviour, understanding disability benefits and understanding the SEN system.

95%
of parent carers reported that caring had affected their wellbeing



Only 5% felt that they looked after themselves well



19% stated that they had never had a day or an evening off from caring



26% said that they often neglected themselves



35% said that they were “struggling” or “not coping”

Recommendations

We recommend that:

- Sheffield City Council prioritises short breaks services when assessing budget cuts.
- Sheffield City Council promotes short breaks services more widely to parent carers, using a range of communication methods.
- Sheffield City Council ensures that the needs of parent carers are taken into account through a distinct carer’s assessment which considers their need to work and to access education, training and leisure activities.
- Sheffield City Council commissions a specialist parenting course which focuses on increasing parents’ knowledge and building resilience (e.g. modelled on the “Insider’s Guide” courses developed by Amaze Brighton).
- Sheffield CCG commissions specialist counselling and wellbeing activities for parent carers.

Impact on siblings

Key Findings

“We can’t get on with homework or do individual reading/ write in reading record when both children are at home. My daughter is missing out on getting reward points which she would otherwise receive if she always managed to do her work”

94% of respondents said that having a disabled sibling had had a negative impact on their other children.

A lack of parental attention was identified as the biggest issue (73%), followed by disrupted sleep (48%) and being actively involved in caring (43%). This, in turn, affected siblings’ mental health, emotional wellbeing and achievement at school.

55% of respondents also identified a positive effect, stating that it had made their other children more considerate, patient or caring.

Having a disabled sibling also increases children’s risk of isolation: around a third of parents said that siblings were missing out on activities (e.g. sports clubs or social events) or could not have friends over.

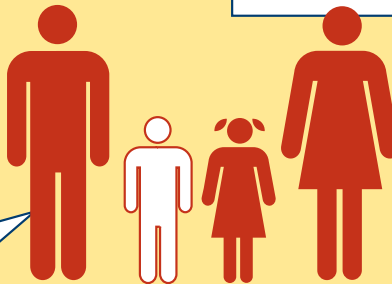
Many studies on siblings of children with a chronic illness indicate that siblings are at risk for negative psychological effects.ⁱⁱ

Short breaks are essential for ensuring siblings get to spend quality time with their parents.

94% of respondents said that having a disabled sibling had had a negative impact on their other children.

“I definitely don’t have the time/energy to put into their school work that I should as I am tired out/run out of time from dealing with the additional needs of my child with a disability”

“It has also made my daughter grow up a lot quicker, she is a lot more mature than her peers”



“They miss out on family activities e.g. cycling trips, playing board games, physical games.”

Recommendations

We recommend that:

- Sheffield City Council considers the views of siblings as part of social care assessments.
- Sheffield City Council ensures that information about short breaks services refers specifically to siblings (rather than using a generic term such as “family members”), and that siblings’ needs are included in the eligibility criteria for short breaks.
- Sheffield City Council ensures that the organisations it funds to provide support for young carers increase their efforts to identify and support sibling carers.
- Schools adjust their policies and procedures to:
 - Formally identify siblings of disabled children and young people;
 - Ensure that all school staff are sibling aware and understand the potential impact on learning and wellbeing;
 - Identify siblings as a vulnerable group in their anti-bullying policies;
 - Help siblings access specialist support and information - in school and in partnership with health and social care;
 - Develop provision for sibling support within school.

Sleep

Key Findings

“Sleeping patterns have meant that we rarely get a good night’s sleep, so the whole household is affected with long-term sleep deprivation.”

53%
said that their child had problems with sleeping

74%
said that caring for their disabled child had affected their own sleep

48%
of siblings were suffering disrupted sleep as a result

“I cry very often during the night because I do not know what will happen with my son if I pass away.”



While most parents go through a period of sleep deprivation while their children are very young, many disabled children have disrupted sleep patterns that persist right through to adulthood. This can have a corrosive effect on the whole family:

53% of respondents said that their child had problems with sleeping.

48% reported that siblings were suffering disrupted sleep as a result.

74% said that caring for their disabled child had affected their own sleep.

Parents’ sleep can be affected by the need to supervise their child while they are awake at night; to be on “high alert” to respond to medical problems (e.g. seizures); to provide medical or personal care during the night; and the impact of stress and anxiety.

Sleep deprivation is a root cause of a wide range of problems; it affects mental and physical health, impacts on resilience and self-esteem, leads to memory problems, affects children’s behaviour and educational attainment, and places a strain on relationships. For parents, it doubles the risk of causing a traffic accidentⁱⁱⁱ and makes operating machinery unsafe.

The financial impact of sleep problems can be significant, as parents may be forced to give up work. They may have to move to a bigger house or build an extension in order to give the disabled child a separate bedroom.

Children’s sleep problems also cost the taxpayer a lot of money. By successfully addressing sleep problems early on, the need for more expensive services could be significantly reduced.

Recommendations

We recommend that:

- Sheffield City Council prioritises overnight respite when assessing budget cuts.
- Sheffield City Council and Sheffield CCG commission sleep seminars for parents as part of post-diagnostic support for a range of neurological conditions – whether or not the child already experiences sleep problems. This would help to head off sleep problems before they become entrenched.
- Sheffield CCG commissions a specialist sleep support service for children with disabilities.
- Sheffield City Council includes questions about sleep problems in relevant needs assessment frameworks (e.g. Family CAF, social worker assessments).
- Sheffield City Council and Sheffield CCG provide training for frontline professionals on the impact of sleep deprivation on the family, and ensure they are aware of referral routes into sleep support services.
- Sheffield City Council publishes information about help with sleep problems in the local offer. This should include information about sleep support services and grants for equipment and adaptations to the home (e.g. soundproofing, safe spaces, sleep monitors, weighted blankets).

Challenging behaviour

Key Findings

“We can never relax as our child needs to be supervised all the time as he wanders off without telling anyone and also throws any object he can lift and can be very dangerous.”

59% of respondents said that their child displayed challenging behaviours. This can include aggression (e.g. hitting), self injury (e.g. head banging), destruction (e.g. throwing objects) and other problematic or unsafe behaviours such as running away, inappropriate sexual behaviour, or pica (eating inedible objects).

Challenging behaviour affects families’ ability to cope. 74% of the families who said they were “struggling” or “not coping” had a child with challenging behaviour.

Challenging behaviour is often a consequence of not being able to communicate needs. It can be exacerbated by sleep deprivation and poor or inconsistent management which inadvertently rewards problem behaviours.

Challenging behaviour contributes significantly to the isolation experienced by families, because it makes it so much harder to participate in everyday activities.

50% of parents said they would like training on managing challenging behaviour.

59%
of all families said that their child displayed challenging behaviours

74%
of the families who said they were “struggling” or “not coping” had a child with challenging behaviour



Recommendations

We recommend that:

- Sheffield City Council and Sheffield CCG commission a specialist behaviour support service, based on a multi-disciplinary approach and operating an open referral system to facilitate early intervention.
- The Sheffield Speech and Language Therapy Service prioritises children and young people with challenging behaviour, as improving communication skills can have a dramatic impact on behaviour.
- Sheffield City Council and Sheffield CCG commission behaviour management workshops for parent carers.

Information for families

Key Findings

"I wish I had had more information about what help is available. My daughter has been ill since she was 7 and we have only had help since she was 16. Things like the Family Fund, I only found out from other parents."

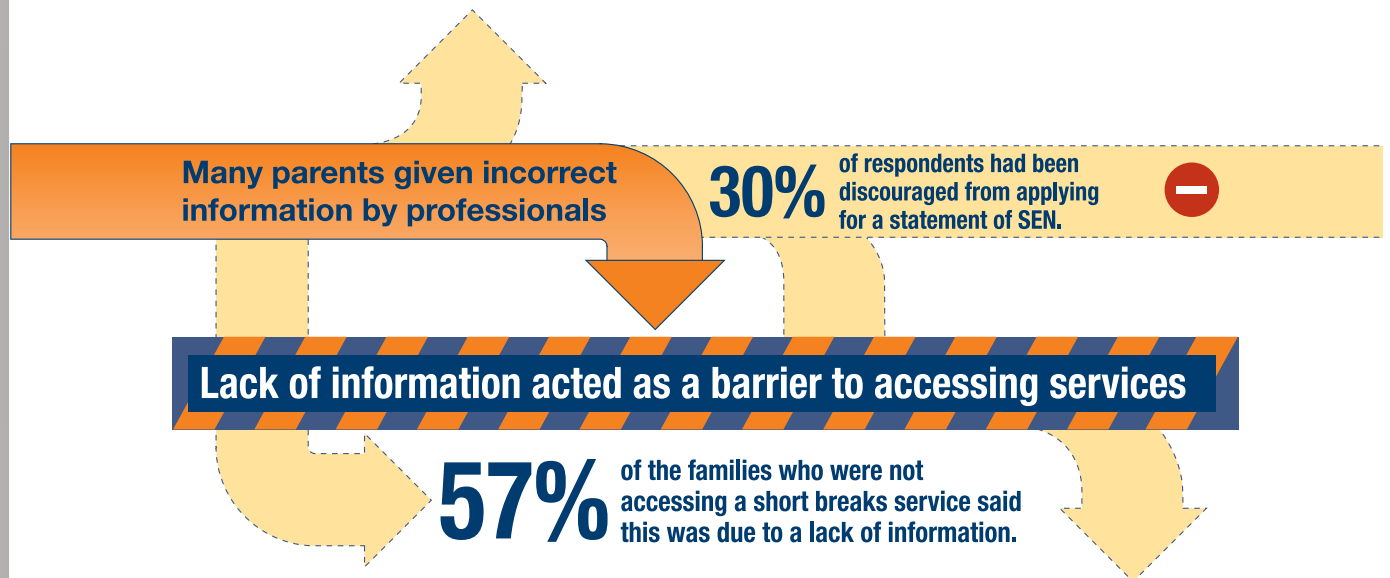
Families are missing out on vital support because of a lack of effective signposting. Being given the right information, at the right time, can have a significant impact on parents' ability to cope.

Many parents told us that they had been given incorrect information by professionals; for example, 30% of respondents told us that they had been discouraged from applying for a statement of SEN, often for reasons which were without basis in the law. Of these, 54% had nonetheless obtained a statement or were going through the statutory assessment process.

Parents also told us that a lack of information acted as a barrier to accessing services; for example, 57% of the families who were not accessing a short breaks service said this was due to a lack of information. A similar percentage said that a lack of information acted as a barrier to accessing health services for their disabled child.

Many respondents said that the most useful information had been given to them by other parent carers.

The local offer has the potential to resolve many of these issues. Over time, it could become a "one-stop shop" of information for families with disabled children in Sheffield.



Recommendations

We recommend that:

- Sheffield City Council continues to develop the local offer in partnership with SPCF to ensure it is written from a user perspective, not a service perspective.
- Sheffield City Council complies with the statutory duty to make the local offer accessible to families without internet access. Throughout the consultation on the local offer, parents highlighted the need for a specialist advisor to help parents navigate the local offer, e.g. via a dedicated telephone line, a "shop front" or outreach activities.
- Sheffield City Council and Sheffield CCG produce a signposting directory for frontline staff (particularly key workers, SENCOS, GPs and health visitors).
- Sheffield City Council ensures that the local offer includes clear information about access pathways and eligibility criteria, particularly for EHC needs assessments and EHC plans.

Education

Key Findings

"[...] he is non-verbal and could not tell me if he wanted to. Very vulnerable. It is a worry but I try not to think about it too much. I have sometimes thought of sewing a little recording device into his clothes just to get a true picture of what goes on during the day but it's probably against the law."

"His placement is amazing (school). I value every day of him being there."

There was a marked improvement in parental satisfaction with both special and mainstream schools, compared to our 2009 survey.^{iv}

However, satisfaction with mainstream schools remains significantly lower than with specialist settings. Fewer than half of all parents of children in mainstream schools felt that the provision met their child's needs.

Where parents rated education provision as inadequate, this was mainly due to insufficient support, expertise and understanding, as well as environmental factors (school too busy/crowded) and poor communication with parents.

A large number of parents told us that they had no idea what went on at school, and that this worried them greatly. Since most children with disabilities/additional needs have some degree of communication difficulties, parents depend on school staff to keep them informed.

Bullying and social exclusion affected a large number of children, particularly in mainstream schools and Integrated Resources (IRs). 63% of pupils with disabilities/additional needs in mainstream schools had suffered bullying "sometimes" or "frequently".

12% of learners in the 5-15 age group did not attend school for five days per week, and were overwhelmingly looked after by their parents during that time. This can have a detrimental impact on parents' ability to work.

Parents valued committed staff in school/education more than anything else. Where a school placement was working well, this inspired a huge sense of gratitude.



There was a marked improvement in parental satisfaction with both special and mainstream schools, compared to our 2009 survey



A large number of parents told us that they had no idea what went on at school, and that this worried them greatly.

63%

of pupils with disabilities/additional needs in mainstream schools had suffered bullying "sometimes" or "frequently"

Recommendations

We recommend that:

- Schools – particularly mainstream settings – address the unacceptable levels of bullying and social exclusion experienced by learners with disabilities/additional needs. This should include peer education and additional pastoral support for vulnerable pupils.
- Sheffield City Council reviews the process of allocating banded funding to learners with complex needs in mainstream settings, and involves SPCF and school representatives in this review.
- Sheffield City Council ensures that providers of after-school clubs know how to request inclusion grants, training and support to help them include disabled children.
- Schools work with parents of pupils with disabilities/additional needs to review how they communicate with this group of parents. Ideally, this should be done consistently across the local authority (e.g. see Rotherham's "Charter for Parents and Child Voice").

Parental satisfaction with services

Key Findings

“Speech and Language - one of my son’s main problems is his communication - however, although the Speech and Language lady is very nice, it simply is not enough support for my son. The service seems rigid in its support where it needs to be flexible and give more support to the children who need it rather than yearly reviews.”

Parents highlighted significant capacity issues in a number of key services accessed by disabled children. The most problematic were Educational Psychology, the Autism Team and Speech and Language Therapy (rated “too little” by 74% of respondents), followed by the Learning Support Service (60%), CAMHS (59%), Physiotherapy (56%) and Occupational Therapy (55%).

Over the next few years, these services will experience additional pressures resulting from increased birth rates and the conversion of statements into Education Health and Care Plans.

There was a correlation between service capacity and quality ratings, as services with higher capacity also did well in the quality ratings. The highest-rated education services were the Vision Support Service and the Service for Deaf and Hearing Impaired Children (rated “good” or “very good” by 94% and 78% respectively). In the health sector, private, community and NHS dentists were all rated “good” or “very good” by over 80% of respondents.

Parents expressed concerns about long waiting times to get assessments and access services, such as Educational Psychology, CAMHS, or the Psychology Service at Ryegate.

Respondents complained about poor communication with parents, e.g. no feedback after assessments. Failure to involve parents in the delivery of therapies and interventions reduces their effectiveness.

The study did not ask parents to rate social care services. However, respondents made numerous comments in relation to social care services, which were overwhelmingly negative. The strength of feeling expressed in these comments gives cause for concern.



Parents highlighted significant capacity issues in a number of key services accessed by disabled children

Recommendations

We recommend that:

- Sheffield City Council and Sheffield CCG review the funding, caseloads and service models of specialist support services, to establish whether higher-performing services (e.g. Vision Support Service, Hearing Impaired Service, dental care services) share specific characteristics which could be adopted by other services.
- Sheffield City Council and Sheffield CCG increase the capacity of underperforming services.
- Service managers work with SPCF to identify and share good practice in working with parents.
- Sheffield City Council and Sheffield CCG publish clear information about eligibility criteria, access routes, target response times, service standards and complaints procedures for all specialist services in the local offer.
- The CYPF Support Scrutiny and Policy Development Committee sets up a working group to investigate the negative feedback about social care services.

Transition to adult services

Key Findings

“Make it simpler! It is currently a long, drawn out process that is carer led! I have spent hundreds of hours emailing, telephone calls, home visits & still his plan has only just been submitted. I have never been so stressed in my whole life & there is no one to guide you through the process.”

The transition to adult services is a particularly difficult time, and this applies equally across education, health and social care. A large majority of respondents found these transitions “difficult” or “very difficult”. The transition to adult social care appeared to be the most problematic, with 96% of respondents rating it “difficult” or “very difficult”.

The main problem appeared to be a lack of information, advice and support for parents, who felt that they were left to figure things out on their own. A lack of responsiveness from services (e.g. failure to answer emails or return phone calls) led to delays which increased parents’ anxiety and frustration. Many parents said that the transition period had been one of the most stressful and distressing times in their life.

The transition to adult social care was described as a drawn-out, faceless and fragmented process punctuated by long delays while families waited for panels to make decisions about their young person.



Recommendations

We recommend that:

- Sheffield City Council and Sheffield CCG review the transition support provided by the Transitions Team, transition nurses, Sheffield Futures and Lifelong Learning and Skills.
- Sheffield City Council and Sheffield CCG set up a transition keyworking service to take the pressure off families and improve communication between services. This may be particularly important given the three new types of assessment relating to transition to adult services included in the Care Act 2014 (Assessment of Children in Transition; Assessment of Carers of Children in Transition; Assessment of Young Carers).
- Sheffield City Council and Sheffield CCG ensure that the local offer:
 - Includes a timeline of the transition process which gives parents a holistic overview of what needs to happen when, with links to more detailed information (e.g. modelled on the Transition Timeline produced by SPCF);
 - Describes the full range of post-16 provision, including specialist bridging programmes, life skills training, supported internships etc.

Direct payments and personal budgets

Key Findings

“Financial info returns needed. Worried about employing PA’s and their tax etc. Will probably have to pay 6 months tax back as I didn’t realize”

“Managing time sheets and payroll is a nightmare and it is in a real mess. I have put my head in the sand lately and am trying to find a brave moment to sort everything out. [...] I have a degree and I struggle, so heaven help parents who have learning difficulties themselves.”

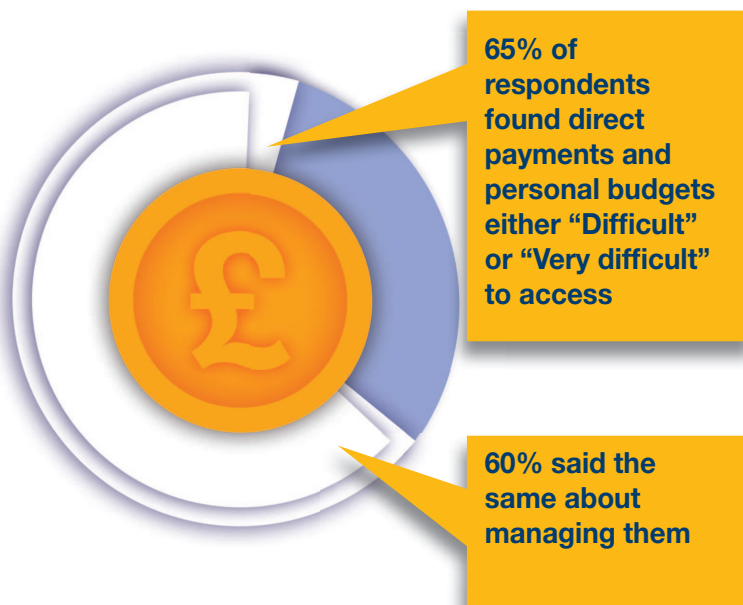
Although many parents liked the idea of direct payments and personal budgets in principle, responses showed that for many families, the reality did not live up to their expectations.

Almost two thirds said that direct payments and personal budgets were “difficult” or “very difficult” to access and manage.

Parents felt that they did not receive enough support in their role as employers, and that they spent too much time dealing with paperwork.

The percentage of parents who felt that their short breaks package was insufficient to meet their needs was higher for those in receipt of direct payments or personal budgets (55%) than overall (34%).

The main reasons given were not enough hours, not enough funding for social activities, and no year-round funding (i.e. funding given either for school holidays or term time, but not both).



Recommendations

We recommend that:

- Sheffield City Council ensures that the local offer includes the following information:
 - A description of the services that currently lend themselves to the use of personal budgets/direct payments;
 - The advantages and disadvantages of having a personal budget/direct payment;
 - The option of having a managed account or using a payroll provider;
 - Alternative ways of accessing flexible and individualised support, e.g. befriending services, sitting services.
- Sheffield City Council works with SPCF to develop an information pack about direct payments which includes detailed checklists, sample contracts etc.
- The Direct Payments Team holds regular training sessions for parents about managing direct payments and recruiting and employing PAs

Work, finances and childcare

Key Findings

“No childminders are available to take my son after school and an after-school club would not be appropriate, so the only other good quality childcare solution is a nanny which would be very expensive. This may mean that I need to leave work.”

Caring for a disabled child has a detrimental impact on parents' ability to work. Only 10% of parents in the study were managing to work full time. 40% had given up work to cope with their caring responsibilities, and 44% had reduced their hours and/or taken a less challenging job.

41% of parents said they couldn't find suitable childcare for their disabled child, and 26% said they couldn't afford it. They highlighted a lack of flexible childcare to accommodate fluctuating needs, insufficient support to access after-school clubs, and a lack of holiday childcare and childcare for older children.

Very few families in the study used any kind of formal childcare; 67% relied on family members and 10% on friends and neighbours instead. 18% used Personal Assistants. 38% said that the childcare they used was not adequate for meeting their child's needs.

57% of parents in the study said they were in receipt of means-tested benefits (excluding child benefit). Low-income families often struggle to meet the extra costs associated with raising a disabled child - calculated to be three times higher than the cost of raising a child without a disability.^v



Recommendations

We recommend that:

- The findings from this study inform the Childcare Sufficiency Assessment.
- Sheffield City Council reviews the sufficiency of inclusion grants for childcare providers.
- Sheffield City Council incorporates information from the DCATCH childcare folder into the local offer. This should include:
 - Specialist childcare options, e.g. specialist childminders, Personal Assistants, direct payments for working parents;
 - Information about inclusion grants, training, mentoring support, resources and physical adaptations available to childcare providers;
 - Brokerage support for parents who cannot find suitable childcare;
 - Guidance for childcare providers regarding the reasonable adjustments duty.
- Sheffield City Council ensures that the Home-based Childcare Team has sufficient capacity to build on and expand the DCATCH-funded project to recruit, train and mentor specialist childminders and Personal Assistants.

Conclusions and next steps

This study investigated the views of parents of children and young people (aged 0-25 years) with disabilities and/or additional needs in Sheffield.

Many families with disabled children lead happy, healthy and fulfilling lives, but it is very much against the odds. The study found that caring for a disabled child in Sheffield often has a negative impact on the whole family - the disabled child or young person as well as their siblings and parents.

The views and needs identified in this local study reflect the findings from wider national research: that the poor outcomes for the family members can be dramatic and far-reaching, but are not inevitable. With good information, support and services tailored to meet their needs, disabled children and young people and their families can flourish.

In an environment where funding reductions are impacting severely on the public sector, it is more important than ever that limited resources are used strategically to achieve maximum impact:

- **Early intervention is the key to improving outcomes for children with disabilities/additional needs and their families; it also produces significant long-term savings for society.**
- **Similarly, improving the transition between**

children's and adult services is critical to preventing young people and their families "falling off the cliff edge" and needing higher-cost acute services across the public system - whether in mental health services, out-of-city specialist education placements, the criminal justice system, or adult social care.

- **Co-production with parent carers and young people leads to services which are more efficient and better targeted to need. In the context of sweeping reforms to the SEN system and wider care system, co-production is vital to avoid costly mistakes.**

This report makes recommendations to commissioners and service providers which would improve outcomes for children and young people with disabilities/additional needs and their families.

The findings and recommendations will be presented to Sheffield City Council, NHS Sheffield Clinical Commissioning Group and relevant providers of education, health and social care services. SPCF will work with them to address the key issues identified in this report.

Funding permitting, this study will be repeated periodically to monitor progress and assess the impact of the reforms under the Children and Families Act 2014 and Care Act 2014.

For questions or comments regarding this report, please contact:

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Notes

- i nef consulting (2009), The social and economic value of short breaks, EDCM.
- ii Rossiter, L and Sharpe, D (2002), Siblings of children with a chronic illness: A meta analysis, Journal of Paediatric Psychology.
- iii Blazejewski S, Girodet PO, Orriols L, Capelli A, Moore N. (2012), Factors Associated With Serious Traffic Crashes: A Prospective Study in Southwest France, Arch Intern Med.
- iv Sheffield Interim Parent Carer Forum (2009), Sheffield Parent View of Provision for Children with a Disability.
- v Dobson, B. & Middleton, S. (1998), Paying to Care: The cost of childhood disability, Joseph Rowntree Foundation.

Acknowledgements

We would like to thank the families who told us about their experiences.



To access the full version of this report, please go to:
www.sheffieldparentcarerforum.org.uk/page/consultations

About the Sheffield Parent Carer Forum

The Sheffield Parent Carer Forum is a parent-led charity which brings together over 1,000 families with disabled children and young people (aged 0-25 years) from across Sheffield to provide mutual support, share information and influence policy.

Registered charity no. 1145913. Company Limited by Guarantee no. 7226540.