State of Sheffield 2014

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

November 2014

Consultation report

About 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.

For questions/comments about this report, please contact:

Acknowledgements

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1. 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.

2. 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** (71 paper responses and 249 online 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.

3. Key findings and recommendations

The key findings fall into the following categories:

1. The cumulative impact of disability
2. High levels of isolation
3. Impact on parental wellbeing
4. Impact on siblings
5. Sleep deprivation
6. Challenging behaviour
7. Education
8. Lack of information for parents and families
9. Parental satisfaction with services
10. Transition to adult services
11. Direct payments and personal budgets
12. Work, finances and childcare

Cumulative impact of disability

Key findings

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.

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

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 Integrated Resources (**54%**) and 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

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.

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".

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 <u>not</u> 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[i] – more than £125,000 per year.

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.

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

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 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.

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

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 accident[iii] 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

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.

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

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

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.

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 Parent and Child Voice").

Parental satisfaction with services

Key findings

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.

Speech and Language Therapy, Physiotherapy, Occupational Therapy and Health Visiting were rated "poor" or "very poor" by **28%** of respondents, followed by the Autism Team (**27%**), CAMHS (**22%**) and the Learning Support Service (**23%**).

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.

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

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

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%**).

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

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].
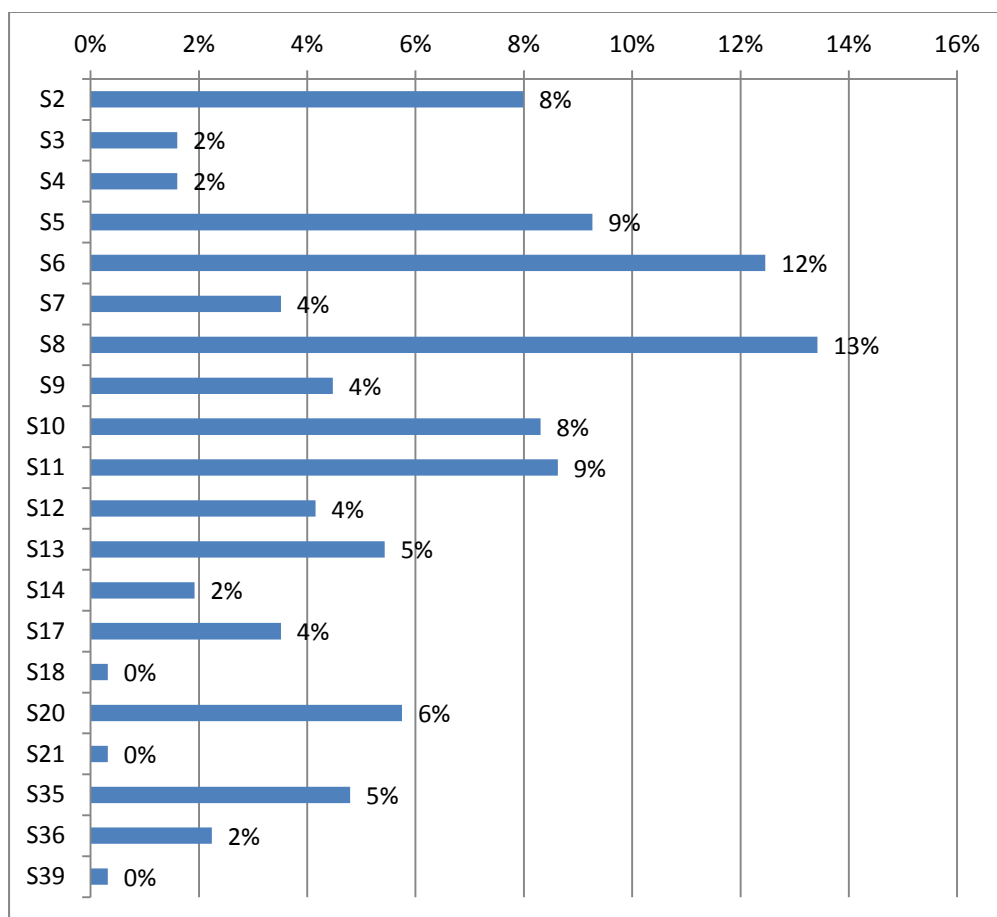
Recommendations

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.

4. Demographic breakdown of respondents

4.1   Postcode areas (315 responses)

There was a good spread across the city with most postcodes showing a level of representation, including areas with high levels of economic deprivation:

Postcode	Percentage
S2	8%
S3	2%
S4	2%
S5	9%
S6	12%
S7	4%
S8	13%
S9	4%
S10	8%
S11	9%
S12	4%
S13	5%
S14	2%
S17	4%
S18	0%
S20	6%
S21	0%
S35	5%
S36	2%
S39	0%

4.2   Gender (314 responses)

89% of respondents were female and **11**% were male.

We find that the pressures associated with raising a disabled child often force parents to assume traditional gender roles, with the father taking on the role of the main breadwinner, and the mother doing most of the day-to-day caring, attending meetings with professionals, and learning to navigate the "system". This can lead to fathers feeling less informed and less competent, which may affect their willingness to take part in consultations.

4.3   Ethnicity (315 responses)

84% of respondents were White British, **15%** belonged to a BME community, and **1.6%** did not state their ethnicity. The biggest BME groups were Any other white background (**3.5%**), Pakistani (**2.2%**), African (**1.9%**) and White and Asian (**1.6%**).

4.4   Language (314 responses)

91% of respondents said that English was their first language; **9%** said that it was not.

4.5   Parental disability or illness (311 responses)

Nearly a quarter of respondents (**24%**) said they had a disability or long-term illness themselves.

4.6   Number of children and young people in the household (314 responses)

33% of respondents had three or more children or young people living in their household. This is significantly higher than the national average (**14%** of all families with dependent children in 2013)[vi].

How many children and young people (0-25 years) are part of your household?

Number	Percentage
6	1%
5	1%
4	7%
3	24%
2	42%
1	25%
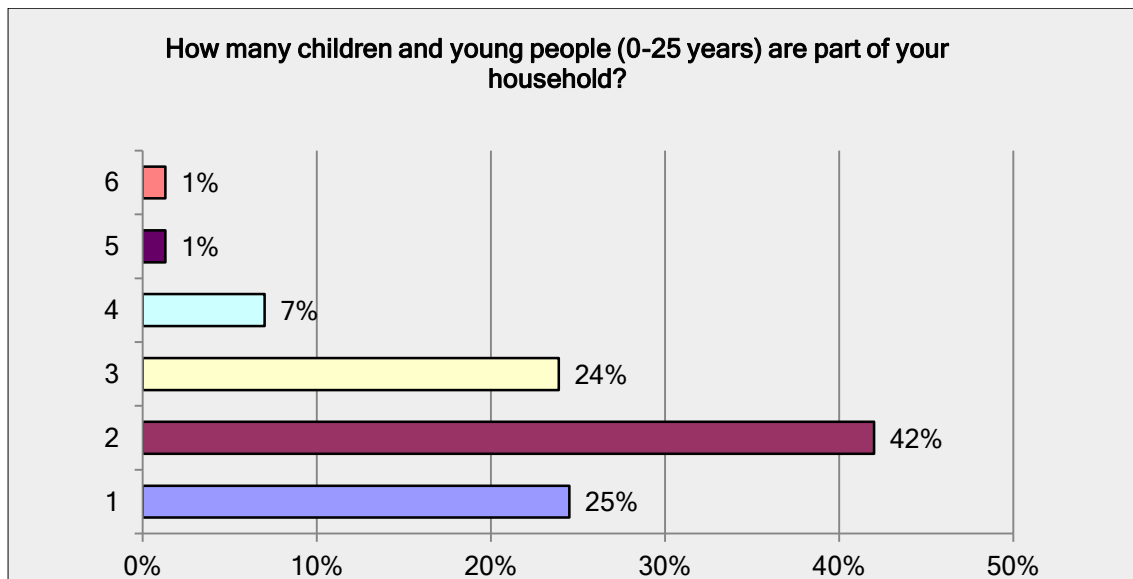
**4.7   Number of children and young people with disabilities/additional needs** (302 responses)

Over a quarter of respondents (**27%**) had more than one child with a disability or additional needs.

Parents with more than one disabled child were instructed to complete the questionnaire in relation to the child with the most severe needs. However, some respondents appear to have provided information in relation to several children, e.g. by selecting several types of education settings.

How many of these children/young people have a disability or additional needs?
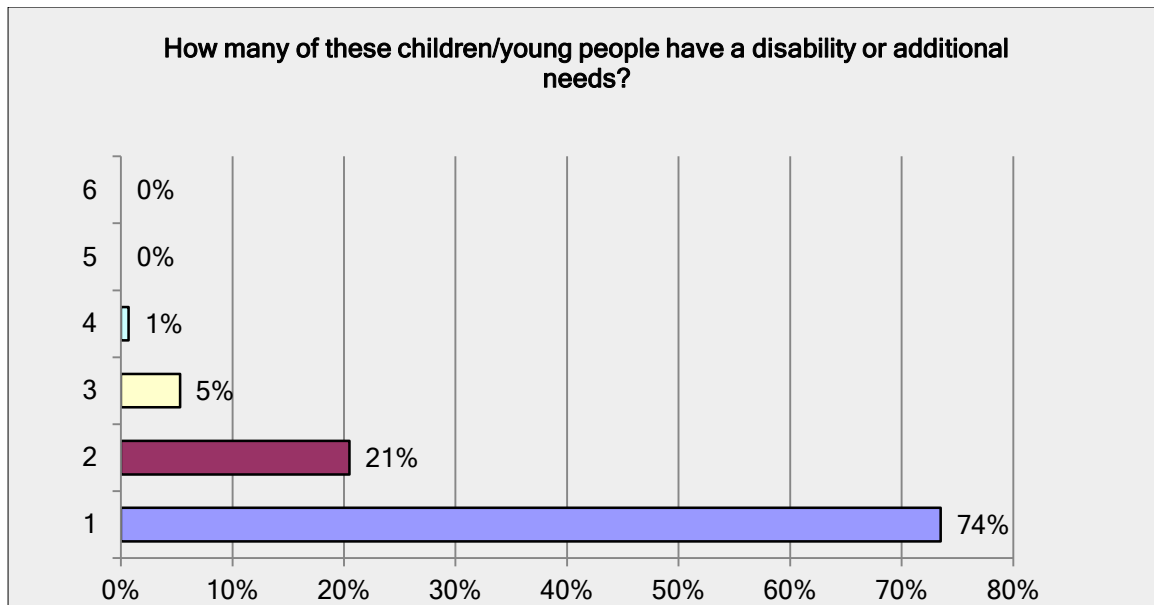
4.8   Providing care for an adult aged 25+ (307 responses)

16% of respondents said they also provided care for an adult over the age of 25, such as an elderly parent or a disabled partner.

4.9   Parenting situations (113 responses)

At **26%**, the proportion of single-parent families in our sample was in line with the national average (**25%** of all families with dependent children in 2013). Research shows that couples raising disabled children are more likely to experience relationship breakdown than parents of non-disabled children[vii].

5% of respondents said that they were kinship carers. We know from contact with grandparent carers that this group faces significant barriers to accessing support, particularly social care services and financial support (benefits and grants).

In relation to your child with a disability / additional needs, please indicate if you are:

Category	Percentage
a lone parent	26%
a foster carer	1%
an adoptive parent	3%
a kindship carer (e.g. grandparent carer)	5%
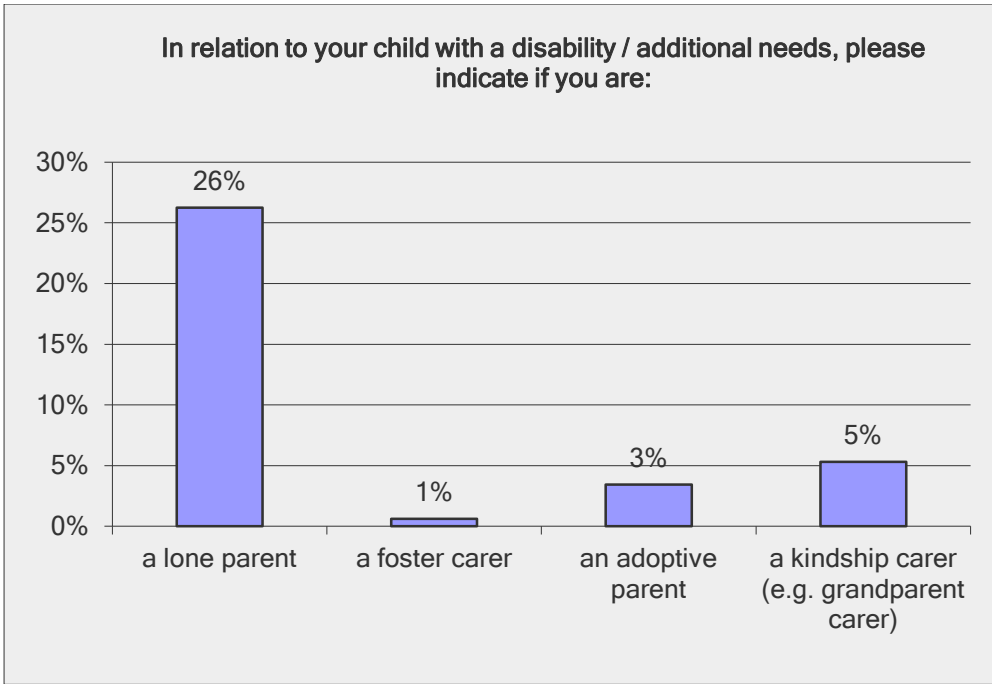
4.10 Sheffield Parent Carer Forum membership (309 responses)

81% of respondents were members of the Sheffield Parent Carer Forum, **19%** were not. This shows that the strategies used to publicise the survey beyond the membership were successful.

4.11 Age of child with a disability / additional needs (306 responses)

Respondents represented a wide spread of age groups, with a cluster around the 5-15 age group. The underrepresentation of parents of pre-school children may be due to the fact that many children do not receive a formal diagnosis until they enter the school system. The underrepresentation of parents of young people aged 19-25 may reflect the fact that until recently, this group was not eligible for SPCF membership.

How old is your child with a disability / additional needs?

| Age range	Percentage
19-25 years	7%
16-18 years	13%
11-15 years	35%
5-10 years	36%
0-4 years	9%
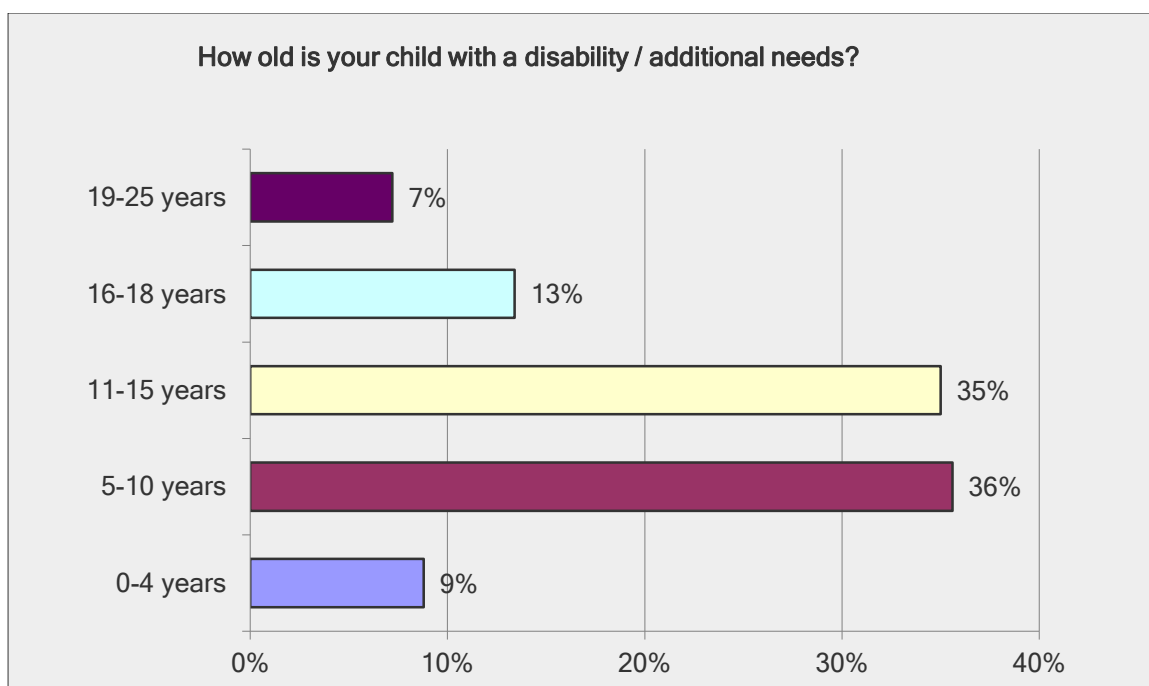
4.12   Impairment type (311 responses)

The survey covered the full range of impairment types. Respondents were asked to select all impairments affecting their child; this makes it difficult to compare the results to local or national statistics, which tend to focus on children's main impairments.

Impairment type	Percentage	Responses
Autistic Spectrum Disorder	62.4%	194
Speech, Language and Communication Needs	40.8%	127
Behavioural Emotional or Social Difficulties	35.7%	111
Severe Learning Difficulty	26.4%	82
Moderate Learning Difficulty	20.9%	65
ADHD/ADD	19.9%	62
Physical Disability / Mobility issues	19.3%	60
Medical Needs or Long-term Illness	16.1%	50
Mental Health Difficulties	13.2%	41
Down Syndrome	11.9%	37
Specific Learning Difficulty	10.3%	32
Visual Impairment	9.0%	28
Hearing Impairment	8.7%	27
Profound and Multiple Learning Difficulty	6.8%	21
Waiting for diagnosis	4.8%	15
Multi-Sensory Impairment	3.5%	11

4.13   Areas of difficulty (281 responses)

More than half of all respondents stated that their child had problems with challenging behaviour (**59%**) and sleep (**53%**). Since sleep deprivation can affect a child's behaviour and mental health, these issues are interwoven.

The percentage of parents who said their child displayed challenging behaviours was higher than in our 2009 survey (**59%** vs. **47%**).

Does your child have problems with:
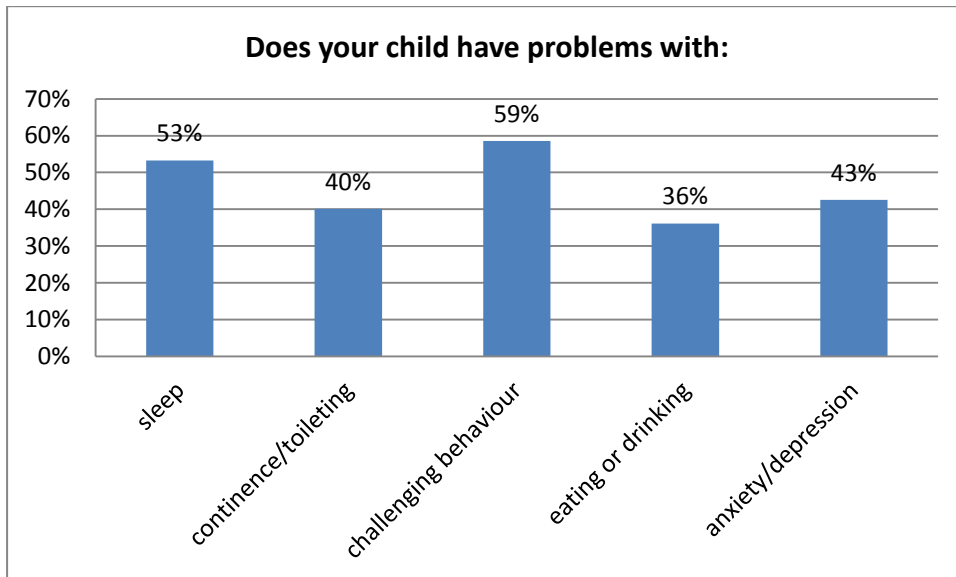
80% of the parents who responded to this question stated that their child had problems in more than one area: **30%** selected two areas of difficulty, **26%** selected three areas, **14%** selected four areas and **10%** selected all five.-

Additional areas of difficulty highlighted in the comments related to medical/physical needs, social impairments, sensory issues, and problems with information processing or concentration. Parents also stressed the need for additional supervision.

5. Family life

5.1   Doing things together as a family (298 responses)

We asked parents whether caring for a child with a disability or additional needs restricted what they and/or their family could do together.

Over half of respondents said it was "Difficult", "Very difficult" or "Impossible" to carry out everyday activities such as visiting friends or family, going out for a meal or to the cinema, taking regular exercise, going out for the day, or going on holiday. Only a minority (less than **15%**) rated these activities as "Easy".

Comments highlighted the significant amount of planning and preparation required:

"Every activity takes extra planning and depends on everyone's ability to cope if there is a crisis."

Several parents highlighted their child's need for constant supervision, and the effect this had on their siblings (missing out on attention) and parents (unable to relax).

"Going out as a family anywhere is only now 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."

5.2   Access to mainstream leisure services (297 responses)

We asked parents how easy it was for them to access non-specialist leisure services with their child. **Over half of the respondents** rated leisure activities like theatres, cinemas, restaurants, museum/galleries, sports and shopping "Somewhat difficult", "Very difficult" or "Impossible" to access.

Sports (spectator and participant), shopping and theatres posed the biggest problems for families. Only parks were regarded as "Easy" or "Very easy" to access by a majority (**60%**) of respondents.

Several parents commented that their children found it difficult to cope with places that are busy or noisy. Parents of children with behavioural issues (e.g. rigid adherence to routines, difficulty understanding or following rules, tendency to run off) said that many places were off-limits to them.

However, whether a setting is accessible depends on multiple factors which affect each individual differently:

"It all depends on the type of activity. Parks such as Endcliffe are tricky if there are rides as we always end up paying a fortune. Swimming is great at Hillsborough but not at Ponds Forge (too small to be allowed on slide, lots of battles and screaming.) Food shopping is tricky but he is helpful. Any other shops he just runs off. So many variants!"

5.3   Feeling included (293 responses)

We asked parents whether they felt their family was included in their local community/neighbourhood, wider Sheffield and the school attended by the disabled child:
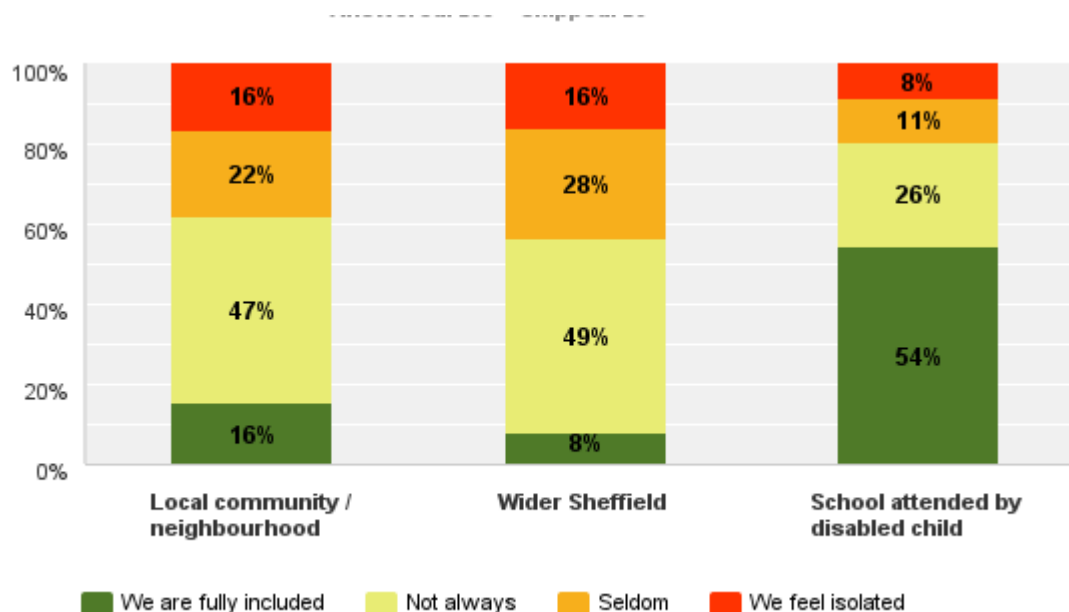
The responses highlight the vital role played by schools in enabling marginalised families to feel part of a community. The level of inclusion experienced by parents varied widely between school types: only **42%** of mainstream parents said they felt fully included, compared to **54%** of parents of children in Integrated Resources (IRs) and **73%** of special school parents.

5.4   Impact on siblings (236 responses)

94% of respondents felt 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%**).

"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. […]"

"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."

Siblings of disabled children are at an increased risk of isolation, as they may not be able to have friends over (**33%**) or miss out on out-of-school activities (**37%**).

Many studies on siblings of children with a chronic illness indicate that siblings are at risk for negative psychological effects.[viii] Siblings are more likely than their peer group to be raised within a family that experiences poverty. [ix]

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

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

Respondents who selected "Other" stated that siblings missed out on normal family activities. They also highlighted the impact on sibling relationships:

"They wish their big brother could act more like a big brother sometimes"

"Relationship between the two has deteriorated greatly in the past 2 years"

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

Impact on siblings	Percentage	Responses
They miss out on attention	73%	172
It has made them more considerate/patient/understanding	55%	130
Their sleep is disrupted	48%	113
They are actively involved in caring	43%	102
They miss out on activities (e.g. sport clubs, Scouts/Guides, social events)	37%	88
They can't have friends over	33%	78
It has affected their mental health or emotional wellbeing	31%	73
It has affected their achievement at school	13%	31
They have been bullied	11%	27
Other	11%	27
It hasn't really affected them	6%	13

5.5   Impact on parents: looking after themselves (296 responses)

Over a quarter of parents (**26%**) said that they often neglected themselves. The corresponding figure for carers of **adults** in Sheffield was **15%[x]**.

Do you have time to look after yourself (relaxing, socialising, exercising etc.)?

- I often neglect myself: 26%
- I rarely have time to spend on me: 35%
- I sometimes find time for myself: 33%
- I look after myself well: 5%
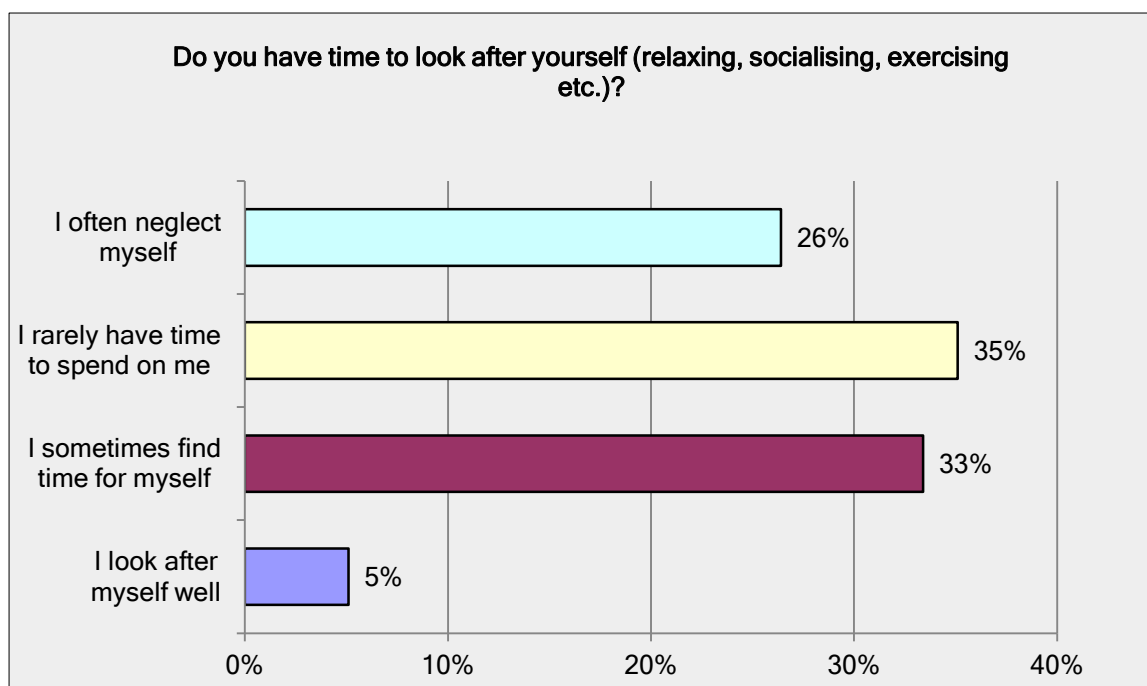
5.6   Impact on parents' wellbeing (294 responses)

95% of respondents reported that caring had affected their wellbeing, particularly their emotional wellbeing and their sleep. **85%** of these selected more than one area of impact.

The total number of respondents who said that caring had affected their sleep (218) was higher than the number of respondents who reported that their disabled child had sleep problems (170).

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.

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

Has caring for your child with a disability/additional needs affected your:

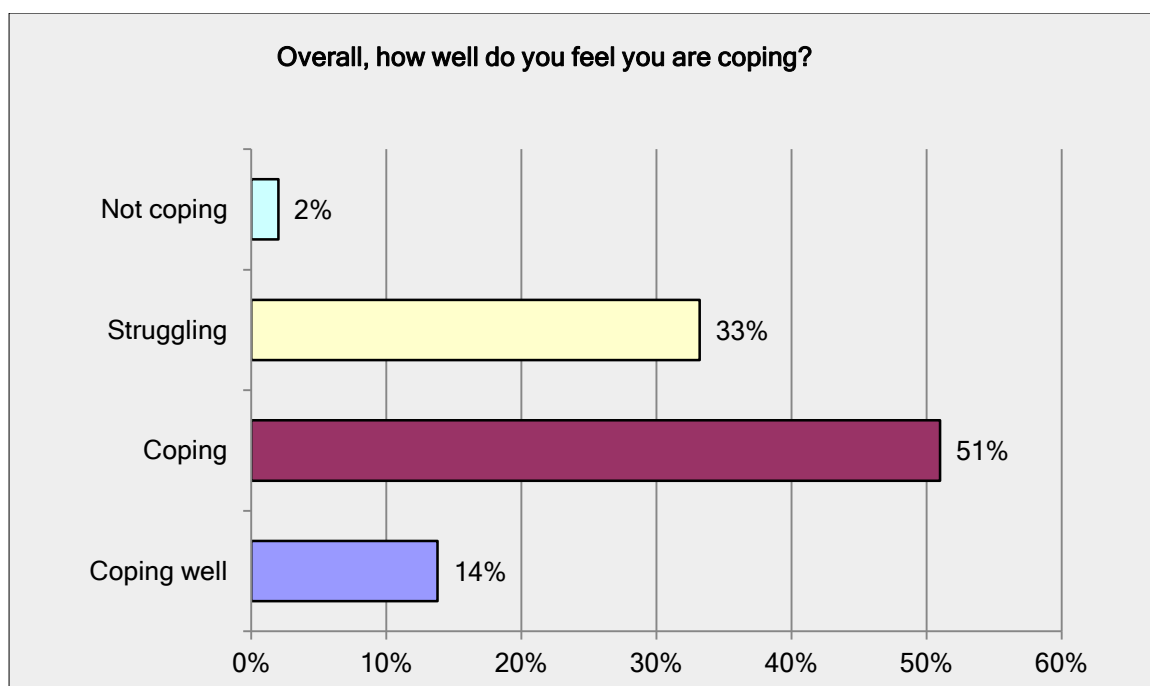| Category	Percentage
mental health	49%
emotional wellbeing	78%
physical health	52%
sleep	74%
relationships	63%
none of the above	5%
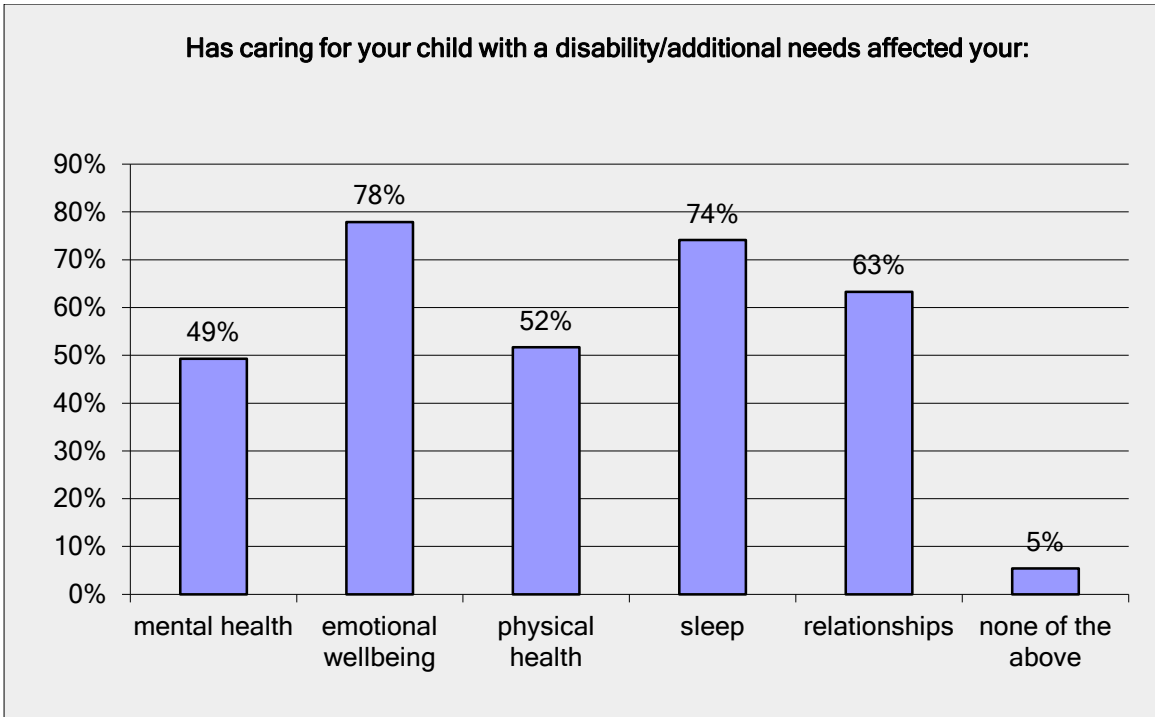
5.7   Coping (298 responses)

Over a third of respondents (**35%**) were either "Struggling" or "Not coping".

This group differed from the overall sample in that it included more parents with a disability or long-term illness, more families with more than one disabled child, and more parents who also provided care for an adult. A significantly higher percentage of respondents reported that their child had problems with sleep, continence/toileting, challenging behaviour, eating/drinking, and anxiety/depression. The biggest area of need was challenging behaviour, which affected **74%** of respondents in this group (compared to **59%** in the total sample).

Consequently, this group found it harder to do everyday things and reported higher levels of isolation. The impact on siblings and parents was more pronounced. Respondents were less satisfied with childcare and educational provision.

38% of those who said that they were "struggling" or "not coping" were not accessing any short breaks services at all.

Almost half (**49%**) of those who did get a short breaks service felt that it was insufficient to meet their needs. (By comparison, **34%** of the total sample said that their short breaks package was insufficient.)

Overall, how well do you feel you are coping?

Response	Percentage
Not coping	2%
Struggling	33%
Coping	51%
Coping well	14%

5.8 Support for parent carers (295 responses)

We asked parents who provided practical and emotional support for them in their caring role. The majority (**71%**) said they relied on their spouse or partner – a support mechanism not available to the large number of lone parents.

Friends (**52%**) and relatives (**47%**) also ranked highly, followed by parent support groups (**28%**), educational staff (**23%**), the Sheffield Parent Carer Forum (**21%**) and health professionals (**19%**).

Comments indicated that parents also valued the support provided by respite care homes and CAMHS.

Providers of practical/emotional support	Percentage	Responses
Spouse/partner	71%	210
Friends	52%	152
Relatives	47%	139
Other parent support groups	28%	81
Educational staff (e.g. nursery worker, teaching assistant, SENCO)	23%	67
Sheffield Parent Carer Forum	21%	61
Health professional (e.g. GP, school nurse, health visitor, therapist)	19%	55
Social Media (e.g. Facebook group)	13%	37
PA or childminder	12%	34
Parent Partnership Service	11%	32
Pastoral organisation (e.g. religious, spiritual, cultural)	8%	24
Private professional (e.g. private therapist, childcare provider)	6%	18
Nobody	5%	16

Social worker	4%	11
MAST (e.g. Family Intervention Worker)	2%	7
Counsellor	2%	6
Parents as Carers Advice Service	1%	4
Portage Service	1%	3

5.9 **Time off from caring** (292 responses)

We asked parents when they had last had a break from caring for their disabled child – a day, and evening, a weekend or a week off:
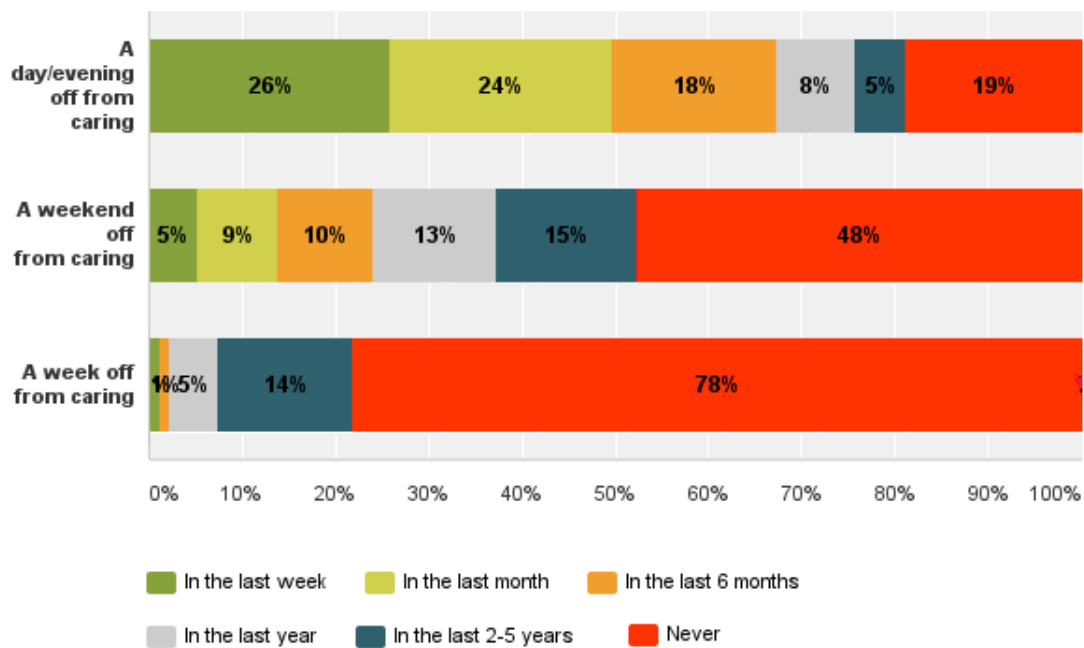
While it may be rare for parents of dependent children to have a week away from their caring responsibilities, having the occasional day/evening or weekend off is not unusual for most parents.

However, **19%** of the parents in our sample had never had a day or an evening off from caring, and **48%** had never had a weekend off from caring.

The percentage of one-parent families in this group was the same as for the whole sample.

6. Combining paid work and caring

6.1   Employment situation (280 responses)

Caring had a significant impact on parents' employment situation, with **41%** stating that they were not in paid work due to their caring responsibilities.

Only **10%** were managing to hold down a full-time job, and **38%** worked part-time. Several respondents stated that they were self-employed, which made it easier for them to fit their work around their child's needs.

There was a significant gender gap: **51%** of the mothers but only **22%** of the fathers in the study were in paid work. According to national statistics, the impact of child disability on parental employment is much more pronounced for mothers than for fathers. However, where fathers are the main carers, they are more likely than mothers to give up work completely.[xi]

It is likely that in two-parent households, the survey was completed by the main carer, which may explain the low paternal employment rate for those men who did take part. Nationally, only **16%** of mothers with disabled children work, compared to **61%** of all mothers[xii].

A small number of respondents stated that they would have chosen to be stay-at-home parents even if they did not have a disabled child.

Employment situation	Percentage	Responses
Not in paid work because of caring responsibilities	41%	114
In part-time paid work	38%	107
In full-time paid work	10%	29
Not in paid work due to own illness or disability	10%	29
Other	10%	28
Voluntary work	9%	26
In education/training	3%	9
Retired	3%	9
Looking for paid work	2%	6
Not in paid work for other reasons (e.g. immigration status)	2%	5

6.2 Impact on the ability to work (258 responses)

Only a minority (**16%**) of respondents said that caring had not affected their ability to work. **40%** had given up work to cope with their caring responsibilities, and **44%** had reduced their hours and/or taken a less challenging job in order to care for their disabled child/children.

Parents who give up work can become very isolated, as they miss out on social contacts with co-workers and have less money to participate in leisure activities.

6.3 Factors determining parents' ability to work (212 responses)

We asked parents who felt that caring had affected their ability to work to tell us why.

Reason for not being able to work	Percentage	Responses
My caring responsibilities take too much time/energy	65%	138
I couldn't find suitable childcare for my child with a disability/additional needs	41%	87
I frequently need time off to look after my child because of their medical needs	37%	79
I frequently need time off to look after my child when they have unscheduled time off school (e.g. exclusions)	30%	63
I couldn't afford the childcare for my child with a disability/additional needs	26%	55
I have to look after my young person on the days when they are not in college	18%	37
SEN transport won't drop off / pick up from childcare setting	11%	24

A lack of time/energy was the biggest factor, cited by **65%** of respondents:

"I need to do all my jobs while my child is at school otherwise they just don't get done. I get up at 5am to do paperwork. I get up at 4am to do ironing as he loves to try to help with but it's too dangerous."

The second biggest factor was childcare. **41%** of parents said that they couldn't find suitable childcare, and **26%** said they couldn't afford the childcare for their disabled child. Parents of non-disabled children often accept that they may need to work for little financial gain during the toddler years in order to improve their long-term career prospects. For parents of disabled children, however, the situation does not tend to improve over time, as their children may still need childcare right through secondary school. Childcare for disabled teenagers is scarce and can be expensive, making work an uneconomical option for many parents.

A parliamentary enquiry into childcare for disabled children found that **86%** of parent carers were paying childcare fees of £5 or more per hour, with **38%** paying £11-20 and **5%** paying more than £20, compared to the national averages of £3.50-£4.50 per hour.[xiii]

"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."

Several respondents mentioned a lack of holiday childcare.

Respondents pointed out that the unpredictability of their children's needs made it difficult for them to fit into rigid work hours. **37%** frequently needed time off due to their child's medical needs, and **30%** said their child often had unscheduled time off school (e.g. exclusions). Traditional childcare is not flexible enough to accommodate the fluctuating needs of these families.

"You are managing a constant, evolving and developing comprehensive care programme and it takes time during the working week to chase people and to have appointments. If you work full-time you

have no slack to accommodate this, so I work part-time and end up doing extra hours to keep the good-will with my employer."

11% said that they were unable to work because of the SEN Transport policy, which only allows children to be picked up and dropped off at their home address, not at a childcare setting.

6.4 Financial impact of change in work status (223 responses)

We asked respondents to assess the financial impact on the family if their own or their partner's work status had changed as a result of caring for a child with a disability/additional needs.

46% said this had had a "significant" impact, **42%** said it had had "some" impact, and only **12%** stated that there had been no impact.

6.5 Families in receipt of means-tested benefits (266 responses)

57% of respondents said that they received 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[xiv]. Contact a Family's *Counting the Costs 2014* survey found that **31%** of families with disabled children were going without food, and **33%** were going without heating[xv].

6.6 Flexible working (142 responses)

56% of those in paid employment said that their employer had agreed to flexible working arrangements.

Nine respondents said they were self-employed, and several stated that they had become self-employed specifically to fit their work around their caring responsibilities.

6.7 Childcare arrangements (103 responses)

We asked **working** parents to tell us what sort of childcare they used for their child with a disability/additional needs:

Childcare provider	Percentage	Responses
Family member	67%	69
Personal assistant	18%	18
Specialist holiday club	10%	10
Friend/neighbour	10%	10
Mainstream after-school club	7%	7

Mainstream holiday club	7%	7
Childminder	5%	5
Specialist after-school club	4%	4
Children's Centre	3%	3
Private nursery	1%	1

Respondents indicated a heavy reliance on informal childcare, with **67%** using family members and **10%** calling on the help of friends and neighbours.

Personal Assistants were the second most popular choice (**18%**), particularly for youngsters in the 5-15 and 19-25 age groups.

Overall, respondents favoured specialist childcare (**31%**) over mainstream options (**22%**). Many parents indicated that they had had to fit their working and family lives around their children's needs, e.g. by taking turns with their partner or working during school hours only:

"None, tried childminders and after school club and they don't want him... So go in work early and home in time for him coming home."

"I work only during school hours and take time off myself if my child is ill."

"None of the above, we juggle as parents between us."

6.8 **Adequacy of childcare** (123 responses)

62% of respondents felt that the childcare they used was adequate for meeting their child's needs, **38%** said that it was not adequate.

The main reasons given were:

- Grandparents getting too old
- Lack of staff training/skills
- High staff turnover (particularly PAs and au pairs)
- Relying on older siblings not appropriate
- Child not stimulated enough
- Child not fully included
- Not enough opportunities for the child to mix with peers

"Current PA is ok, but have had to employ 6-8 in last 3 years as they move on."

"They are bored and not stimulated at all when they are there, but I have no choice!"

Several parents commented that the childcare they used was not meeting **their** needs, and gave the following reasons:

- Too expensive
- Too much responsibility and paperwork in relation to direct payments

- Patchy provision during school holidays
- Lack of childcare for secondary age children

"Holiday provision is very patchy and very expensive as our child needs one-to-one care, we receive a direct payment and this adds tremendous responsibilities to our work load as employers, e.g. supervision for the PA, payroll, end of year finances, sorting out training for PA, sorting out cover when PA is on holiday or ill."
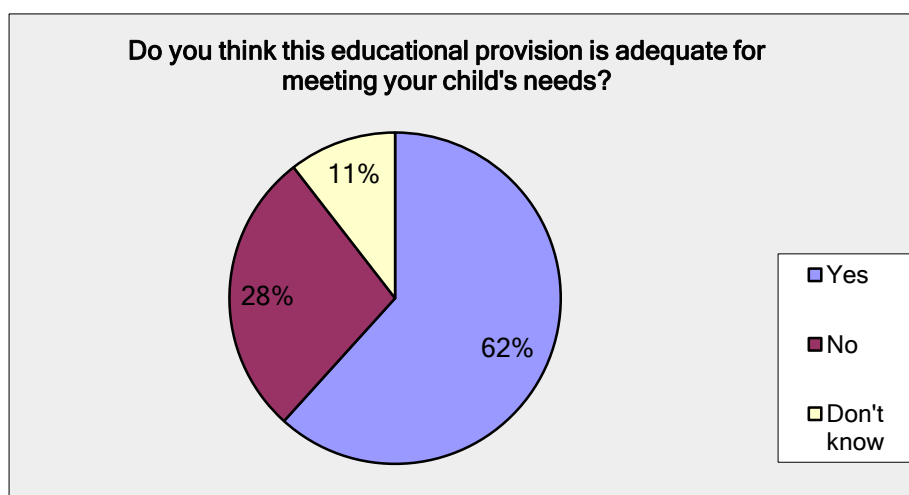
7. Education

7.1 Type of setting attended (266 responses)

There was a fairly even split between mainstream and specialist settings, with slightly more children attending specialist provision.

Type of setting attended	Percentage	Responses
Primary school - mainstream	27%	71
Secondary school - special	23%	60
Primary school - special	17%	44
Secondary school - mainstream	14%	36
Secondary school - Integrated Resource	8%	20
Primary school - Integrated Resource	7%	18
Nursery/children's centre	4%	10
Independent specialist provider	4%	10
Sheffield College	3%	8
University	2%	5
Home and Hospital Service	2%	4
Home educated as no other option	1%	3
Home educated by choice	0%	1
Unit for permanently excluded pupils (PRU)	0%	0

Six respondents stated that their child did not attend any educational setting, but none of these children were of statutory school age. A small number of parents listed alternative arrangements, e.g. home tutoring, waiting to start using the Home and Hospital Education Service, work placements or using PAs.

7.2   Adequacy of provision (277 responses)

Do you think this educational provision is adequate for meeting your child's needs?
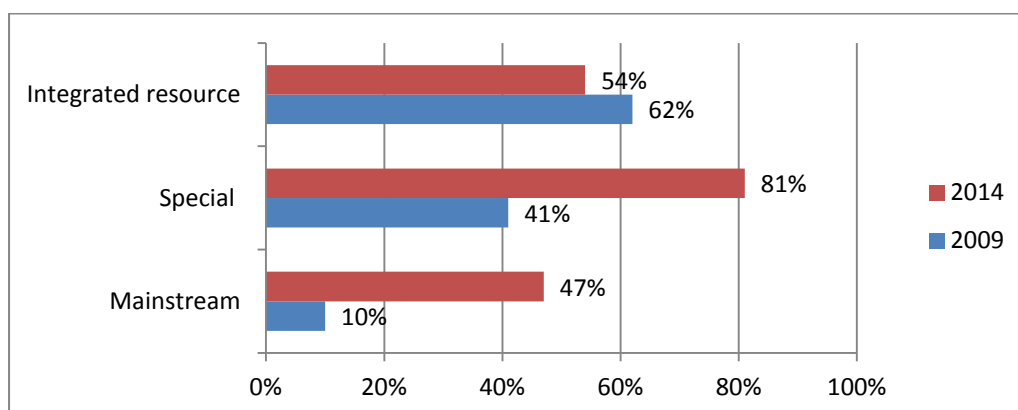
- Yes 62%
- No 28%
- Don't know 11%

Satisfaction with educational provision varied significantly between school types:
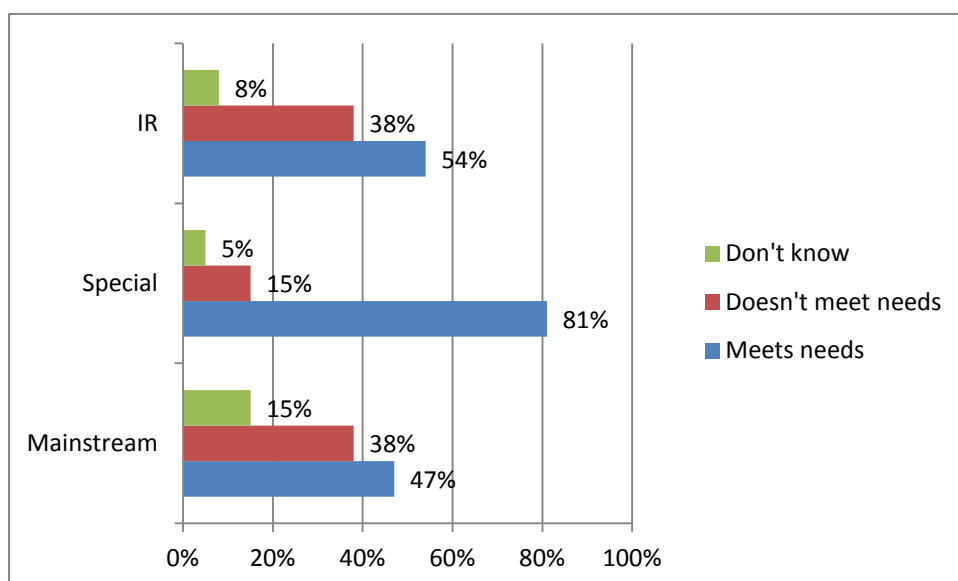
Parental satisfaction with educational provision by school type

Compared to our 2009 survey, the percentage of parents who felt that the educational provision was adequate had increased significantly for both mainstream and special schools:

Percentage of parents who felt the educational provision received by their child was "adequate"

The main reasons given for rating the provision as "Not adequate" were:

- Not enough support
- Not the right school for child's needs (e.g. too crowded / busy)
- Lack of staff expertise / understanding
- Staff not listening to / communicating well with parents
- Child not making enough progress or not achieving their potential

Several respondents provided more specific information about these issues, e.g. a lack of access to specialist services, inadequate differentiation, failure to implement the statement or LDA, inadequate Individual Education Plans IEPs) or infrequent reviews, and failure to address social difficulties or deal with bullying.

7.3   Days of provision per week (259 responses)

For how many days per week does your child receive this educational provision? (1 day = 6.5 hours)

Days	Percentage
5 days	83%
4 days	3%
3 days	4%
2 days	4%
1 day	3%
Less than one day	4%
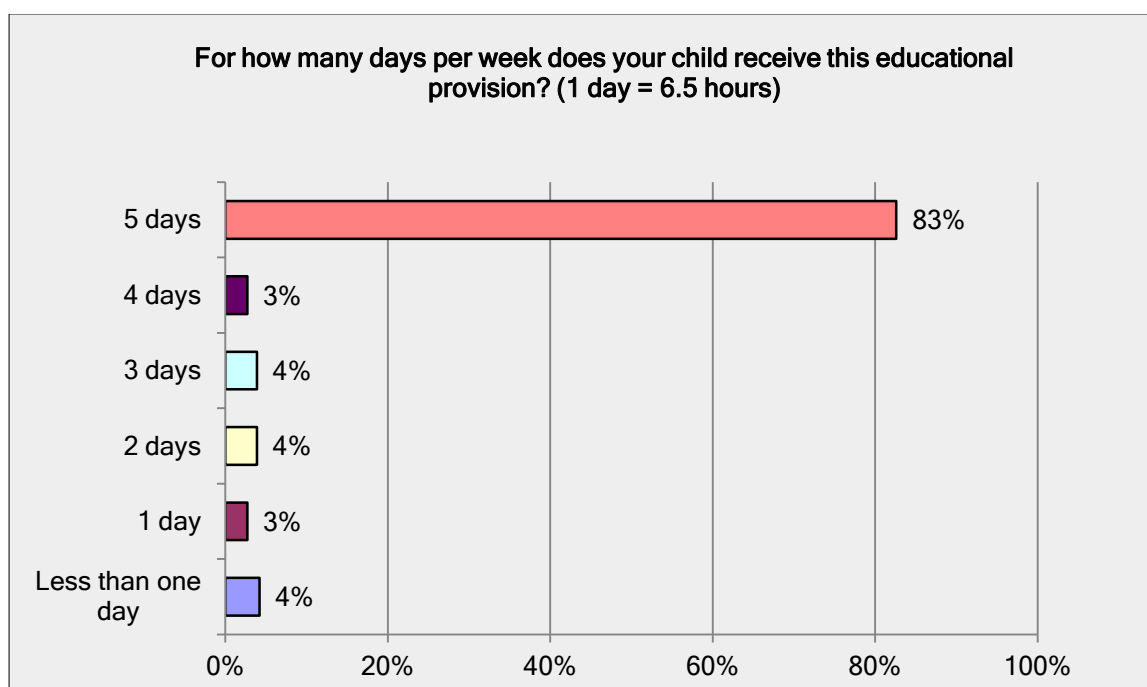
For **12%** of children in the **5-15 age group**, provision was less than 5 days per week. The majority of these children attended mainstream schools.

7.4   Looking after learners who do not attend school or college full time (46 responses)

What happens on the days when the young person does not attend school or college?	Percentage	Responses
I look after them as they are not safe to be left on their own	74%	34
A Personal Assistant looks after them	15%	7
Independent study	13%	6
Day care centre for disabled people	13%	6
Work placement	4%	2

Having to look after a child or young person who doesn't attend school or college full-time can have a detrimental effect on their parents' ability to work; **47%** of these parents said they were not in paid work because of their caring responsibilities.

7.5   Level of additional support in education (265 responses)

The majority of respondents (**70%**) had a child with a statement of SEN, which indicates that our sample reflected the more severe end of the spectrum of needs.

Level of additional support	Percentage	Responses
Has a statement of SEN	70%	186
School Action Plus	16%	43
Is being assessed for a statement of SEN	6%	16
Has a Learning Difficulty Assessment (Section 139a)	5%	12
Not getting any additional support	4%	11
School Action	4%	10
Don't know	4%	10
Request for assessment refused	3%	7
Statement refused after assessment	2%	4

7.6   Discouraged from applying for a statement of SEN (257 responses)

30% of respondents said they had been discouraged from applying for a statement of SEN; of these, **44%** had nonetheless managed to obtain a statement, and **10%** were going through the statutory assessment process.

39% said they had been discouraged by school staff – SENCOs, head teachers and teachers. Others said they had been discouraged by Educational Psychologists, the SEN Assessment and Placement Team, social workers, Parent Partnership Service, other parents, nursery, Ryegate Centre, Mencap and the Autism Team.

The reasons given included:

- Makes no difference / would not provide additional support
- Child too young
- Child too old
- Don't do them for secondary
- Needs not severe enough / would not be eligible
- Too intelligent / making sufficient academic progress
- Not challenging / disruptive enough
- Only given to children who need all-day supervision at special school
- Sheffield don't do statements any more
- Lengthy and difficult process
- Not necessary
- Stigmatising - don't want to label children
- Pointless as system is changing
- Don't do statements for children with Asperger's Syndrome

Many of these statements have no basis in the law, and highlight the need for clear eligibility criteria.

"Professionals often say ridiculous things, like your child is not deaf enough or they're "too clever". Which smacks of being patronising and insults parents' intelligence to make a rational decision for their family."

7.7   Parental satisfaction with educational support services (134 responses)

We asked parents to rate educational support services in terms of quality and quantity.

Quality ratings show that the Vision Support Service (VI Service) and the Service for Deaf and Hearing Impaired Children (HI Service) are particularly well regarded by parents.

The fact that **27%** rated the Autism Service and **23%** the Learning Support Service as "Poor" or "Very poor" gives cause for concern.
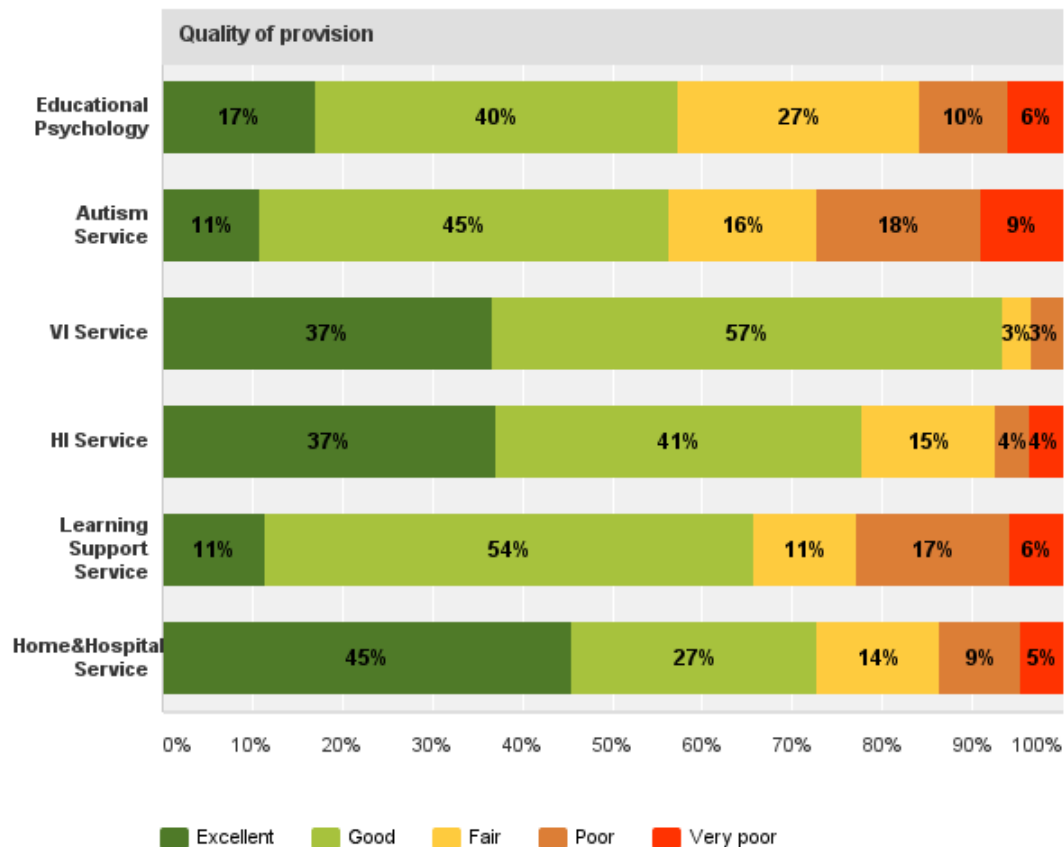
Quality ratings must be considered in the context of service capacity, which is a known issue for many services. **Three quarters** of respondents stated that provision by the Educational Psychology Service and the Autism Team was "Too little".

Quantity of provision

Service	Too little	About right
Educational Psychology	74%	26%
Autism Service	75%	25%
Learning Support Service	60%	40%
HI Service	38%	63%
Home&Hospital Service	44%	56%
VI Service	14%	86%

Legend: Too little / About right / Too much
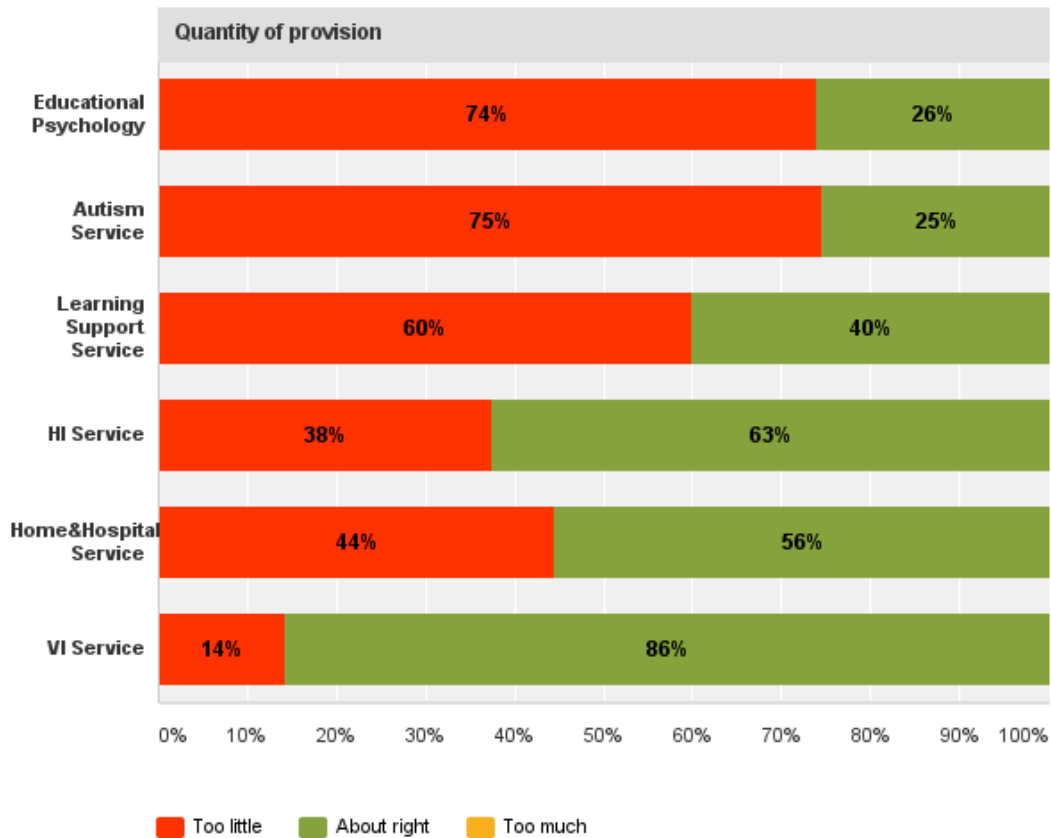
Free format responses highlighted the following issues:

- Lack of communication, e.g. not providing feedback to parents after assessments
- Lack of support for children who can't cope with five days of mainstream education
- Difficulty getting an assessment of children's needs
- Schools not putting recommendations into practice

"Have requested an up to date assessment (one and a half years ago) but still waiting."

"Never got any feedback after child was seen by Educational Psychologist. Psychologist asked "What do you want from us?" - but we were expecting him to tell us how our child should be supported."

7.8 Education services that are needed but not provided (181 responses)

36% of respondents said that there were education services which their child needed but was not currently getting.

Respondents listed a large number of services. However, many of these are provided by Health, and have been covered in section 10.

The following *educational* services were mentioned:

- Help with learning / classroom support
- Autism Service

- Educational Psychology
- Help with homework
- Social skills training / pastoral support
- School placement, e.g. residential college, special school
- Sporting facilities
- Transition support to post 16
- Support and instruction how to use specialist equipment
- Mentoring / studies support in rural location
- Applied Behavioural Analysis (ABA)
- Quiet space in school
- Home and Hospital Service

7.9   **Support in education setting** (251 responses)

We asked parents what kind of support their child received in their education setting, and whether this was sufficient to meet their needs:
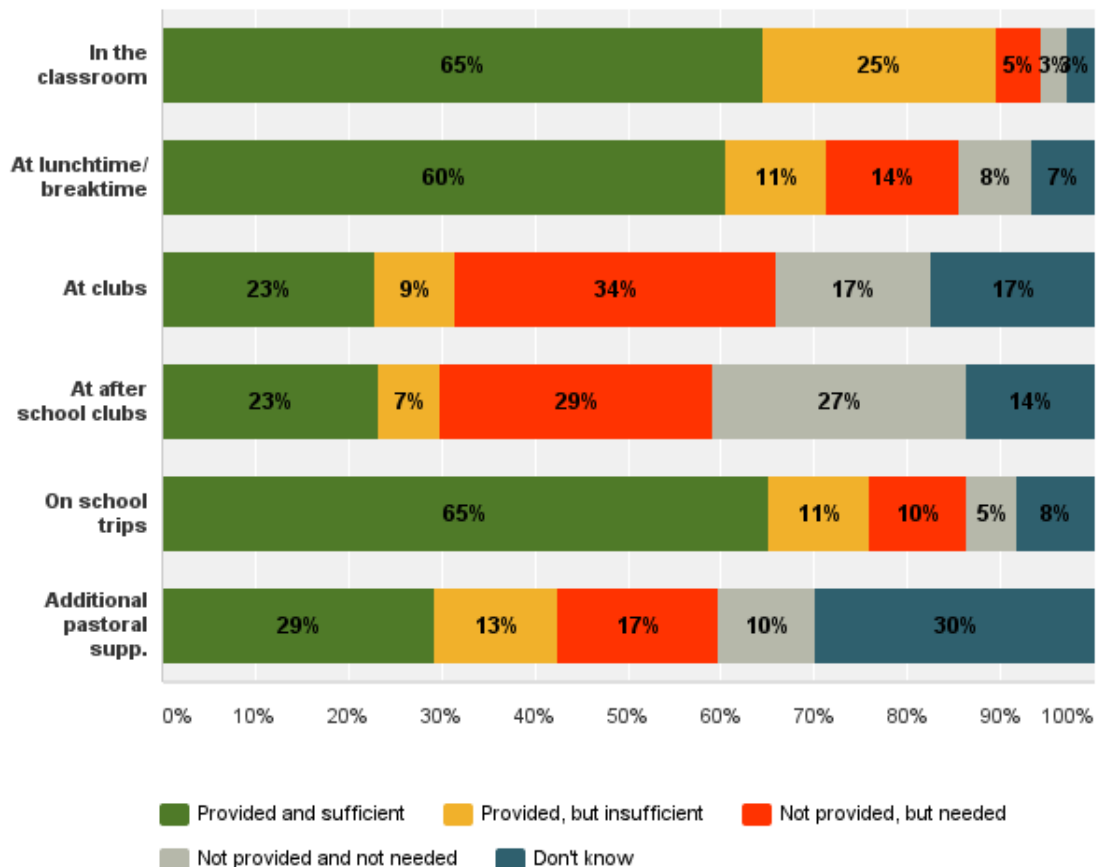
Responses differed significantly between school types, with parents of children in specialist settings indicating a much higher level of satisfaction with the support provided than parents of children in mainstream schools, with Integrated Resources (IRs) falling somewhere between.

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However, this only applies to support in the classroom, at breaktimes/lunchtimes and pastoral support. There was a high level of dissatisfaction with support to access clubs and after-school provision across all three school types.
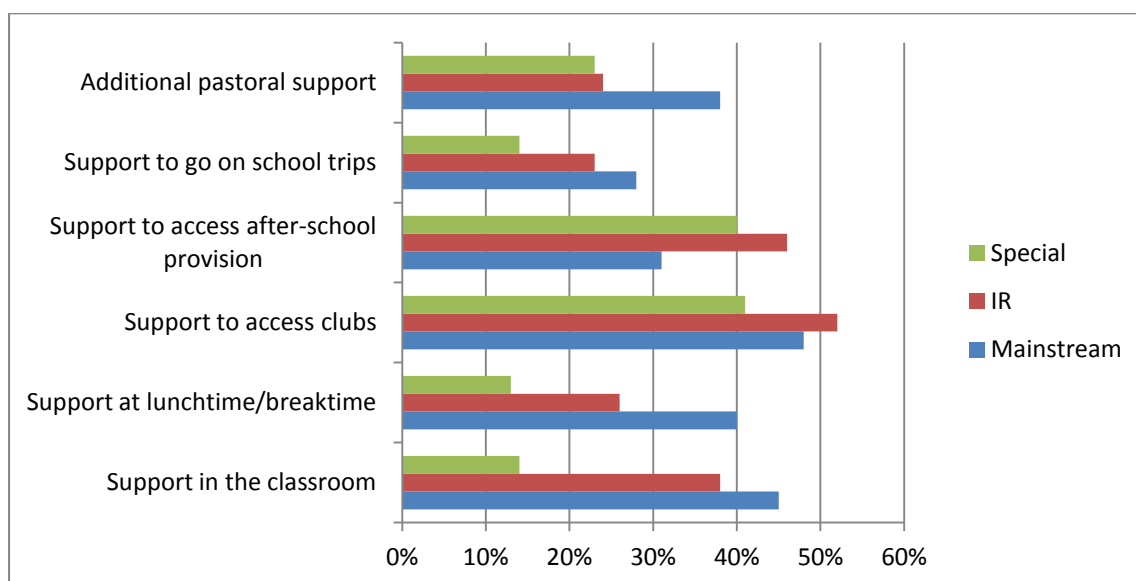
Percentage of parents who felt that support was "Insufficient" or "Not provided but needed"

Many parents seemed to be unaware that providers of after-school clubs have make reasonable adjustments to include disabled children and can get support to help them do so, so had ruled this out as an option.

"Our child has no option or choice to attend extracurricular school clubs as I don't believe support would be available. E.g. with sporting activities - he enjoys sports but would need 1 to 1 support. He is happy to come home at the end of the school day so this isn't an issue but it has felt in the past that this is just something that isn't available to our child."

There were no strong themes in the free format responses to this question. A number of respondents pointed out that the support provided was insufficient because staff did not have the right skills or training. Several parents indicated that they help out on school trips.

7.10   Bullying, social ostracism and exclusions (271 responses)

Responses in this section show that bullying from other children continues to affect a large percentage of children with disabilities/additional needs. **53%** of parents said that their child had "sometimes" or "frequently" been bullied by other children. This is higher than in our 2009 survey, where **39%** of respondents said that their children had been bullied (the survey did not ask how often this happened).

According to recent research published by the Institute of Education (IOE), University of London, primary school pupils with special educational needs are twice as likely as other children to suffer from persistent bullying.[xvi]

A third of the children in our sample had "frequently" suffered social ostracism (e.g. being excluded from a group, being the only child in the class not invited to a birthday party).

While it may seem unthinkable that these vulnerable children would also suffer bullying from staff, a total of 45 parents (**18%**) said their children had experienced this "sometimes" or "frequently".
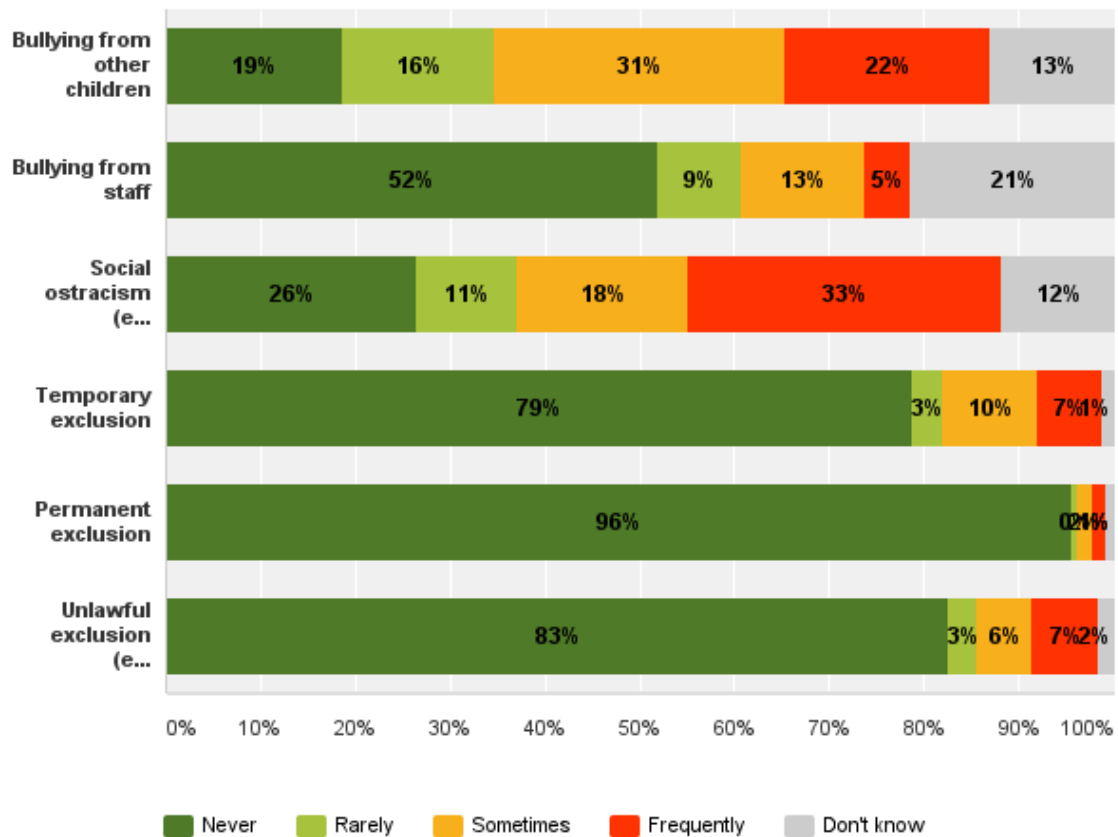
We analysed the responses by school type and found that bullying and social ostracism were much less frequent in special schools than in mainstream schools and IRs. **63%** of pupils in mainstream school pupils had been bullied "sometimes" or "frequently" – again, this was significantly more than in our 2009 survey (**53%**).

We were surprised to find that **18%** of special school pupils had experienced unlawful exclusions (e.g. child sent home or asked to stay at home because school did not have enough support staff) – a much higher percentage than in mainstream schools and IRs.

Overall, **17%** had "sometimes" or "frequently" been given temporary exclusions. Data published by the Department for Education shows that in 2012, **8.3%** of statemented pupils and **7%** of pupils at School Action Plus in Sheffield received at least one fixed-term exclusion, compared to only **1.8%** of pupils without any identified SEN.
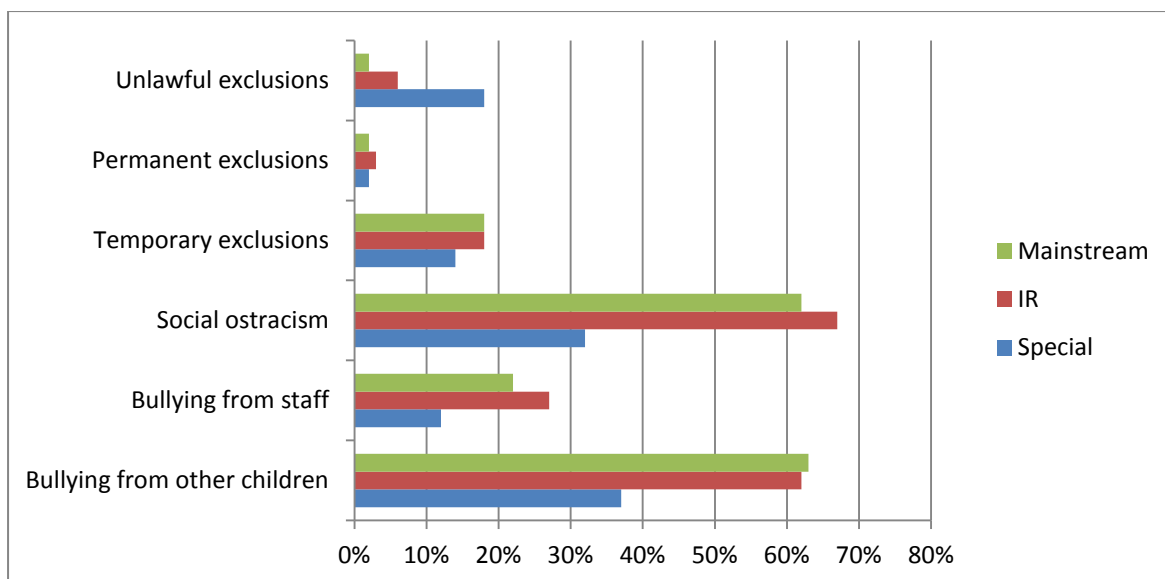
Percentage of pupils by school type who had experienced these issues "Sometimes" or "Frequently"

However, many parents pointed out that they simply don't know what goes on in school:

"Poor communication from school means I don't have a clue what happens here."

"Very difficult to answer as 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."

"I have answered this 'as far as I know'. My son rarely tells me things that may have happened at school and I do feel that there are more things than we are aware of. I only know of 3 incidents of bullying and that is because I saw marks on my son in one instance and the other two I was advised by a teacher."

There were several comments about unofficial internal exclusions, e.g.:

"Lots of inappropriate detentions, he is 8. Internal exclusion to other classrooms without informing us. Only found out through sibling."

Several parents talked about escalating difficulties in mainstream provision before transferring to a special school:

"Prior to specialist provision the mainstream setting forced us on to a part time timetable, asked us to pick our child up at lunch when Ofsted were in & often did fixed term exclusions for 2 days at a time."

Several children had been excluded from school trips, sports days etc. Two parents said they had been asked to take their child home due to illness, when actually their child wasn't ill.

7.11   Transition to post-16 education (46 responses)

If your child is over 16: how would you describe the transition to post-16 education?

Very difficult	44%
Difficult	33%
Easy	22%
Very easy	2%
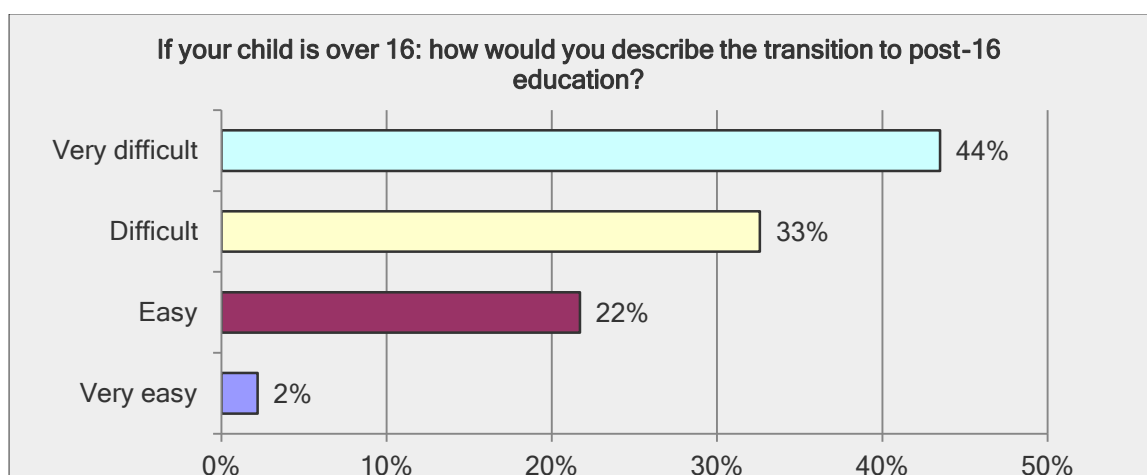
76% of respondents found the transition to post-16 education "difficult" or "very difficult".

Most comments centred around the need for more communication and better information about the options and support available, earlier on. Several comments highlighted a lack of tailored support, e.g.*:*

"Could be more supportive, you are left on your own to work out what is best for your child and to fight for what is best."

Other issues included:

- Health and social care not communicating with each other
- Phone calls not answered/returned
- Actions not completed within the correct time frame
- Social workers not explaining things clearly

Where pre- and post-16 education were provided by the same special school (e.g. Bents Green), the transition was described as unproblematic. However, for some families the "cliff-edge" then came when the young person left school at 19:

"No transition at 16 but the transition at 19 was the most disruptive and traumatic experience we have faced. Almost destroyed our marriage and caused depression and stress."

7.12   Other comments about education services (81 responses)

The main comments in order of frequency (descending) were:

- Need more staff training, better understanding of children's needs
- Lack of provision for specific groups of children, e.g. high-functioning autism
- Poor communication with parents
- Lack of access to outside expertise
- Lack of information about post 16 options

- Need more social skills / life skills training, pastoral support
- Lack of information generally
- Underfunding
- Lack of information about schools, application processes
- Poor secondary provision

"You would have thought that a provision where 'all' the children are statemented and most have communication difficulties would be really good at home-school communication. I asked repeatedly for feedback but was told 'we encourage the children to communicate'. This is all very well but when they can't communicate it is very frustrating."

"No clear/concise/consistent information available about the schools in Sheffield. It is like a game of hide and seek. We were not even told officially which school our child had got into this year. This first thing was last week (first week in April) getting a letter from the actual school arranging some visits."

"In our experience of my son's school they are doing all they can with what they have, but getting more support is an ongoing and difficult battle which unfortunately I can see stretching further in to my son's school life time. Whilst we battle to get the help he needs to be successful in the school environment, my boy loses valuable time in school that he will not get back EVER. To get the help, it feels as though you are running an assault course that keeps changing as you progress through it."

8. Short breaks

8.1 Families in receipt of a short break service (281 responses)

60% of respondents were receiving a short break service, **40%** were not.

8.2 Reasons for not accessing a short break service (100 responses)

We asked those respondents who were not accessing a short break service to tell us why. By far the biggest barrier was a lack of information about these services (**57%**). Several parents indicated confusion about eligibility criteria, e.g.:

"We're not on benefits so I don't think we're eligible."

30% said they were not eligible or did not need/want a short break service. **13%** said that they did not access short breaks because the activities were not suitable for the child's age, needs or interests, or too far away. (NB percentages do not sum to 100 as many respondents selected more than one answer.)

Reasons for not accessing short breaks	Percentage	Responses
Lack of information about these services	57%	57
We are not eligible	16%	16
We don't need them	13%	13
Too complicated - we tried and gave up	10%	10
We don't want them	6%	6
There were no activities suitable for my child's age group	6%	6
There were no activities suitable for my child's needs	4%	4
There were no activities my child wanted to do	4%	4
The activities were too far away	4%	4

8.3 Types of short break/respite services accessed (190 responses)

Of those accessing a short break service, the vast majority had received the short breaks grant (**75%**). This was followed by direct payments up to 5 hours per week (**17%**), overnight respite during term time (**15%**) and specialist SNIPS holiday clubs (**13%**).

Type of short break/respite services accessed	Percentage	Responses
Short breaks grant	75%	142
Direct Payments - up to 5 hours per week	17%	32
Overnight respite - term time	15%	28
SNIPS specialist club - school holidays	13%	25
SNIPS mainstream club - school holidays	10%	19

Club/activity run by parent support group	9%	17
Overnight respite - school holidays	8%	15
Direct Payments - more than 5 hours per week	7%	13
SNIPS specialist club - term time	6%	11
SNIPS mainstream club - term time	4%	7
Ryegate House	2%	3

8.4 Sufficiency of short breaks/respite package (192 responses)

42% of respondents were happy with the level of support they received, **24%** said they just about managed, and **34%** said their care package was not enough to meet their needs.

The main reasons given by those who felt their care package was insufficient were:

- Lack of suitable activities for child's age (particularly teenagers) or needs (not enough specialist provision)
- Not enough direct payment hours
- Difficulty accessing support due to lack of information/communication, long waits (particularly in relation to direct payments)
- Not enough provision for families with more than one disabled child
- Not enough overnight respite
- Managing direct payments is too stressful

Several comments indicated that many families didn't necessarily want more <u>hours</u>, but provision which was better tailored to their individual circumstances:

"The direct payment arrangements have brought a lot of extra work as employers for us, our child receives 4 hours per week but we spend an additional at least 1 hour per week to keep on top of everything to do with direct payment. Originally we received 3 hours of a befriending service provided by Crossroads on behalf of Sheffield City Council, which suited us much more."

"Holiday time is especially difficult as more support is needed then. It would not mean more hours but the flexibility to spread the 10 hours over the week. He has overnight respite but only stays to 6.45pm through our choice. Again we would benefit from more respite that wasn't over night but after school till 7pm."

"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."

There were numerous positive comments about the short breaks grant, although a few respondents felt that £400 was not enough.

8.5   Potential impact of reduced short breaks/respite (136 responses)

67% of respondents felt that a reduction in short breaks/respite services would have a "significant" or "devastating" impact on their family.

If your child's short breaks/respite were to be reduced in the future, what impact would this have on your family?

Devastating impact: high risk that our family might end up in crisis	24%
Significant impact: we would struggle to cope	43%
Mild impact: life would be more difficult but we would manage	28%
No impact: it wouldn't make a difference	5%
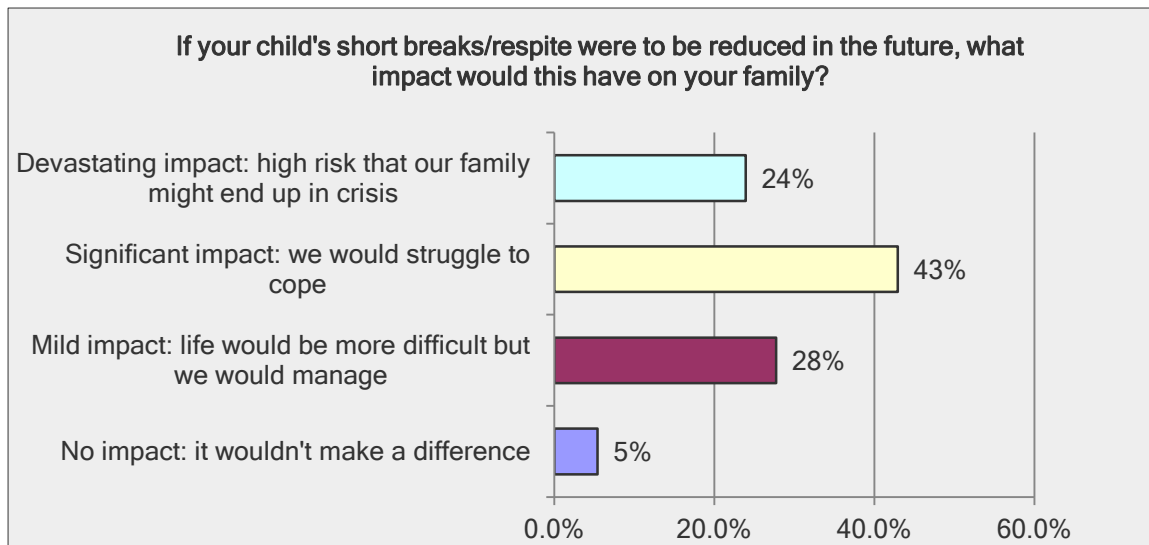
Several parents highlighted the vital importance of overnight respite for their family. The short breaks grant was also mentioned several times, and some parents said that they wouldn't be able to go on holiday without it.

Parents pointed out that a reduction in short breaks would not only affect their own wellbeing, but would also impact negatively on the disabled child, their siblings and parents' ability to work:

"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."

"The impact to my daughter would be devastating as my son is challenging and this is a break for her. It boosts her confidence."

"I would have to give up work as it would be too much of a strain on my health working and also looking after my son without respite support. Our other children would not have time to spend with us."

8.6   Transition to adult social care (24 responses)

There were only 24 responses to this question, due to the low number of respondents with children over the age of 18. Of these, 23 parents (**96%**) said that the transition to adult social care was either "Difficult" or "Very difficult":

If your child is over 18: how would you describe the transition to adult social care?

Very difficult	71%
Difficult	25%
Easy	4%
Very easy	0%
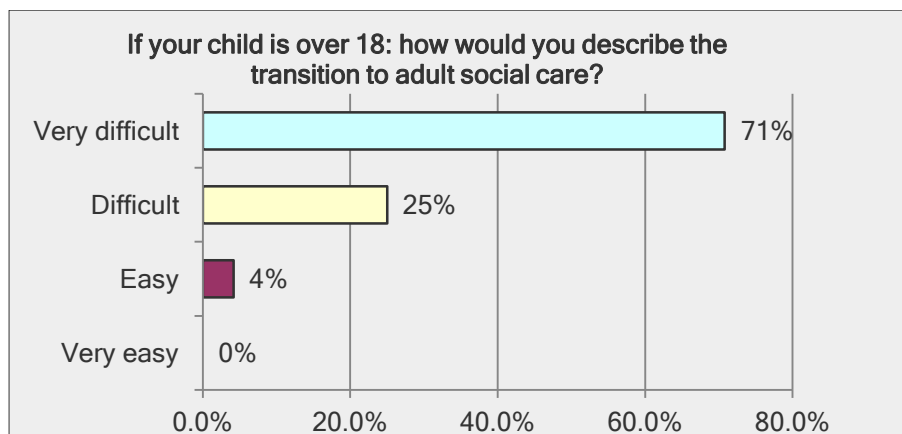
The main reasons given were:

- Fragmented process which takes too long and is started too late
- Lack of information, advice and support for parents
- Social care Transitions Team is underresourced
- Stressful/traumatic for parents
- Intransparent decision-making (not knowing who sits on panels)
- No social worker allocated

We asked parents to suggest how the transition process could be improved. Most respondents focused on what had gone wrong (see previous list), but a few also made suggestions for improvements:

- Transition process should be overseen by one central department to ensure good communication/continuity
- Continue children's services until adult plan is in place
- More support/information offered to parents, rather than having to find things out "by chance"
- Start the process earlier
- Things need to happen more quickly - paperwork, social workers replying to messages, cases taken to panel
- Need an allocated social worker early on in the process

"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."

"Very limited support offered. As a parent we have to search for it, not automatically offered."

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8.7   Other comments about social care services (56 responses)

Most of the comments in this section were negative, and the strength of feeling expressed gives cause for concern. The main themes were:

Lack of clear information/criteria

Parents said they needed more information about the support available and the criteria used for allocating it – including criteria for carrying out assessments. They gave examples of being given incorrect information, or receiving conflicting advice from different people.

Difficult/slow process and poor communication

Parents felt that the process was too slow, and that the service was not responsive enough, e.g. not responding to emails or returning telephone calls. They also criticised the way in which decisions were communicated to parents.

Poor professional standards

Several respondents raised concerns about poor professional standards.

Direct payments slow/difficult to set up and time-consuming to manage

Parents said that setting up direct payments took too long, and that managing them was stressful and time-consuming.

Lack of continuity

Respondents raised concerns about frequent changes of personnel. They felt that they needed an allocated social worker and not a duty social worker, so that the person could get to know them and their disabled child.

9. Direct Payments and Personal Budgets

9.1   Families in receipt of a direct payment or personal budget (277 responses)

18% of respondents had a direct payment and **4%** had a personal budget.

77% did not receive a direct payment or personal budget, although **30%** of them said they would like to.

9.2   Accessing and managing a direct payment or personal budget (63 responses)

65% of respondents found direct payments and personal budgets either "Difficult" or "Very difficult" to access, and **60%** said the same about managing them:
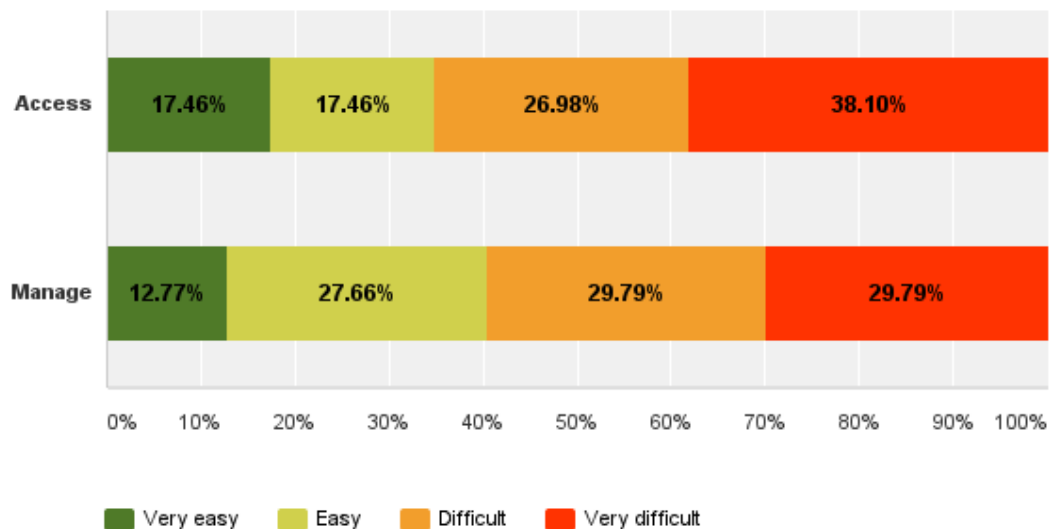
There were several comments about long waits in the process, e.g. getting approval for funds, or getting a support plan agreed:

"Social worker dealing with personal plan. Still haven't received any approval for funds. Individual budget was agreed last September but haven't been able to access it." [written in June]

Several parents commented that they had not received enough support in their role as an employer, and had got themselves into difficulties as a result:

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

The time needed to deal with paperwork was seen as a major drawback:

"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."

9.3 Use of direct payment / personal budget (67 responses)

The overwhelming majority (**87%**) used their direct payment or personal budget to employ a personal assistant.

24% used their direct payment or personal budget to fund leisure activities. Only a small number of families had a direct payment or personal budgets for overnight respite, support in education or training, or equipment (five families in each category).

"I wish we could use it for support in education. We would much rather employ our own support staff for school and then we can be sure that [our child] is receiving the right support for his needs but they refused to allow us to do this."

9.4 Sufficiency of direct payment / personal budget (66 responses)

45% said that their direct payment or personal budget was sufficient to meet their child's needs, **55%** said it was not.

By comparison, **34%** of <u>all</u> short breaks users said that their package was insufficient to meet their needs (see section 8.4).

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).

9.10 Preference for direct payments or council services (70 responses)

73% of respondents said they preferred direct payments, and **27%** favoured a council service.

Several parents commented that they did not understand the difference between direct payments and council services.

Others said that there were pros and cons for both; they liked the control and flexibility offered by direct payments, e.g. being able to choose a Personal Assistant, but found being an employer and managing the payroll quite stressful.

10. Health services

10.1 Quality and quantity of health services (277 responses)

We asked parents to rate health services in terms of quality and quantity.

	Quality of provision				
	Excellent	Good	Fair	Poor	Very poor
Speech & Lang. Therapy	14%	30%	28%	18%	10%
Physiotherapy	23%	33%	17%	17%	11%
Occupational Therapy	19%	37%	16%	16%	12%
CAMHS	35%	33%	11%	18%	4%
GP	28%	38%	23%	10%	2%
Health Visitor	41%	9%	23%	14%	14%
Dentist (NHS)	48%	40%	8%	3%	1%
Dentist (private)	50%	31%	6%		13%
Dentist (community)	41%	41%	10%		7%
Hospital (Ryegate)	33%	38%	21%	5%	3%
Hospital (A&E)	29%	38%	23%	10%	
Hospital (Outpatients)	32%	46%	18%	4%	
Hospital (Inpatients)	34%	41%	16%	9%	
Continence service	18%	46%	22%	6%	7%
School nurse	25%	46%	17%	10%	2%

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Quantity of provision

Service	Too little	About right	Too much
Speech & Lang. Therapy	74%	26%	
Physiotherapy	56%	44%	
Occupational Therapy	55%	45%	
CAMHS	59%	41%	
GP	20%	79%	1%
Health Visitor	40%	60%	
Dentist (NHS)	6%	94%	
Dentist (private)		91%	9%
Dentist (community)	14%	86%	
Hospital (Ryegate)	41%	59%	
Hospital (A&E)	21%	79%	
Hospital (Outpatients)	10%	85%	5%
Hospital (Inpatients)	5%	90%	5%
Continence service	26%	74%	
School nurse	27%	73%	

Legend: Too little · About right · Too much

Sheffield's **Speech and Language Therapy** team is around **40%** smaller than the national average.[xvii] There were several negative comments about speech and language therapy, both in relation to quality and quantity:

"SLT therapist changes every year no continuity. Very little or no guidance for parents even when requested. Poor communication. School don't prioritise SLT despite child's huge needs."

Parents said it was **left to them to chase up appointments and coordinate services**, and to **research information**:

"Hospitals are generally okay and GP is good but we have had problems because tests done at hospital are not available to GP (different computer system). I have had to chase up test results myself to pass it onto GP (It's frustrating)."

"Hearing scientists have also been good, but I had to research this and then do a lot of the ground work for my son to be referred to them, otherwise he would have gone to the ENT specialist and probably I would have been told there was nothing they could do."

"We use the Sheffield salaried dental service which is essential for our child but we're never given information about his service and only found out by chance."

Respondents complained about **long waits to access specific services**, such as CAMHS, dental treatment and Ryegate:

"We previously had a 3 month wait for my disabled child to have decayed teeth taken out in hospital, as required by her paediatrician, because of waiting lists. During that time my child was in pain, and on constant antibiotics for permanent abscesses. A non disabled child would have been able to access a mainstream dentist and have the tooth removed within days."

"Trying to access CAMHS but waiting is months."

There were several very positive comments about **individual health professionals**, particularly dentists:

"GP is a rock, visit surgery as often as we like to. Private dentist marvellous with grandson, totally understands how to deal with him. Appointments & any treatment accepted with trust and calmness - a godsend."

"Had OT support to ensure property she is now a tenant of had 'extras' she needed so that it was safer for her. Good service, appropriate help and genuinely good practical ideas."

A number of parents said that their children **needed speech and language therapy or physiotherapy but were not receiving this service**.

Two parents said they were **paying privately for extra nappies**:

"We have asked for more nappies but we are only allowed 4 a day (my son is 9 so he needs changing more often than 4 times in 24 hours). We have to top up and pay £40 three times a year for a back up supply."

Several parents commented on a **lack of flexibility** which creates barriers for children with additional needs:

"Our difficulty is accessing the services because of my child's mental health. Very difficult, and sometimes impossible to get him to an appointment. I would like a home service when this is the case."

"Ryegate waiting times mean that our son won't wait. Our appointment is almost an hour late every time. He is now a Ryegate refuser. Will have to get blood pressure and heart checked via GP for meds."

"We wanted help to teach bike riding but were told she had wrong disability so couldn't access the courses that were available for other kids."

10.2   Health services which are needed but not provided (225 responses)

24% of respondents said that their child was in need of a health service which was not currently being provided. Several parents pointed out that they simply did not know whether there were any services that their child should be accessing:

"This is a major concern to me. How are we expected to know which services our children need when we are not clinically trained to identify their needs and you are made to feel when asking for any service that unless your child is an extreme clinical case then there is no need for your child to receive that service, or to improve/update the service that they have received."

We asked parents to tell us which services their child needed but was not receiving, and have listed these in order of frequency (descending):

- CAMHS
- Speech and Language Therapy
- Psychology
- Continence service
- Physiotherapy
- Occupational therapy
- Sensory integration therapy
- Anger management
- Nutritionist

The following services were mentioned only once: Counselling, Hearing test, Help with motor skills, Social / life skills, Autism support, Neurology, Specialist dentistry, Talk tool therapy, Chiropodist.

10.3   Paying privately for health services (253 responses)

11% of respondents said they were paying privately for health services. The services they were paying for are listed in order of frequency (descending):

- Speech and Language Therapy
- Dentist
- Physiotherapy
- Sensory integration therapy

The following services were mentioned only once: Orthotics, Personal trainer, Acupuncture, Hypnotherapy, Osteopathy, Homeopathy, Massage, Talk tool therapy, Clinical psychology.

10.4   Barriers to accessing health services (213 responses)

We asked parents what made it difficult for them and/or their child to access health services:

Barriers to accessing health services	Percentage	Responses
Lack of information about services	56%	119
Child finds waiting very difficult	53%	112
Unclear referral routes	36%	76
Professionals not taking my concerns seriously	32%	67
Staff don't understand child's needs	31%	66
Waiting area too busy	30%	64
Transport	12%	26
My own health/disability	7%	14
English is not my first language	1%	2

Other issues listed included:

- Lack of parking
- Not allowed to be involved as parent of an adult
- Long waiting times
- Poor post-diagnostic support
- Insufficient resourcing for speech and language therapy
- Required services not available on the NHS
- Lack of staff training/understanding

"Hard not to conclude that services are not concerned about or interested in children who were born disabled. Have they simply assumed that no progress can be made or that they are worthless? We know that she is still progressing in her abilities to communicate and we believe that when the expert knowledge of SLT is actually shared with those who work with her every day then she could progress further, be understood more and maybe her behaviour would be better as she would be happier. Being able to communicate is a fundamental part of being human. Health services seem to think that it is okay to discriminate in this way."

10.5   Transition to adult health services (34 responses)

29% of respondents found the transition to adult health services "Easy", and **71%** found it "Difficult" or "Very difficult".

The main issues were:

- Transition done at different times for different services - no consistency
- Lack of information for parents
- Too easy for children to slip through the net
- Falling between children's and adult services (no 16-17 mental health service)

"My son slipped through the net until I called to ask why we'd not received an appointment they admitted they missed for the transfer what would happen if I had not chased this up? But then again they are saying they can't offer him any help anyway."

"Some areas are well done, others are just box ticking. To take time off work to attend a hand over meeting in which the person handing over my child has never met them or been involved in their care is a waste of time for all concerned."

10.6   Other comments about health services (41 responses)

Many of the comments in this section repeated information from other parts of the questionnaire. The most frequent comments were:

Appointments not adjusted to fit child's needs

"The last two assessments had gone wrong because by the time health professional has finished getting information from us (parents), our child has been sat for 5 to 10 minutes and has had enough. Nothing can be done to redeem this situation. I am getting better and need to reorganise these times differently so that my child does not get upset plus the health professional gets the right information and I don't feel like a failure!"

Lack of information about what is available and how to access it

"Don't know what is available or how to get it"

"I think that a lot of health services are accessed through schools, and therefore we have missed out as we have home educated. For instance there was no provision of counselling for my daughter when her father died, as it was all provided through schools, and we have not had any information on any services which may be available."

Long waits / difficulty accessing services

"Long waiting list for psychology services at Ryegate. Our child was only put on waiting list 6 months after asking and only with referral from paediatrician. 2 months later still no news. Autism team not involved in school despite issues arising there."

"Was extremely hard to access CAMHS but once in the system getting the support needed."

Lack of staff training/understanding

"Lacks knowledge about how to care for learning disabilities"

"Health services and the people working for them do not try to see things from the autism perspective. Yet we are expected to see everything from their point of view."

Lack of joint-up working

"All paper files need to be on a computer system. My child's file is about 75 mm thick no doctor has the time to find important notes and so they rely on us to ask if we can remember what happened and when."

"There is no holistic approach, so areas that need support go missed."

"I'm finding that increasingly I'm not being reminded about some of the annual appointments - my daughter's hearing, thyroid (annual) and respiratory appointments (quarterly) were late and only made because I rang up to check when they should be - I find it difficult to keep on top of all the appointments."

Difficulties around transition

"Adult health starts at 18 years old but in mental health you become an adult at 16! This should be raised to 18."

"No transition route until after it was needed happened too late and no help at all"

"When my child gets to adult services, I am scared that I will not be able to go into the appointment with him, all what he will do to answer "yes" to everything"

Lack of provision

"There is an immense amount of short sighted planning and service delivery. What is the point of all that training being used to assess without then delivering an intervention that makes a difference. Assessment is not therapy. My daughter is unlikely to ever need a less supportive care service than she receives now. But there is a huge risk that without therapeutic intervention she will need more expensive provision in the future. If she was a young man who behaved as she does then her 'danger to others' would be taken more seriously."

11.   General

11.1 Training for parents (242 responses)

We asked parents if there was any training that would help them cope with the demands of caring for their child. **76%** of respondents indicated a need for training:

Training required	Percentage	Responses
Understanding my rights as a carer	59%	143
Coping with stress	54%	131
Managing challenging behaviour	50%	121
Understanding disability benefits	46%	112
Understanding the SEN system	46%	112
Helping my child be safe in traffic	42%	102
Preparing for transition	36%	88
Supporting speech & language development	32%	78
Understanding my child's condition	28%	67
Helping my child with sleep	27%	65
Assertiveness/communication training	23%	56
Helping my child with toilet training	21%	51
Helping my child with eating/feeding issues	19%	45
Lifting and handling	5%	13

Several respondents indicated that they wanted more individualised support than a training session could provide, e.g. help with form filling, help with everyday things.

Respondents suggested a number of other topics they would like training on:

- Managing direct payments and employing PAs
- Making a will and setting up trusts
- Making your home safe for children with sensory needs
- Preparing for meetings
- Primary to secondary transition

Parents pointed out that training needed to be provided early in order to be effective:

"All the things are good ideas but need to be offered early on or be available when parent or carer wants it and not one year later."

"This would have helped at an earlier age. As he did not have a statement we found it all out for ourselves."
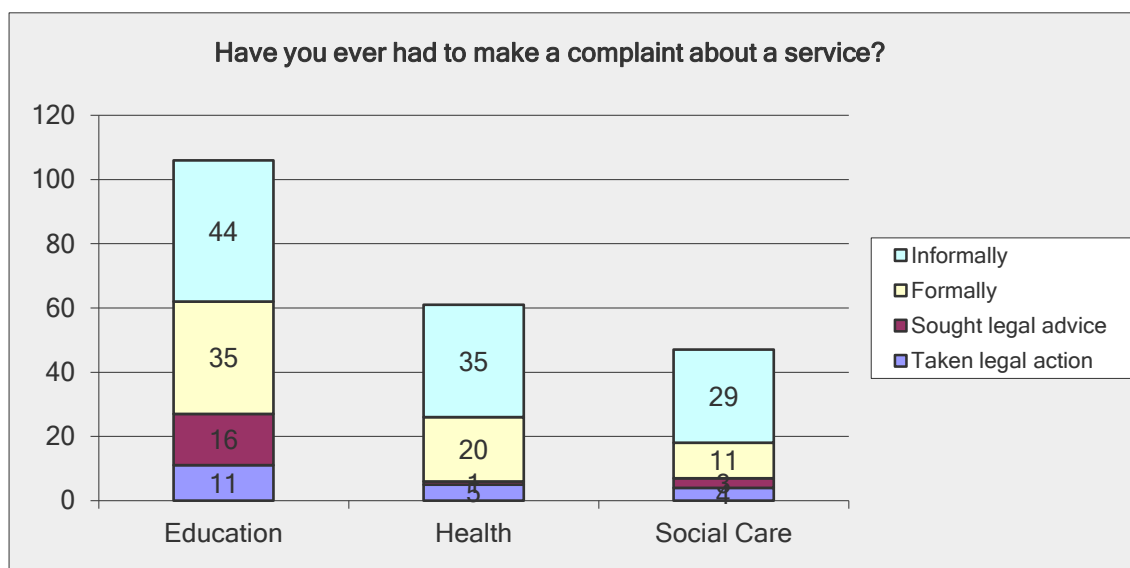
Several parents had been on other training courses:

"I attended a course run by ADHD project to understand child behaviour and coping methods. It was invaluable."

"Found Triple P course useful, but would like something more disability specific."

11.2   Complaints (134 responses)

We asked parents if they had ever had to make a complaint about a service. Significantly more parents had complained about education services than health or social care services:

Have you ever had to make a complaint about a service?

Service	Taken legal action	Sought legal advice	Formally	Informally
Education	11	16	35	44
Health	5	1	20	35
Social Care	4	3	11	29

N.B. Numbers shown in the table reflect the actual numbers of respondents who selected this option.

There were 41 free format comments, which broadly fell into the following categories:

- **School related complaints:** failure to implement statement, failure to meet needs, exclusions, disability discrimination, bullying, failure to make reasonable adjustments
- **Disputes about educational placements**: mainly to get specialist secondary placement
- **Disputes about refusal to carry out a statutory assessment or issue a statement**
- **Complaints in relation to social care:** errors in assessment report, direct payments assessment process, SNIPS
- **Complaints in relation to specific health services:** long waiting times, problems with referral process, no diagnosis given, no genetic counselling service
- **Complaints in relation to specific individuals**

Several respondents said that they had involved their MP. Some parents said that they would like to make a complaint but didn't know how to do this. Others said that they were reluctant to make a complaint because it took too much time, or because they feared the repercussions:

"Have never found the time to write half the letters I wanted to write."

"I am sick of making complaints to get the right service, it makes us as a family look bad and not the service."

11.3   What would make life better? (227 responses)

We asked parents to tell us three things in relation to the child with a disability/additional needs that would make life easier or better for their family. The top ten responses were:

1.   Time off/respite
2.   More clubs and activities (weekend, after school) and opportunities to socialise
3.   Some/more help or support
4.   More understanding/tolerance/awareness/acceptance in community
5.   Information about services/support and how to access them
6.   More support in school
7.   Better social care services/support/information
8.   Speech and Language Therapy
9.   Personal assistant/mentor/buddy/befriending
10.   Schools better able to understand and meet needs of individual children

Parents clearly felt the need to have **time away from caring** for their child/children with disabilities (1). This might be time for themselves to protect their own wellbeing, or time to spend with other family members:

"Time off sometimes to refresh and de-stress"

"Some respite so that I can spend time with my husband/other child"

Parents wanted **more activities for their children to take part in** after school and at the weekends (2):

"More groups for my daughter to meet up with friends safely in school holidays/weekends"

This ties in with wanting support from a **Personal Assistant/mentor/buddy** to help their child access activities in the community (9):

"A mentor to take our grandson out bowling and show him how to play computer games –we are getting too old".

A number of comments highlighted this alongside the **need for their child to be able to socialise**:

"More social opportunities for families with disabilities – that are run to a high standard and offer inclusive fun so that my daughter can build friendships, as this does not happen at mainstream school."

Parents wanted **more support to help them in their caring role** (3):

"More emotional support for carers particularly services such as specialist counselling"

This is linked to their need for **information about services/support and how to access them** (5):

"To have more support for us as carers. To know where to find it easily, which is hard when you're emotionally and physically exhausted"

Awareness and understanding of children with disabilities in the wider community was also something that parents would like (4):

"Understanding and compassion from members of the public about disability and the huge impact this can have on the family"

"Safe places to go where people understand"

"Awareness of disabled children should be made more public, especially in supermarkets. The public are too quick to judge sometimes."

Parents would like more **support for their child in school** (6) and to feel **more confident that schools understand and meet the needs of individual children** (10):

"Better understanding and support at school"

"More support in school to help him develop and learn"

"Improved education provision, more personalised, meeting individual need within special school"

Easier access to better social care services would help parents (7):

"Prompt action and involvement from social services"

"More understanding from social services"

"Responsive social care service"

In particular, parents of young people **transitioning to adult services** wanted more support from social care:

"Social care contacting us and supporting us through the transition process. Doing their job quickly and efficiently with good line of communication"

Parents also wanted **access to, or more intervention from, therapy services** - **particularly Speech and Language Therapy** (8)

"Adequate speech and language provision and physiotherapy on a regular basis"

"More speech and language therapy support"

"More Makaton training for education, health and care workers so they can communicate with my child."

Parents wanted **schools that are better able to understand the needs of individual children and respond to them** (10):

"A better education system, one suited to her needs and not one she is made to fit into"

"A school in Sheffield that could meet his needs"

"Improved education provision, more personalised meeting individual need within special school"

11.4   Examples of good practice (63 responses)

We asked parents to tell us about examples of good practice that we could share. Most respondents just listed specific services or individuals, but did not specify what it was that made them good.

Education: Integrated Resources (King Ecgberts), special schools (Robert Ogden, Brantwood), Home and Hospital Education Service, Hallam University Dyslexia Support, Dobcroft school, Parent Partnership Service, Portage Service, Aston Academy (pastoral support), PHSE programmes that support understanding of difference

Social care: MAST Family Intervention Worker, direct payments (flexibility offered), respite centres (Mulberry Lodge, Rushey Meadow, Gibson House),

Health: Ryegate (Dr Gentle), CAMHS (specific mention of LD team coffee mornings), Continence Service (Jo Searles), Broomhill Surgery (Dr France), Rheumatology, Respiratory Team, Salaried Dental Practice, transition to Hearing Impaired Unit at Hallamshire

Other: Mencap Gateway, Saturday playscheme at university, SPCF newsletter (tips section), Motability, e-dance, ACCT, Interchange, Down Syndrome speech therapy groups in other local authorities, Hanen programme

Where respondents provided more detail, comments often focussed on good communication and key working:

"Secondary school SENCO was excellent. Timely communication, easy to contact, always ready to meet and discuss any issues"

"My son's rheumatology team have been excellent, they ensure we see the same consultant, fortnightly, in between this they will contact us and we have contact details for them should he become unwell."

"Transition to hearing impaired unit at Hallamshire was a dream! Easier than Children's, and attended an adolescent clinic & was given a key worker who hopefully we will see each time."

Parents valued joined-up services:

"Joint working of audiologist scientist with our private therapist to formulate joint strategies to treat my child's sensitivity hearing problems. Professionals willing to work with other people and also being open minded and welcoming of new information and learning."

"My child's independent specialist provider offers respite care, which allows a streamlined service between school and respite, and vital information sharing."

"Sheffield Children's respiratory team have been involved even with my sons other conditions to make it easier for them and him"

Several respondents praised professionals who were willing to go the extra mile:

"Received excellent support for our chosen pathway with our son regarding incontinence. Support/calls out of hours and backing us up to consultants from Jo Searle, Incontinence Nurse."

"Our GP, Dr France, at the Broomhill Surgery has been fantastic - even phoning at 10pm when he's received an urgent message from me. Dr Sue Gentle at Ryegate has been very supportive, even though J has recently turned 16. It's very difficult when your child turns 16 when services for your child often change."

Parents valued services which were efficient and well run:

"Sheffield Hallam University undertook dyslexia testing as soon as we made contact, waited only a week for an appointment. They outlined and provided equipment and support in a timely manner. From diagnosis to support in place took only 8 weeks and was in place prior to her course starting."

"It would be wonderful if the quality of service that is provided by Motability was matched by that provided by other services. It meets your needs. Has choice, has good quality staff. Does effectively and efficiently what it says on the tin."

Parents appreciated services which were flexible and willing to adapt:

"Heeley dentist working with us with specialist equipment to help autistic children access dental examinations"

"We have used our direct payment to pay for people with dogs to walk [our child] to school which has really helped. We have also used it to pay for overnight respite with families we know and trust who also have animals."

"Fast tracked through A&E when we told them his needs"

11.5   Who or what do you value most? (181 responses)

We asked parents to tell us who or what they valued most in relation to their child with a disability/additional needs. Respondents listed a wide variety of people and services, the top ten being:

- School / education staff
- Family / friends
- Parent support groups
- ACCT
- Other parent carers
- Personal assistants / carers
- People who show empathy/understanding

- My child
- My partner
- Family time

School/education staff were mentioned by a large number of respondents. Where a school placement was working well, this inspired a huge sense of gratitude:

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

"Excellent support that we have received via Portage Service and Wharncliffe School IR nursery as in both instances the staff are well-trained and see SEN as a professionally interesting challenge NOT a burden. These people also support the whole family and this was invaluable to us in our early days as we had no other form of support."

11.6   Is there anything you wish you'd known earlier? (141 responses)

The top ten responses (in descending order) were:

1. **Information about help/support/services generally, and how to access them:**

"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."

"No one told us anything about benefits or the SEN system"

Many parents said that they often found out about services from other parents and friends:

"I've only just found out from a friend that we are entitled to have our home adapted for my child's needs. This information should have been given to me at an earlier stage of my child's diagnosis"

"From early days all the support e.g. SNIPS after school club support/respite/getting PA's/managing PA's has been info from other parents. Council website and advice has always been very vague and not understood big picture."

Parents said they needed the right information, at the right time:

"When she was born we were bombarded with information that, at the time, didn't seem relevant. The information wasn't delivered appropriately. It would be useful if packs of information on disabled children and support available were offered at stages (new-born, pre-school, primary, secondary, transition)."

"I am glad I had so little knowledge about what we would be facing at the very beginning. The information that is now available to families of children with her syndrome tends to be unremittingly negative and pessimistic - so I am happy that we were so ignorant."

2. **Information and advice about financial support / benefits / grants:**

"Didn't know we could apply for DLA or any other benefits until a year after diagnosis."

"About benefits and entitlements"

"What help is out there and for someone to link all the help together e.g. tax credits, grants, etc."

3. **Information about SEN provision and statements:**

"All about SEN provision and what support is available"

"More about provision which might be available in non-school settings, for example Home and Hospital Education Service"

"Just how the statement process works, what I needed in place (such as Ed Psych) – it all felt a bit like a secret club that you can only access once you are through the door"

4. **Earlier diagnosis**:

"Diagnosis and support at a much earlier time, our relationship and mental health were put under an enormous strain"

"How to get the diagnosis. School knew he was ADHD, but didn't broach it with us; they only referred to Community Paediatrics when I had a breakdown at school because I couldn't cope - he was 6 by this time. Community Paediatrics could not properly diagnose - we had to be referred on to Ryegate and he was nearly 8 by the time he was formally diagnosed and now we can get help. But I still don't really know what sort of help we can get - I think he might be grown up before I figure it all out"

"I wish his dyslexia had been detected earlier"

"I wish I'd known to trust my instinct that something wasn't right when she was a baby. It may have led to quicker diagnosis and more support for her in those vital early years."

5. **Information about direct payments and employing personal assistants**:

"How to employ your own childcare person, access to direct payments"

"That you can use direct payments to employ a PA for your child. Unfortunately I still don't know how to apply"

6. **Information about specific disabilities or conditions / post-diagnosis support:**

"ADHD – would have liked to have known before he turned for the worst"

"More about Asperger's. There was no follow up whatsoever from Ryegate after diagnosis. We have learnt slowly and some guidance would have been very helpful"

"What life would be like, how difficult and challenging it would be bringing twins up with their condition"

7. **What difficulties lie ahead, and how resilient and assertive parents have to be:**

"It will be a life-long battle to fight for the care and education that your child needs. Treat it like a job and don't expect anyone to look out for your child or your family, you are on your own. Don't worry about offending people, put your child's needs first and if they are any good at their job they will also do that so you will have shared ground. I'm not advocating an aggressive approach, just the need for resilience and perseverance by all parents of children with disabilities."

"Not to trust or believe professionals, to be more vocal as soon as problems occur (although the head teacher at my son's school recently told me I had always been uncooperative!). To have complained formally about previous consultants attitudes."

"That my brick wall would be needed so frequently to bang my head upon due to inefficient services requiring so much wheel-oiling. Adds to stress of an already difficult family life."

"How hard you have to fight, never to accept any other person's word for it and learn quickly to be your child's project manager and spokesperson. Never give up when the system wants you too!!!!"

8. **Information about transition (to secondary school / post 16 / adult services):**

"How transition to adult services process worked and how long it takes"

"To start finding out about transition at 16 and visiting day centres etc. then. Also that assessment forms can be downloaded from the internet and read through BEFORE the social worker comes to do the assessment."

"That my son would leave school early on his last year- As I work and need to sort childcare. I was the last to know"

9. Information about short breaks/respite:

"Short breaks grant, as we might have been able to access it earlier"

"Which services were out there and clubs she could have accessed"

10. Information about support groups:

"I wish I had known about the Sheffield Autistic Society earlier"

"I wish I had contacted ACCT earlier as I felt very isolated before that"

12.   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.

13.   List of recommendations

1.	**Sheffield City Council** and **Sheffield CCG** 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.
2.	**Sheffield City Council** ensures that social care assessments take account of the cumulative impact of providing care for more than one disabled person.
3.	**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.
4.	**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.
5.	**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).
6.	**Sheffield City Council** funds a range of peer support projects (e.g. parent support groups, befriending schemes).
7.	**Sheffield City Council** prioritises short breaks services when assessing budget cuts.
8.	**Sheffield City Council** promotes short breaks services more widely to parent carers, using a range of communication methods.
9.	**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.
10.	**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).
11.	**Sheffield CCG** commissions specialist counselling and wellbeing activities for parent carers.
12.	**Sheffield City Council** considers the views of siblings as part of social care assessments.
13.	**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.
14.	**Sheffield City Council** ensures that the organisations it funds to provide support for young carers increase their efforts to identify and support sibling carers.
15.	**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.

16.	**Sheffield City Council** prioritises overnight respite when assessing budget cuts.
17.	**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.
18.	**Sheffield CCG** commissions a specialist sleep support service for children with disabilities.
19.	**Sheffield City Council** includes questions about sleep problems in relevant needs assessment frameworks (e.g. Family CAF, social worker assessments).
20.	**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.
21.	**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).
22.	**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.
23.	**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.
24.	**Sheffield City Council** and **Sheffield CCG** commission behaviour management workshops for parent carers.
25.	**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.
26.	**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.
27.	**Sheffield City Council** and **Sheffield CCG** produce a signposting directory for frontline staff (particularly key workers, SENCOs, GPs and health visitors).
28.	**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.
29.	**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.
30.	**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.
31.	**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.
32.	**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 Parent and Child Voice").
33.	**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.
34.	**Sheffield City Council** and **Sheffield CCG** increase the capacity of underperforming services.
35.	**Service managers** work with SPCF to identify and share good practice in working with parents.
36.	**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.
37.	The **CYPF Support Scrutiny and Policy Development Committee** sets up a working group to investigate the negative feedback about social care services.
38.	**Sheffield City Council** and **Sheffield CCG** review the transition support provided by the Transitions Team, transition nurses, Sheffield Futures and Lifelong Learning and Skills.
39.	**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).
40.	**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.
41.	**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.
42.	**Sheffield City Council** works with SPCF to develop an information pack about direct payments which includes detailed checklists, sample contracts etc.
43.	The **Direct Payments Team** holds regular training sessions for parents about managing direct payments and recruiting and employing PAs.
44.	The findings from this study inform the **Childcare Sufficiency Assessment**.
45.	**Sheffield City Council** reviews the sufficiency of inclusion grants for childcare providers.
46.	**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.
47.	**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.

[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 Pediatric 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*

[vi] Office for National Statistics (2013), Labour Force Survey

[vii] Department for Work and Pensions (2008), Exploring disability, family formation and break-up: Reviewing the Evidence

[viii] Rossiter, L and Sharpe, D (2002), Siblings of children with a chronic illness: A meta analysis, *Journal of Pediatric Psychology*

[ix] Harrison, J and Woolley, M (2004), Debt and Disability: The impact of debt on families with disabled children, *Contact a Family & Family Fund*

[x] Personal Social Services Carers Survey 2012/13

[xi] Department for Work and Pensions (2007), Disability and caring among families with children: Family employment and poverty characteristics

[xii] Langerman, C. & Worral, E. (2005), Ordinary lives – disabled children and their families, *New Philantrophy Capital*

[xiii] Parliamentary Inquiry into childcare for disabled children (2014)

[xiv] Dobson, B. & Middleton, S. (1998), Paying to Care: The cost of childhood disability, *Joseph Rowntree Foundation*

[xv] Contact a Family (2014), Counting the Costs 2014

[xvi] Chatzitheochari S., Parsons S. and Platt L. (2014), Bullying experiences among disabled children and young people in England: Evidence from two longitudinal studies

[xvii] Sheffield Joint Strategic Needs Assessment (2013)