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1 **Reasonable Adjustments for Disabled Pupils: What support *do* parents want for their child?**

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1 Reasonable Adjustments for Disabled Pupils: What support *do* parents want for their child?

3 Summary

4 Schools in England (as elsewhere in Europe) have a duty to promote equality for disabled people and make
5 reasonable adjustments for disabled children. There is however a degree of uncertainty about how well
6 placed parents are to use the legislation to ensure their child's needs are addressed. This paper presents
7 data drawn from a national questionnaire designed for schools to use to identify their disabled pupils and
8 examines in detail parental responses to a question on the kinds of support their child finds helpful in
9 offsetting any difficulties they experience. It illustrates the complex and varied nature of the "reasonable
10 adjustments" that are required and an overriding sense these need to be underpinned by the values of a
11 responsive child centred approach, one that recognizes that parents' knowledge and understanding of their
12 child is important. Schools need to have in place the two way communication process that supports them in
13 "knowing" about the visible and invisible challenges that pupils with difficulties and disabilities face in
14 participating in school life.

15
16 **Key words:** disabled pupils; parents; support.

18 Introduction

19 There has been a series of legislative acts in England as elsewhere in Europe designed to safeguard disabled
20 people from discrimination. This rights based approach draws on a social model of disability and makes an
21 important distinction between an impairment and a disability, the latter resulting from the interaction
22 between the person and the environment, putting due emphasis on the barriers and supports that are in
23 place. The definition of disability was set out in the Disability Discrimination Act 1995 with a duty placed on
24 schools to take reasonable steps to ensure that disabled students were not placed at a disadvantage. Schools
25 were required to develop plans for improving access in relation to the curriculum as well as the physical
26 environment. This duty was strengthened in the 2005 Act by requiring schools to publish their plans and
27 strategies and make an annual report. It required schools to monitor the impact of their activities and to
28 make reasonable adjustments to policies, practices and procedures. The Equality Act 2010 extended the
29 range of adjustments that schools might reasonably be expected to make to include (from September 2012)
30 auxiliary aids and services although it also removed some of the bureaucratic demands. Through this
31 legislation, schools have also been required to be proactive in promoting disability equality by anticipating
32 barriers that pupils could encounter and removing or minimising them "to put [disabled children].. on a
33 more level footing with pupils without disabilities" DfE (2010).

34
35 Research by the Equality and Human Rights commission indicates that schools have responded to many of
36 these expectations. Almost four in five schools have an Action Plan with targets set, and report actions that
37 have had a positive impact on provision for disabled pupils (Bukowski et al 2011). The most frequently cited
38 response has been to improve access to facilities and resources, however it is unclear how schools have gone
39 about identifying disabled pupils. To promote consistency in this process, the Government commissioned
40 the development of tools for schools to use and this paper draws on data from the final stages of this
41 research.

42
43 Gaining consistency in identifying disabled pupils is not straightforward. The legislation defines disability as
44 an impairment or health condition which has gone on for a year or more which has had a substantial (more
45 than minor or trivial) adverse effect on normal day to day activities. This definition therefore goes beyond
46 ascertaining whether the child has a physical or mental health condition. A pivotal element is the experience
47 of an impairment, its impact on participation in daily life. The views of parents and children are therefore
48 central to the identification of disability, including the supports and barriers they encounter. Schools will
49 have already formally identified around half of disabled children as they will also have a special educational
50 need (Author et al 2008), that is they will experience difficulties in learning. However there will also be a
51 group of children with health conditions that impact on classroom life. Many of these may be cyclical with
52 conditions that lead children to be in the grey area of not really ill or very well (Closs 2000). There will also be
53 children whose disability remains largely invisible to schools, including those with mental health difficulties
54 and children who have developed coping strategies that draw attention away from their struggles to
55 participate fully in school life. There is some evidence that disabled children may be vulnerable to
56 underachievement, particularly those who demonstrate early potential for high attainment which is eroded

1 through school absence and ill health (Author et al. 2008). It is important therefore that schools are aware of
2 children and young people's physical or mental health conditions, the challenges they face in school life and
3 what supports and adjustments are particularly helpful. It is important to adopt a universal approach to
4 ensure that data are collected from *all* children who are struggling, rather than targeting already identified
5 children.

6
7 It is too early to report whether legislation has helped parents who have concerns about whether their
8 child's needs are being met. Parsons et al (2009) found that the knowledge of parents with a child with
9 special educational needs about previous Disability Discrimination Acts was limited, and Lewis et al. (2007)
10 noted that although parents were aware of the legislation they did not fully understand how it related to
11 their child. Despite the UK government's attempts to define disability there is still uncertainty amongst
12 parents and children about whether the term disabled applies to them and a conflation with the term special
13 educational needs (Lewis et al 2007). Moreover, although parents may be aware of their child's difficulties,
14 they may be uncertain whether additional support is provided for them (Lewis et al 2007). It would appear
15 that parents are not yet sufficiently well-informed to use the legislation to ensure that their child's needs are
16 addressed. In recognition of these and allied issues the Government set up the Lamb inquiry to investigate
17 SEN and Disability information and to look specifically at parental confidence in the systems in place:
18 "The content of information, though crucial, is only part of the story. It is the involvement of the parent in
19 the process of discussion and engagement about their child with the school that creates confidence. Such
20 confidence can sustain working relationships even in situations where there is not always agreement about
21 provision." p9.

22
23 Previous research indicates that the interaction between schools and this group of parents may be
24 particularly problematic. Parents of children with special educational needs are strongly represented
25 amongst those who make formal complaints about schools (McKenna and Day 2010). Additionally, Ofsted
26 while reporting that primary and special schools are usually effective in communicating with parents whose
27 children have special educational needs noted that there are parents who feel that they are not able to
28 "request something more or different without appearing overly demanding" (Ofsted 2011 p5). Reports that
29 consider *specifically* parents of disabled children and their levels of satisfaction with children's services
30 present a broadly similar picture, although survey data may over-represent parents with the strongest views,
31 making overall levels of satisfaction difficult to gauge (Parsons et al 2009). With this caution in mind Grant
32 and Hamlyn (2009) found that only 37% of parents reported a positive experience of education and that
33 overall just 11% found the school to be supportive with 47% reporting that they needed more help or
34 support. They found that parents did not feel that education services either elicited or acted upon their
35 feedback. Parents of children with depression were least satisfied. This is consistent with the broader study
36 of Parsons et al (2009) who concluded much the same in relation to parents with children described as
37 having psychosocial difficulties. A qualitative survey of parental satisfaction with services for disabled
38 children (Slade et al 2009) suggested that limited knowledge about disability amongst professionals in
39 mainstream led to misunderstandings of children's behaviour and not knowing how to manage and support
40 children. Again parent's expressed concerned that children's mental health issues were not being properly
41 recognised: "There was evidence of parents 'struggling' to gain an accurate diagnosis in the case of
42 disabilities described as being less identifiable, for example, non-physical disabilities such as psychological or
43 mental health issues and this was felt to have impinged on the ease with which parents were referred to
44 relevant services." (p.9).

45
46 Previous research therefore indicates there are still gaps in the interaction between parents and schools in
47 relation to disabled children and the support that they receive from school, and that those with mental
48 health difficulties may fare particularly poorly.

49
50 This paper presents data on the support that parents of children who experience difficulties with school life
51 find helpful. It is drawn from a national questionnaire devised for schools to use to collect data from parents
52 about disability in line with the Disability Discrimination Act 2005 definition, i.e. to identify children with an
53 impairment or health condition which has continued for a year or more and which has a substantial effect on
54 daily life. The survey of disabled children reported here was the first to be developed to provide reliable data
55 for schools and local authorities to report to Government testing new measures of impact and based on
56 earlier developmental work with schools and Local Authorities (Author 2008)

1 **Methods**

2 Local Authorities nationwide were invited to nominate between 5-10 schools and twelve were able to meet
3 the project deadlines identifying 52 participating schools using a variety of approaches (some authorities
4 approached particular schools; some put out a general call for responses; and one authority nominated
5 schools without their prior notification. A total of 49 schools returned data. These included 25 primary, 15
6 secondary and 9 special schools representing inner city, urban and rural areas including those of high social
7 deprivation, neighbourhoods that were more affluent, and schools with high numbers of pupils with English
8 as a second or additional language. Schools trialled the use of a parent questionnaire to identify the children
9 who met the legislative criteria for disability, namely that they had an impairment or health condition which
10 had gone on for a year or more that had a substantial impact on daily life which was not offset by the use of
11 equipment or aids. Schools chose which year groups to target, sending the questionnaire to parents of all
12 children and in some cases opted to send it out to every parent in the school. The questionnaire comprised
13 9 closed questions that sought information from parents including whether their child experienced
14 difficulties in aspects of schooling and life in and outside the home; if their child had a physical or mental
15 health condition, impairment or difficulty and if so whether it had persisted for a year or more (or was likely
16 to). Where parents had answered yes to any of these items they were then invited to state if their child had
17 seen a professional and what diagnosis was given; they were asked about the impact of the condition; the
18 nature of their child's needs; about medication, physical aids and diet. There was also a 10th open question,
19 (the focus of this paper) that asked parents about the support that their child found helpful. The
20 questionnaire also provided an opportunity for parents to indicate if they wished to speak to a member of
21 school staff, and to state if there was anyone they would prefer not to have access to the information they
22 provided. Full details of the procedures can be found in author (2010).
23

24 **Sample**

25 Staff from the 49 schools distributed the questionnaire to 6,208 pupils of which 2537 (41%) were returned
26 and form the basis of the analysis below. The returns were almost equally divided across boys and girls (52%
27 and 48% respectively) with 92% of the returns from mainstream provision (48% primary and 44% secondary)
28 and 8% from special schools. The children ranged in age from 2-19 years but as figure 1 reveals the schools'
29 choice of year groups resulted in more 11 and 12 year olds being included in the returns.
30

31 Insert Figure 1 around here.
32

33 **Children with an Impairment or Health Condition**

34 In total 523 of the 2537 (21%) parents identified that their child had a physical or mental health condition
35 that had gone on for a year or more and 270 met the Equality Act/DDA disability criteria as the condition had
36 a substantial impact on their daily life. Of the 523 all but 11 provided details of the diagnosis that had been
37 given, although in 16 cases parents were still awaiting confirmation and a further 18 had a generic diagnosis
38 of global developmental delay. The children had a range of conditions, but by far the most prevalent was
39 asthma affecting 167 (32%) of the 523 children. The second most prevalent condition was being on the
40 autistic spectrum: 119 children (23%) had this diagnosis although in many cases it was one of several. All
41 other groups were relatively small with 35 children (7%) diagnosed as having 'ADHD' again often in
42 combination with other conditions, 28 (5%) epilepsy, 17 (3%) Down Syndrome and 16 (3%) cerebral palsy.
43

44 The main focus of this paper is on the responses that parents made to the open question: "*Please describe*
45 *the support that your child finds particularly helpful to enable them to take part in daily activities in school, at*
46 *home or in the community*" and examples were given to illustrate the breadth of the question " *e.g. access to*
47 *therapy, computers, respite care, support from friends, skills training*". Answers to this question were
48 analysed through an iterative process of coding parental responses for units of meaning, with two
49 researchers each at the complete data set to reach agreement on the context of their statements, whether
50 they referred to school, home or community participation; what type of support was identified; and whether
51 parents had identified support that was provided or gaps in provision. The data was then examined for
52 differences between the support identified for children for whom a substantial impact was noted by parents
53 and those who reported a minor or no impact; and differences between the two largest groups of children,
54 those on the autistic spectrum and those with asthma; and those with mental health conditions, as parents
55 in previous surveys appeared to be least satisfied with their provision.
56

1 In total 439 parents made a written response on the form. These included 230 parents whose child met the
2 disability criteria (85% of this group of parents) and a further 133 parents whose child had an impairment or
3 health condition but which was not seen to make a significant impact on daily life (62% of this group of
4 parents). However all parents who reported that their child experienced a difficulty were invited to respond
5 so an additional 76 parents also commented. Taking all comments together, these were distributed across
6 primary (32%) secondary (30%) and special (38%) school returns.

7
8 Insert 1 table around here

9
10 Table 1 provides data on parent's ratings of the context of the child's experienced difficulties. For the group
11 of 230 children who meet the legal definition, this suggests that more than 80% experience difficulties
12 participating in each area of life and this was more likely to be a regular occurrence with a fewer proportion
13 experiencing difficulty only sometimes. This is consistent with the definition of disability. In contrast, for the
14 second group of children whose parents reported no significant impact, the challenges to participating are
15 more likely to be felt sometimes (except in relation to daily activities) and then by a smaller proportion of
16 the children. Interestingly classroom life is a particular site for experiencing difficulty, followed by interacting
17 with other pupils and participating in activities outside the home. In the third group, those whose parents
18 reported no impairment and no substantial impact, children's difficulties are similar to the previous group in
19 that the most likely site for difficulty is again the classroom followed by difficulties interacting with peers,
20 and in general difficulties are described as sometimes occurring. Taken together the three groups represent
21 a continuum, with challenges to participation most likely to be experienced in the context of school life.

22
23 It is with this range in mind that we turn to examine the content of parental comments. Over a third of
24 parents (38%) responded by writing about aspects of their child's condition and this was particularly true of
25 parents of children in mainstream provision where 43% in both primary and secondary wrote about these.
26 This is well illustrated by a quote from the following parent:

27
28 *Chris copes mostly very well. It's the unknown or something new or different that can cause him to worry or*
29 *become stressed. As sleeping is one of his major difficulties he is often exhausted and this can magnify things*
30 *for him.*

31 Parent of 12 year old boy in secondary school .

32
33 Parents of children with no reported impact were slightly less likely than the other two groups to report on
34 aspects that give rise to particular needs

35
36 Insert table 2 around here

37
38 The majority of parents, 90% of the combined three groups, described what support their child found helpful.
39 Figures were particularly high for parents of children in special provision and slightly lower for mainstream.
40 Some parents (17%) also included comments on the supports that were missing, the barriers to participation,
41 and predictably there were slightly fewer of these comments in relation to special schools (14%) compared
42 to primary (21%) and secondary (18%) schools.

43
44 Insert 3 table around here

45
46 Perhaps surprisingly the group that reported no impact to the health condition were slightly more likely to
47 raise the issue of barriers to participation than the other two groups.

48
49 Insert table 4 around here

50
51 The focus of the majority (69%) of comments of the 439 parents was school- unsurprisingly as this was the
52 context in which most children experienced challenges to participation and learning with much fewer (28%)
53 specifically about home-life and much more likely to be made by parents of children who attended special
54 school (45%) than primary (18%) or secondary (17%) schools. Just 12% of comments concerned support in
55 relation to the community, a surprisingly low number given the high proportion of children in some groups
56 that experienced difficulty participating in activities outside the home. However a number of parents (33%)

1 also made generic comments, ones that were not specific to any particular setting including general
2 comments about their child.

3
4 *Joseph is a lovely young man who needs support and understanding, he has a lot to give.*

5 Parent of a 13 year old boy in special school
6

7 *Katie is able to manage herself by asking for repetition where necessary and by explaining to people that
8 sometimes she finds it hard to hear them, and it is helpful for them to look at her face.*

9 Parent of a 5 year old in primary school
10

11 *Ann needs medicines, water and milk given to her very regularly throughout the day.*

12 Parent of a three year old in a first school
13

14 The balance of responses in all probability reflects the origin and perceived audience of the questionnaire
15 given the relatively high proportion of parents who said their child experienced difficulties participating in
16 activities outside the home.

17
18 Insert table 5 around here
19

20 **Support in School**

21 This report focuses on the largest category, support that parents reported their child found helpful in school
22 (including those comments which were generic) and these responses are grouped into eight categories:
23 comments that concerned the organisation for learning, notably reference to 1:1 support or small group
24 learning; staff responses that communicated to the child positive understanding and being generally
25 supportive; access to specialist advice both internal and external to the school; comments that related to the
26 curriculum; mention of aids or equipment; description of particular teaching styles or approaches; aspects of
27 the environment including space and finally reference to particular medical support including diet.

28
29 Insert table 6 around here
30

31 Table 6 reveals the variation in types of support by phase and perhaps most notably, aspects of organisation
32 are cited by 30% of parents in special and primary schools. The focus here is not just on better access to
33 teaching support with parents describing what their child finds supportive is small group or one to one
34 teaching or with a Teaching Assistant by their side.

35
36 *The extra one to one lessons have greatly helped Chloe to gain confidence in herself as well as to improve her
37 reading and maths ..*

38 Parent of a 8 year old girl in primary school.
39

40 *Maria has one to one within the school environment. This is essential for Maria to get around school and for
41 toileting. The teaching assistant stays with Maria during playtimes in the classroom as she doesn't go
42 outside.*

43 Parent of a 10 year old girl in primary school.
44

45 In second place for parents of children in primary schools were curriculum issues and access to specialist
46 advice for parents of children in special schools. The concern for parents of children in secondary schools
47 seems more likely to relate to staff communicating positive attitudes and understanding as this is specifically
48 mentioned by one in five parents. Responses then mirror both primary and special schools as the joint
49 second position was specialist advice and the curriculum. A particular feature of comments concerning the
50 curriculum lay in relation to additional and often extra-curricular elements that helped children develop their
51 skills for social interaction and for raising self-esteem, as indicated in the following comments:

52
53 *Mike would like to do activities before school. I think there is a group that meets in the morning. This was
54 talked about previously. Maybe this could be introduced to help with his interaction.*

55 Parent of 6 year old boy with speech delay in primary school.
56

1 *Gill's support group every Wednesday lunchtime - helps with low esteem issues and increases self-confidence.*
2 Parent of a 14 year old girl with learning difficulties in secondary school.

3
4 Amongst the 439 parents, pedagogic responses are relatively few with just 1 in ten parents commenting on
5 teaching approaches and similarly on aspects of the environment, (such as space and noise) or medical
6 support.

7
8 We next consider if there were differences between parents in relation to whether their child's health
9 condition was judged to impact on daily life. Among parents who had reported that their child's impairment
10 did have an impact, the most important areas of support mentioned were in the area of organisation for
11 learning and access to specialist advice, but these areas were less important for those whose child
12 experienced no impact. For the latter group the most important areas for support were positive attitudes
13 and effective communication strategies. Of least importance were environmental aspects.

14 15 **Children with ASD**

16 The data were also analysed to investigate whether as previous writers have found there were issues that
17 were specific to autism, as this constituted one of the largest groups of children identified by parents as
18 having a difficulty or disability. Of the 119 children who were diagnosed as placed on the spectrum all but
19 thirteen experienced a significant impact on daily life and 107 parents, 90% of this group, provided
20 comments. The majority of these children were educated in special schools. As with all groups it is evident
21 that their needs are varied. Low figures in each cell preclude the use of percentages but looking at the totals
22 it is clear that organisation for learning stands out as an issue for the pupils in primary and special school
23 settings. In both these settings parents either wrote about the importance of 1 to 1 or having a Teaching
24 Assistant supporting their child. (N=35) Much less often was the virtue of small groups espoused (N=8) and
25 this was almost always in the context of special school settings.

26
27 *One to one support at school, clear routine and instructions, structured day, continued re-affirmation of*
28 *behaviour and expectations. Computer access at school and home. One to one support to access music*
29 *tuition, gym.*

30 Parent of an 11 year old boy in special school.

31
32 Insert table 7 around here

33
34 The second most frequent set of responses concerned access to specialist advice and to curriculum. In the
35 case of the latter only 2 parents responded with reference to Maths and English, the remainder referenced
36 additional curriculum aspects, most notably those which would support developing interaction skills. With
37 respect to specialist advice sources for this varied widely from: nurse, OT, music therapist, speech and
38 language therapist, SENCO, trained teachers, psychiatrists, social worker and hospital consultant. These two
39 items were closely followed in frequency by attitude and understanding of the staff and resources and aids.
40 Perhaps surprisingly only 3 (11%) of the mainstream parents mentioned aspects of attitude and
41 understanding compared to 17 (22%) of the special school parents.

42
43 *Visits to the school nurse. Sessions with learning support worker. Having a dedicated person she can go to*
44 *with problems. Social skills course - excellent. Understanding from her teachers / peers. Homework club.*
45 *Good, structured routine for lessons & homework. Good disciplinary procedures, knowing her boundaries,*
46 *knowing what is expected of her and when use of her planner so she doesn't forget things.*

47 Parent of a 12 year old girl in a secondary school.

48
49 As with the quote above, a number of parents wrote comments that revealed the package of support that
50 their child found helpful:

51
52 *Full time support of classroom TA's to access learning.*
53 *The use of a communication book between home and school.*
54 *Use and development of IT equipment which is lacking at home.*
55 *Fantastic SENCO.*
56 *A school ethos that actually welcomes disability diversities.*

1 Parent of an 8 year old in primary school.

2 3 **Children with Asthma**

4 Turning now to consider another of the largest groups- 167 children had asthma varying from very mild to
5 more significant (76 in primary, 85 in secondary and 6 in special schools) although only 37% (61) of these
6 parents provided comments on what their child found helpful, 29 children in primary, 27 in secondary and 5
7 in special schools.

8
9 Insert table 8 around here

10
11 As anticipated the most commonly mentioned support was medical in nature with 21 of the 56 (38%)
12 parents of children in mainstream referring to some element of medication in their responses,. This largely
13 reflects the emphasis that parents place on allowing the child to carry and use their inhaler.

14
15 *J's asthma is very mild and controlled with inhalers, but he is allowed to carry his ventolin inhaler with him at*
16 *school. So I think that is good when the school allows him to do that, so he is in control of his own medication,*
17 *if he needs to use it at anytime.*

18 Parent of a 13 year old boy in secondary school.

19
20 However, taking the group as a whole, attitudes and understanding are in second place in order of support.
21 As one parent of an 11 year old boy in a secondary school stated:

- 22 - *P.E. teacher showing understanding of problem - asthma*
- 23 - *Understanding that school absence is sometimes unavoidable*

24
25 Additionally, 13 parents also mentioned aspects of the curriculum: five of these concerned supporting maths
26 or English or both but the remainder referred to additional or alternative approaches to the curriculum:

27
28 *Having missed periods of 2-3 weeks at a time my daughter would benefit from extra help to 'catch-up' the*
29 *time she has missed either in classroom support or extra work at home relating to the period she has missed.*

30 Parent of an 8 year old girl in a primary school.

31
32 *Alternatives to outdoor play, physical activities when in recuperation.*

33 Parents of a 7 year old girl in primary school.

34
35 These comments illustrate the important role for school in responding to the health needs of their pupils.

36 37 **Children with Mental Health Difficulties**

38 Finally we turn to the last group- a small group of children with mental health difficulties which includes
39 children whose needs may be less obvious to staff. Sixty seven parents indicated that their child had mental
40 health needs (depression, anxiety, phobias) of which 55 (82%) provided comments in relation to support.
41 The results set out in table 9 need to be viewed with some caution as many of this group, especially those in
42 special schools, had a complex array of needs and parents did not necessarily write explicitly about the
43 support for mental health issues. This challenge is expressed by one parent:

44
45 *Jocelyn needs people around her who understand her needs- This question is too difficult to answer.*

46 Parent of a 7 year old in a special school.

47
48 Insert table 9 around here

49
50 In secondary school settings the attitude and understanding of others were particularly important whereas
51 in primary and special schools reference was made to access to one to one support and being in small groups.

52
53 *James needs constant support from familiar consistent adults who understand his difficulties and can*
54 *accurately assess his level of stress at any given time. James needs an environment that is both predictable*
55 *and calm so he feels able to try new experiences. James needs space to be by himself for short periods*
56 *throughout the day to enable him to cope with situations that are demanding and/or stressful.*

1 Parent of a 13 year old boy in special school

2
3 *Skilled Teaching Assistant really helps Michael get through a day at school. He has occasionally received*
4 *counselling, which was beneficial, and advice from a psychiatrist. Michaelbecomes emotional quite easily*
5 *and so I am glad of any support I can get.*

6 Parent of a 12 year old boy in secondary school.

7
8 *Pacing in relation to physical activities and mental activities.Support from friends. Consideration of*
9 *timescales for homework. Consideration of periods of absence. (Alice currently takes Thursdays off, but has*
10 *often taken further days off due to extreme fatigue. Being allowed to stay in class breaks, enter dinner hall*
11 *early....*

12 Parent of a 14 year old girl in secondary school.

13
14 A number of parents made reference to counselling although specialist services were not always viewed
15 positively:

16 *Helen has seen CAMHS for several years, also the school psychologist, counsellors and a family support*
17 *worker, none of which she found helpful.*

18 Parent of a 13 year old girl in secondary school.

19
20 Many children, especially those with the most complex needs, require an array of support:

21 *Tim needs lots of support to get along with his teachers and accept direction. Tim needs support to*
22 *understand communication with friends, to control his behaviour and reduce anxiety. Thomas is very upset at*
23 *school and hates his teacher, he needs lots of support to deal with this. Tim receives mental health support*
24 *via psychologists, psychotherapy and psychiatry. He is often very depressed and talks about ending his life.*
25 *Tim needs support when out and about to reduce anxiety and stay safe (noise, unexpected change etc). Tim*
26 *needs to control his asthma and migraines with medication which gets worse with anxiety, allergies and*
27 *stress. Lots of adult support needed.*

28 Parent of a 12 year old boy in special school.

29
30 This quote illustrates the ways in which different conditions inter-relate and require sensitive and informed
31 interactions from others.

32 33 **Discussion**

34 Our sample reflected the range of challenges children experience from those which occur regularly in every
35 setting to those which are only occasionally experienced. However a common factor that united the children
36 was their effect on classroom life and in consequence the pivotal role to be played by schools to enable their
37 full participation in daily activities. Given the opportunity provided by the questionnaire, a large proportion
38 of parents whose child had a physical or mental health condition communicated with schools about what
39 support their child found helpful. This was particularly true of parents of children with ASD who formed the
40 largest group of respondents. Just under half the parents of children in mainstream provision explained their
41 child's needs indicating the importance of a supportive response from the school. Equally parents in
42 mainstream provision were more likely than those whose children were in special provision, to write about
43 the barriers that were encountered, again indicating the possible adjustments to be made.

44
45 For many parents the greatest area of support was seen in the way that learning was organised and in
46 particular their child's contact with adults. Overall a quarter of parents wrote that this was an aspect that
47 was important for their child, especially for those in primary and special school settings. This data is
48 consistent with an earlier study (author 2008) where access to adults featured heavily in parental responses
49 with almost a quarter specifically referring to individual support, small groups or small classes. This earlier
50 data saw this requirement linked in parental comments to providing a positive emotional climate, one where
51 staff gave encouragement and reassurance. While schools may view the organisation for learning as a
52 pedagogic response there is also a relational or affective element. Research has raised some important
53 questions about the efficacy of support provided by classroom assistants in one-to-one and small group
54 settings in mainstream schools (Webster et al 2010). A longitudinal UK study of everyday provision in schools
55 revealed that teachers were almost entirely engaged in whole class work in both primary and secondary
56 settings and that it was teaching assistants (TAs) who provided small group and individual support. The data

1 suggests that this had a negative impact on pupil progress in core subjects even when controlling for factors
2 such as prior attainment and SEN status (Blatchford 2009) as TAs lacked the pedagogical skills to promote
3 pupil understanding. Instead their focus was on task completion, prompting pupils even by supplying the
4 answers. Where TAs are trained to deliver a highly structured programme the outcomes are more promising
5 (Farrell et al 2010).
6

7 Given that parental comments less frequently referred to other elements of pedagogical support, it is
8 possible that their view of the supportive nature of these organisational arrangements reflects additional
9 values. Howes et al (2003) in a review of previous research suggests that the style of interactions of a TA is
10 different to that of a teacher and more likely to be informal and personalised, helping pupils to engage and
11 stay on task. Webster et al (2009) refer to this as developing the “soft skills- confidence and motivation,
12 dispositions towards learning” p331, and this is consistent with the views of pupils themselves (Fraser &
13 Meadows 2008). Given the personalised and more extended interaction that TAs have with pupils it is quite
14 possible that this increased interest and attention is what parents value, and they, like others, are not aware
15 that this does not necessarily lead to improved learning outcomes.
16

17 Consistent with this analysis is the finding that in secondary schools there was a slight shift in parental
18 responses to focus on the nature of the relationships children have with adults, whether they are
19 understanding and supportive in their attitude towards the child. Notably this was also cited as an aspect
20 that created barriers for their child. This difference is also reflected in the views of the children themselves
21 (Georgeson in press) where younger children value more contact with adults and for older pupils it is the
22 quality of that contact that is important. Research has consistently addressed the importance of attitudes in
23 promoting the inclusion of children with disability and SEN in school life, “being helpful” can be as important
24 as the help received.
25

26 Although fewer parents argued for different pedagogic responses their comments did suggest that access to
27 specialist advice was helpful. This was often about the knowledge and understanding of children’s particular
28 difficulties. Parsons et al (2009) also refer to the “strong desire for children’s individual needs to be
29 adequately recognized, understood and supported” p54 although they conclude that equally important is
30 the knowledge and understanding of the “impact of different conditions, disorders, disabilities or difficulties
31 on children’s individual experiences and capabilities.”p54. The emphasis here can be placed on pupils’
32 experiences and well-being rather than on a more narrowly conceived view of attainment. Notably parental
33 comments about the curriculum were largely about providing opportunities for children to develop their
34 self-esteem and self- confidence, often to promote their social and communicative skills rather than to
35 address particular areas of academic knowledge.
36

37 Within the data are hidden the needs of different groups. In this paper we have drawn out contrasts
38 between pupils with ASD, pupils with asthma and those with mental health difficulties. Notably parents of
39 children with ASD and those with mental health difficulties were particularly forthcoming about the support
40 needs of their child. Previous research on parents of children with ASD has highlighted the factors that
41 appear to be associated with parental levels of satisfaction with the educational provision of their child.
42 Whitaker (2007) writes “The extent to which parents felt that school staff understood (and empathised) with
43 their children’s difficulties, and the perceived flexibility of the schools’ responses to the children’s needs...
44 The extent and quality of reciprocal communication between school and home.. [were] strongly associated
45 with levels of satisfaction.” p170.
46

47 The numbers of children diagnosed with asthma has been increasing over the past 20 years (Wolf et al 2002).
48 Unsurprisingly medical support is the highest reported form of support for those with asthma (and low for
49 those with ASD), as parents place emphasis on children having access to their inhalers and being able to self-
50 medicate. While the evidence of effectiveness is not clear cut, self-management is an important strategy for
51 children with asthma (Wolf et al 2002). However there are also important reminders in the data that health
52 needs can generate the need for other educational responses. Asthmatic children for example may also
53 require curriculum adjustments, partly due to absences that mean they may need the opportunity to catch
54 up on learning that they have missed.
55

1 Children with mental health needs are also a growing group (Nuffield Foundation 2010) with a doubling in
2 the last 30 years of the number of young people who report that they frequently feel anxious or depressed.
3 Where children have additional difficulties, it may be particularly challenging to identify these needs
4 (Hackett et al 2010) and it's likely that the returns of this survey under-represented this group. The data that
5 was provided however illustrate finely the need for schools to be supportive and to provide an environment
6 that does not exacerbate the challenges the child faces. The support of a predictable and safe environment
7 was a repeated message. There was a plea by some parents to look beyond the behaviour to understand
8 what may lie beneath it. Again the emphasis on being part of a smaller classroom unit and having access to
9 a teaching assistant speak not just of a pedagogic response to the way that learning is organised, but also of
10 the desire for a closer relationship, one which is flexible and responsive to children's changing needs.

11
12 However the data also revealed some ambivalence about the schools and professional involvement with
13 some parents being concerned that their mental health child's difficulty should not be discussed. Schools
14 therefore have a sensitive role to play in providing genuine opportunities for parents to contribute to
15 enabling their child to participate fully in school life. It is likely that the "reasonable adjustments" that
16 parents want are first and foremost to understand the needs of their child. Where absence plays a key part
17 in the child's coping, staff may be unaware of the challenges they face in participating in school life. While
18 Local Authorities assess their services for children with mental health difficulties as high, including those for
19 children with learning difficulties (Statistical Release 2011), the data from parents suggest that everyday
20 contact with understanding adults within the school has a vital role to play in supporting their child.

21
22 The findings of this study are highly consistent with research on the social dimensions of schooling and the
23 impact of relationships with teachers and others on a pupils' sense of well-being. McLaughlin and Clarke
24 (2010) review a body of research that reveals the interconnectedness of learning, relating and belonging.
25 Particularly relevant here is the evidence that teachers who are "good" and in particular perceived as kind
26 and supportive play a particular role in emotional well-being, an example of the way you are treated being as
27 important as how well you are taught. A technical approach which is so characteristic of policy and practice
28 may fail to tackle institutions as social organisations. It may in particular overlook the issue of pupil-teacher
29 relationships which appear to be as central in the everyday experience of young people in contributing to
30 emotional well-being.

31 32 **Conclusion**

33 The questionnaire provided an important vehicle for ensuring that all parents had the opportunity to provide
34 information on the supports to learning rather than simply targeting those parents whose child's needs were
35 already known to schools. In this way schools were opening up the possibilities to learn about the needs that
36 had been invisible to them but which impacted on the child's experiences in school. Parents took the
37 opportunity to explain aspects of their child's experience, such as the effect of not sleeping or the impact of
38 absences on children's confidence, setting up the potential for a two way dialogue for establishing the "level
39 footing" required by the legislation.

40
41 However this should be seen as simply the first step. Parents in general would rather avoid an escalation of
42 issues through "more open and less formalised communication between parents and schools" (Opinion
43 Leader 2009 p8). Parents are therefore unlikely to want recourse to a legal system to pursue the rights of
44 their child unless no other avenue is open to them. As others have indicated the law is an imperfect device
45 for dealing with the complexities of "what's best for the child" when the driver to decision-making is "what's
46 lawful" (King and King 2005). The potential of the Equality Act lies with setting up a process for a two-way
47 partnership where detailed knowledge of the child can be exchanged to promote understanding of how the
48 learning environment can be developed to enhance the capabilities of the child, in the broadest sense.

49
50 Parents want to be assured that someone in the school truly "knows their child" and has regular contact with
51 them, a finding consistent with the Lamb inquiry (Lamb 2009). This calls for understanding and empathy,
52 most usefully employed where that person has some insight into the child's condition and is also aware of
53 the variety of ways that it manifests. Parental responses clearly revealed that a standard one-size- fits- all
54 was not the appropriate approach. A personalized approach is not easily amenable to the setting of
55 institutional targets and an action plan. Reasonable adjustments are too frequently seen only in terms of
56 changes to physical layout or the provision of aids and equipment. Instead parental responses reinforce the

1 need for schools to retain flexibility in their provision for children. Above all however schools need to have in
2 place the two way communication process that supports them in “knowing” about the visible and invisible
3 challenges that pupils with difficulties and disabilities face in participating in school life, processes that go
4 beyond simply having data on file.

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