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WHAT KINDS OF SUPPORT *DO* PARENTS WANT FOR THEIR DISABLED CHILD?¹

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Schools in England (as elsewhere in Europe) have a duty to promote equality for disabled people and make reasonable adjustments for disabled children. This paper presents data drawn from a national questionnaire designed for schools to use to identify their disabled pupils and examines in detail parental responses to a question on the kinds of support their child finds helpful in offsetting any difficulties they experience. It illustrates the complex and varied nature of the reasonable adjustments required and an overriding sense these need to be underpinned by the values of a responsive child centred approach, one that reflects parents' knowledge and understanding of their child. Schools need to have in place the two way communication process that supports them in "knowing" about the visible and invisible challenges that disabled pupils face in participating in school life.

Keywords: disability; parents; inclusion; reasonable adjustments; child-centred

Introduction

There has been a series of legislative acts in England as elsewhere in Europe designed to safeguard disabled people from discrimination. This rights based approach draws on a social model of disability and makes an important distinction between an impairment and a disability, the latter resulting from the interaction between the person and the environment, putting due emphasis on the barriers and supports that are in place.

Legislation in the UK defines disability as an impairment or health condition which has gone on for a year or more which has had a substantial (more than minor or trivial) adverse effect on normal day to day activities. This definition therefore

¹ Текст публикуется в авторской версии

goes beyond ascertaining whether the child has a physical or mental health condition. A pivotal element is the experience of an impairment, its impact on participation in daily life. The views of parents and children are therefore central to the identification of disability, including the supports and barriers they encounter. Schools will have already formally identified around half of disabled children as they will also have a special educational need (Porter et al 2008). However there will also be a group of children with health conditions that impact on classroom life. Many of these may be cyclical with conditions that lead children to be in the grey area of not really ill or very well (Closs 2000). There will also be children whose disability remains largely invisible to schools, including those with mental health difficulties and children who have developed coping strategies that draw attention away from their struggles to participate fully in school life. There is some evidence that disabled children may be vulnerable to underachievement, particularly those who demonstrate early potential for high attainment which is eroded through school absence and ill health (Porter et al. 2008). It is important therefore that schools are aware of children and young people's physical or mental health conditions, the challenges they face in school life and what supports and adjustments are particularly helpful. It is important to adopt a universal approach to ensure that data are collected from *all* children who are struggling, rather than targeting already identified children.

This paper presents data on the support that parents of children who experience difficulties with school life find helpful. It is drawn from a national questionnaire devised for schools to use to collect data from parents about disability.

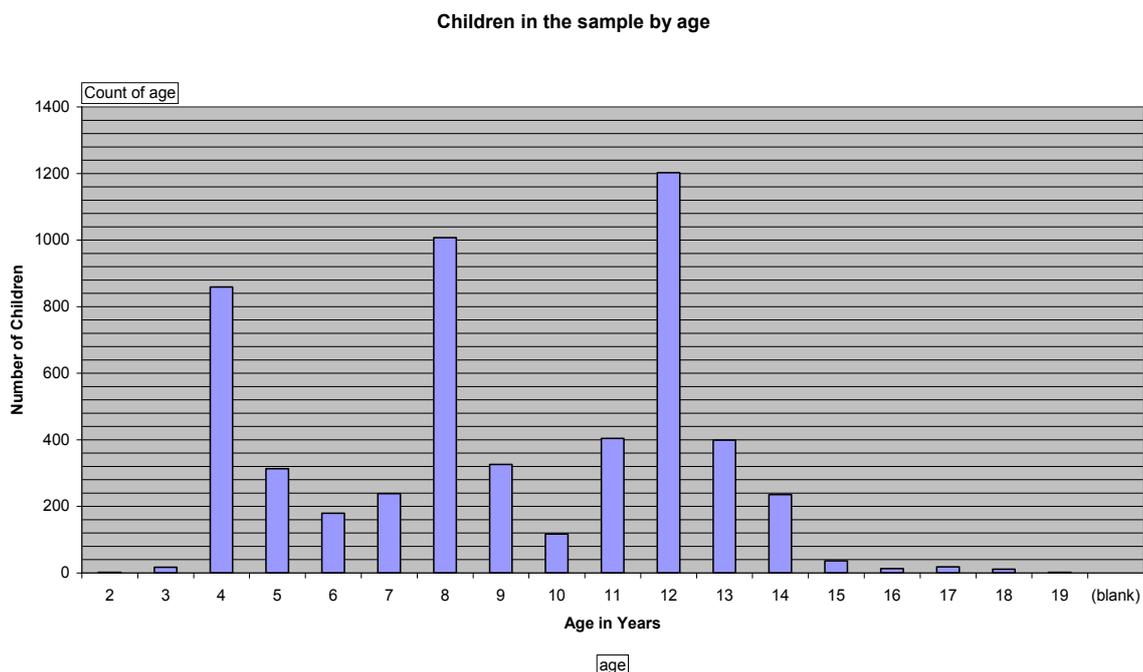
Methods

Staff from 123 schools across England (71 primary, 28 secondary and 24 special schools) distributed a questionnaire to parents of 13,200 pupils. The questionnaire comprised mostly closed questions that sought information from parents including whether their child experienced difficulties in aspects of schooling and life in the home; if their child had a physical or mental health condition, impairment or

difficulty and if so whether it had persisted for a year or more (or was likely to). Where parents had answered yes they were then invited to state if their child had seen a professional and what diagnosis was given; they were asked about the impact of the condition and the nature of their child's needs. There was also an open question, (the focus of this paper) that asked parents about the support that their child found helpful. Full details of the procedures can be found in Porter et al (2008; 2010).

Findings

In total 5432 (41%) questionnaires were returned and form the basis of the analysis below. They were almost equally divided across boys and girls (51% and 49% respectively) with 94% of the returns from mainstream provision (56% primary and 38% secondary) and 7% from special schools. The children ranged in age from 2-19 years but more 4,8 and 11 year olds were included in the returns.



Children with an Impairment or Health Condition

Of these returns, 1227 parents indicated that their child had a health condition or impairment 23% of the questionnaires returned with 9% experiencing a substantial impact on their participation in daily life activities. 17% had a

diagnosis of ASD, 14% asthma, 8% had a visual impairment and 8% hearing impairment, 5% had ADH, 4% epilepsy, and 2% cerebral palsy.

Parents were asked what support their child found particularly helpful and 732 (60%) parents of children with a health condition or impairment provided comments to this open question. An iterative process of data coding was adopted. Comments were grouped around eight emergent categories: comments that concerned the organisation for learning, notably reference to 1:1 support or small group learning; staff responses that communicated to the child positive understanding and being generally supportive; access to specialist advice both internal and external to the school; comments about the curriculum; noting aids or equipment; description of particular teaching approaches; aspects of the environment and finally reference to particular medical support including diet.

| | Primary N=272 | Secondary N= 203 | Special N= 257 | Total N=732 |
|---|------------------|---------------------|-------------------|----------------|
| Organisation for learning | 75 28% | 32 16% | 77 30% | 184 25% |
| Attitudes, understanding and being supportive | 48 18% | 39 19% | 54 21% | 141 19% |
| Specialist advice | 47 17% | 28 14% | 65 25% | 140 19% |
| curriculum | 43 16% | 36 18% | 32 12% | 111 15% |
| Aids and resources | 31 11% | 19 9% | 39 15% | 89 12% |
| Instructional Responses | 48 18% | 28 14% | 29 11% | 105 14% |
| Environmental | 19 7% | 20 10% | 20 8% | 59 8% |

| | | | | |
|--------------------------------------|--------|--------|-------|---------|
| Medication/ diet/ medical aids | 75 28% | 40 20% | 11 4% | 126 17% |
|--------------------------------------|--------|--------|-------|---------|

Parental Responses – All children with health condition or Impairment

Organisation for Learning

The most frequently mentioned support concerned the organisation for learning- namely individual help, the presence of a teaching assistant, or being in a small group. In secondary school parents were more likely to mention a teaching assistant supporting their child than the benefits of individual teaching or working in small groups. Parents often explained why their child found it helpful, as this quote from a parents of a child in primary school illustrates:

Support assistant is extremely important – enables/facilitates access to the curriculum, support with communication, equipment, emotional, social support.

Working one to one he finds very helpful, especially if he's with someone he has clicked with...

Organisation for learning is also about the contact or relationship with an adult and this brings us to the second important theme.

Attitudes, Understanding and Being Supportive

Just under one in five parents wrote about the importance of staff attitudes towards their child. A common theme across all three settings was the need for patience, understanding and reassurance. Parents wanted staff to be sympathetic to their child's difficulties and understanding rather than judgemental.

Acceptance and allowance for her special needs means that she is more relaxed, happy and confident in the classroom, and this will help her learning.

Pupil in primary school.

Help when in difficulty. Not to feel that he is not good enough. Pupil in secondary school.

Parents wanted staff to promote confident and raise self esteem and were particularly mindful of the impact when this did not happen.

Elsa gets frustrated if she is not listened to when she has a problem. If people hurry her or get irritated this will exacerbate the situation and she will get upset and aggressive and anxious. General support encouragement and understanding works wonders. Pupil in primary school.

Sometimes find difficult to take part in physical education because he feels tired and drained of energy. When sent a note to school to exclude him he was forced to join in and told "if you are not well enough to do P.E. you should not be at school". The one time he collapsed after P.E. Pupil in secondary school.

A few parents wrote about the importance of the school ethos:

The school understands his limitations .. they accept him just to get on with his everyday life and treat him as normal as all others. Pupil in secondary school.

The importance of this category of responses is further emphasized by parents who did not write to explicitly identify support but provided comments to explain their child's behaviours.

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

Specialist Advice

In addition to the attitudes of staff, unsurprisingly parents also valued specialist advice. One in four parents of children in special schools and 1 in 6 in primary and 1 in 7 in secondary identified particular types of specialist who they had found particularly helpful. These were a wide-ranging group including Occupational, Physio and Speech Therapists, Consultants, Dieticians and Nurses, Counsellors, Social workers as well as specialist teaching staff. Speech therapists were the most frequently identified specialist to provide their child with support, especially for parents with children in special schools and primary schools:

He finds speech therapy very helpful because this would help him to talk and express his feelings and making other people understand him... Pupil in special school.

Parents also mentioned speech therapy as support from the past:

Through intensive speech therapy since the age of 30 months Ciaran's speech has improved dramatically. However he still struggles with some pronunciation and needs time to think and articulate himself. He needs to be allowed to finish his sentences and to let his train of thought be fully voiced, so time and patience are vital. Pupil in primary school.

Parents with children in secondary schools were more likely to mention specialists that provided counselling:

Just started talking to school counselor. Waiting for appointment [at] ... Hospital. In regular contact with members of staff concerning K panic/anxiety attacks. Pupil in secondary school.

Doctors, Nurses and Paediatricians were also mentioned:

becoming Diabetic has limited Danielle's activities during school sometimes if she has a hypo or feels unwell. Danielle has been a Type 1 Diabetic for 3 years. She finds helpful support from her family, friends, teachers, diabetic nurses, dietician and consultant paediatrician. Pupil in primary school.

Specialist teachers were much more rarely mentioned and even rarer were references to psychologists or social workers.

Instructional Responses

Overall 14 % of parents wrote to suggest instructional strategies that supported their child's learning. Often their child found structure and routine particularly helpful, especially pupils in special schools.

Visual timetable; calm environment; consistency; understanding of sensory modulation dysfunction; self-calming strategies; confidence and self-esteem building strategies Pupil in special school.

Everything has to be routine – if things change we have to let Tim know what is going to happen or where we are going. – Picture exchange cards have been very useful with helping Tim to talk and communicate. Pupil in primary school

Three other prominent themes included aspects of the way teachers communicated to pupils, especially from parents of children in primary school settings.

I attended an early birds course and was told to slow ones speech and repeat the same phrase. That seems to have brought her speech on no end. Pupil in primary school.

A further theme that was cited by parents of children in mainstream was providing encouragement and motivation. Parents also wrote about the importance of the child sitting at the front of the class or near the teacher.

Sitting at the front of the class in a position of her choice so that she can accommodate her 'null point'. Clear diction. Consideration of the balance issues without excluding her from activities. Pupil in secondary school.

Parents also made reference to the child needing more time to respond and a slower a slower pace to the instruction and more repetition A few also wrote about small steps or smaller targets. Some pupils clearly needed a range of particular instructional strategies.

Visual support, including demonstration and practice, mind-maps, pictures etc. Having his attention drawn to key points. Small class / group or individual teaching. Being seated in a position in the classroom where he won't be distracted and will be able to attend to teacher more easily (at the front ?) Very hesitant about starting new things, joining groups so needs encouragement and preparation to ease the process. Specific anger management strategies positive reinforcement (any negative feedback has huge impact on self-esteem, anxiety, and increase negative behaviour. Pupil in secondary school.

Medical Support

Overall 17% of parents mentioned support that would be provisioned outside the school setting, including medication, special diets, and medical aids such as

hearing aids although notably this was unequally skewed towards mainstream settings with parents in special schools by contrast rarely mentioned these as particular forms of support. The availability of medication and in particular the use of inhalers featured prominently amongst parent comments in both primary and secondary school returns.

Alex needs an inhaler on a regular basis. He has a normal healthy lifestyle otherwise and needs no extra support other than to be reassured that I'm there and he has access to his inhaler. Pupil in primary school.

Although much less frequent parents also cited particular appliances such as hearing aids and grommets. For a minority of parents the most important aspect was their child's diet, particularly where the child had an allergic reaction.

Severe eczema on back of leg – cream and antibiotics meant Cally could use (stretch and bend) her leg without difficulty. Animal hair allergy – keeping away from cause of allergy but inhaler helps wheezing if there is contact. Pupil in secondary school.

For diabetic pupils the monitoring was a vital part of the support.

Aids and Resources for Learning

In comparison to medical aids, school based aids or resources were much less frequently mentioned, with one in eight parents writing about some tangible aid and were more likely to be mentioned by parents of children in special schools. Perhaps unsurprisingly computers were the most likely to be mentioned, although in some instances this also referred to working at the computer at home.

Parents also wrote about low tech support such as aids for reading:

Blue or green paper not white. Black print moves around on paper.

Pupil in primary school.

Curriculum

Parents of children in secondary schools were slightly more likely to mention aspects of the curriculum than those in other settings with 18% of these parents making reference to what was or should be taught to their child. 16% of parents in primary schools and 12% in special schools also referred to the content

of teaching. Parents wrote about the need for both additional work in a particular area and alternatives or adapted work. By far the most frequently mentioned area was reading or English, which was more than four times likely to be cited than maths.

Abigail has poor concentration. She is improving reading by attending extra classes promoting improvements to aid her problem in phonics. Pupil in secondary school.

It is mainly his handwriting and spelling. I make Stephan do handwriting practice at home, but I feel he needs more, cannot understand his writing sometimes. Pupil in secondary school

Parents also wrote about physical aspects of the curriculum and pupils needing alternatives to sport and PE. In contrast social skills were infrequently mentioned, and only by parents in primary and special school settings.

Environment

The most infrequently mentioned area of support was the environment with only 8% of parents directly noting this as being important for their child, with few differences between mainstream and special school returns. Reference was usually made to two elements, firstly that of noise and the acoustic properties of the environment and the second to that of providing a safe, calm environment.

Some parents linked aspects of a child's health condition to the properties of the physical environment. As a mother of a child in primary school wrote:

My child suffers from eczema and as a result finds it difficult to learn if the heating arrangements in the classroom are too high. Extremes of heat and cold cause great irritation, and therefore, distract. Keeping the environment (room) at an even temperature.

One strategy that teachers used which helped pupils access the right environment was a pass card

Pat has a pass-out card that when she needs to she may prepare to leave the school site at the end of the afternoon a little earlier than her peers to avoid being

jossled, this has been most appreciated by Pat when her joints have been painful during a flareup. Pupil in secondary school.

Discussion

Our sample reflected the range of challenges children experience from those which occur regularly in every setting to those which are only occasionally experienced. However a common factor that united the children was their effect on classroom life and in consequence the pivotal role to be played by schools to enable their full participation in daily activities. For many parents the greatest area of support was seen in the way that learning was organised and in particular their child's contact with adults with a quarter specifically referring to individual support, small groups or small classes. This requirement was often linked in parental comments to providing a positive emotional climate, one where staff gave encouragement and reassurance. While schools may view the organisation for learning as a pedagogic response there is also a relational or affective element. Research has raised some important questions about the efficacy of support provided by classroom assistants in one-to-one and small group settings in mainstream schools (Webster et al 2010). A longitudinal UK study of everyday provision in schools revealed that teachers were almost entirely engaged in whole class work in both primary and secondary settings and that it was teaching assistants (TAs) who provided small group and individual support. The data suggests that this had a negative impact on pupil progress in core subjects even when controlling for factors such as prior attainment and SEN status (Blatchford 2009) as TAs lacked the pedagogical skills to promote pupil understanding. Instead their focus was on task completion, prompting pupils even by supplying the answers. Where TAs are trained to deliver a highly structured programme the outcomes are more promising (Farrell et al 2010).

Given that parents commented less frequently on other elements of pedagogical support, it is possible that their view of the supportive nature of these organisational arrangements reflects additional values. Howes et al (2003) in a review of previous research suggests that the style of interactions of a TA is

different to that of a teacher and more likely to be informal and personalised, helping pupils to engage and stay on task. Webster et al (2009) refer to this as developing the “soft skills- confidence and motivation, dispositions towards learning” p331, and this is consistent with the views of pupils themselves (Fraser & Meadows 2008). Given the personalised and more extended interaction that TAs have with pupils it is quite possible that this increased interest and attention is what parents value, and they, like others, are not aware that this does not necessarily lead to improved learning outcomes.

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

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

confidence, often to promote their social and communicative skills rather than to address particular areas of academic knowledge.

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

Conclusion

The questionnaire provided an important vehicle for ensuring that all parents had the opportunity to provide information on the supports to learning rather than simply targeting those parents whose child's needs were already known to schools. In this way schools were opening up the possibilities to learn about the needs that had been invisible to them but which impacted on the child's experiences in school. Parents took the opportunity to explain aspects of their child's experience, such as the effect of not sleeping or the impact of absences on children's confidence. Parents want to be assured that someone in the school truly "knows their child" and has regular contact with them (Lamb 2009). This calls for understanding and empathy, most usefully employed where that person has some insight into the child's condition and is also aware of the variety of ways that it manifests. Adjustments are too frequently seen only in terms of changes to physical layout or the provision of aids and equipment. Instead parental responses reinforce the need for schools to retain flexibility in their provision for children and to have in place the two way communication process that supports face in participating in school life.

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