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Young People with health problems - their views on how schools can help

The Government has identified school as an important setting for reducing health inequalities, but pupils with medical needs are not always supported as well as they should be. There is a need for inclusive education, which means that more children with disabilities and health problems are being included in mainstream schools. What can teachers do to help such children cope with their condition in order to minimise any impact on their education?

Listening to children and young people who have had experience of a long term health condition can give some insights. This article describes three evidence-based examples of pupils with illness and disability in mainstream school. Their views are discussed in relation to ways in which schools and teachers can contribute to reducing health inequalities. The three examples are:

- Pupils with disabilities in mainstream school
- School children's perceived sources of asthma support
- Website of young people talking about their experiences with health problems

Pupils with disabilities in mainstream school

A study of 33 children with illnesses and/or disabilities being educated within mainstream schools was carried out as part of a wider research study to assess the impact on school life (Lightfoot, Wright and Tizard, 2004). Of these children some were already in school with the children showed that, although they had a wide variety of conditions, they had common concerns about the impact of their illness on their lives. An important aspect of the illness was absence from school, which could be due to illness, treatment or medical appointments. They were kept to know absence to a minimum, as pointed out by a 12 year old girl:

"...I'm missing 8 of 1 when I'm really poorly and I just enjoy when I'm there. So if we get a bit of a headache I don't feel any better...I have a lot of days but I don't really want to come home..."

Many expressed their appreciation of teachers who had helped them to keep up with their education. A variety of ways were highlighted such as teachers providing homework, giving extra work following absence, and having time to explain parts of the curriculum they didn't understand on return to class.

Mobility problems were a cause of concern for many pupils, for example being excessively tired, or in fear of being knocked over. They felt that teachers encouraged them to stay put or do nothing. For example, by allowing the pupil to leave class early in order to safely travel to and from school. Those who found PE to be problematic, and a third didn't (join in at all. If not taking part pupils were likely to be given a constructive alternative activity, such as catching up with work, and were grateful to teachers who allowed them to have a friend with them. They wanted to make their own decision about whether or not to join in a particular session, and were concerned if they felt they were pushed beyond their capabilities, as illustrated by the following quote by a 14 year old girl with cystic fibrosis:

"...I had him running round the field. He had me walking, jogging, running and I said, ‘I can’t do that, I’m already doing P.E. Teachers know but they don’t see that..."

Bullying due to being different was highlighted by over a third, and pupils felt that too often teachers were not aware of their concerns. They felt they were experiencing bullying such as name-calling, teasing, or not included in activities. They felt the teachers could do more to help by intervening in bullying situations, but this didn't always happen, as exemplified by a 14 year old girl with cystic fibrosis:

"...I get picked on, pick, pick, pick and I got called the hornet and when I go off crying people go and tell (the deputy head) she doesn’t do anything at all. I can’t really do anything..."

Nearly all the pupils felt they had supportive relationships with individual teachers, usually the Special Educational Needs Tutors. Simple kindnesses, such as offering to wait for you at the end of a lesson, asking about their absence, or how they were feeling, were much appreciated. However, teachers and pupils felt schools could have very different approaches, some which appeared to lack any awareness of how the pupil was coping. For example, a quote from a 16 year old boy:

"...The more people who know the less mistakes are made... ignorance is the root of all problems that I’ve had, it’s people who lack a basic knowledge of what have made it difficult..."

Knowledge of individual needs was important, for example those with communication problems to access the internet as required. Essentially, pupils wanted schools to tailor their responses to their needs so that they could cope with their condition so that appropriate arrangements could be made, "without making fun".

School children’s perceived sources of asthma support

As the most common chronic condition of childhood, asthma provides a suitable model of how schools can support pupils in managing a long-term health problem. The impact on school life for those whose asthma is poorly controlled has been shown, for example in a survey of over 4,000 children from the charity, National Asthma Campaign (NAC, now called Asthma UK). This indicated that around one third missed a week or more of school per year, and a similar proportion missed out on sports matches as well (NAC, 1999).

Asthma can, for the vast majority, be effectively controlled with appropriate inhalers. There are national guidelines for treatment, asthma clinics at GP practices, and a number of action plans. However, those whose asthma is poorly controlled may still be suffering from the condition. These descriptions can be hugely helpful to other young people and their families who are going through similar illnesses. They can also provide insight for teachers if they have a young person with asthma in their class. The National Asthma Campaign (NAC) school life advice is available online at www.asthma.org.uk and is supported by the Asthma UK school life site from contributors to the site that is given below:

"The experience of children with asthma has determined some of the messages that we present to schools:"

Several questions on asthma at school were included as part of a survey of asthmatic children aged 11-17 years, carried out in cooperation with the American College of Allergy, Asthma and Immunology (Gelber et al, 2005) within the National Asthma Education Program's Expert Panel on the Management of Asthma in School Age Children (2002).

Pupils felt that their asthma and the disruption to school life had been managed well. The following quote from a 14 year old boy, typical of the rest, stated:

"...I had an asthma attack while I was studying..."

Asthma UK has identified some of the common problems that asthmatic children feel can be improved and has proposed some ways of addressing these. These are presented as a series of "top tips" for schools and can be downloaded from the www.asthma.org.uk website.

Home if tired, sending work home, giving extra work up, giving extra time if they are absent, and being given extra time during exams.

Most children felt they were treated very supportively, but unfortunately not all werel experienced positive care. For example, one pupil stated that they had been told to stay out of school for review and information, and over half said they would, but a few (less than 20%) felt there was no help at all. When asked where they used for asthma information, responses included parents / family, nurses, doctors and other professionals, as well as schools. Children at the two GP practices attended a wide variety of schools, 37 in all.

Website of young people’s views

In contrast to asthma, children may become ill with rare but serious conditions such as cancer, and they and their families may find very few appropriate websites, such as www.youthhealth.org (UK). A charity, called DIFE, recently added this young person’s site to its adult modules which give personal accounts of health problems and illnesses. A major strength of DIFE is that the patient experiences are supplemented by educational impact information, as well as contact details for useful organisations (the site which is not always the case with medical Internet sites). DIFE has since added a number of modules related to cancer professionals and others, such as teachers and parents, who may be supporting a young person over time.

The website, www.youthhealth.org, has videos of young people who have been diagnosed with cancer. They describe their feelings about their illness and treatment, as well as their own experiences and future life. These descriptions can be hugely helpful to other young people and their families who are going through similar illnesses. They can also provide insight for teachers if they have a young person with cancer in their class. The National Asthma Campaign website also includes a school life advice item contributed by teachers to the site that is given below:

"...I had a cancer treatment..."

How can teachers be adequately informed about children’s health problems with medical needs? Written information about their condition is helpful, particularly in the classroom. They talked about giving enough information to the class (more than only what they can). Confidentiality is a paramount concern for young people. A study of 66 young people (1990) found that firstly they did not have a consensus of view of who should know about a condition, and secondly, they knew about the school’s individual approach is required.

For long-term conditions like asthma, the school has to work with the parents to provide guidance, as well as with other professionals. They need to figure out how to incorporate a child’s illness into their everyday life, and how to incorporate it into school life.

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