Improving health/school communication for pupils with special health needs

RESEARCH works

RESEARCH FINDINGS FROM THE SOCIAL POLICY RESEARCH UNIT

SPRU

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Previous research with pupils, parents and teachers has shown the importance of support in school to meet the needs of pupils who have a chronic illness or physical disability. For pupils, successful support depends on teachers having an understanding of their health condition and its impact on school life. In practice, such understanding varies widely, due largely to inconsistent communication between health and school staff. New research by the Social Policy Research Unit investigated the views of health staff to add to existing research evidence. Based on the research findings, a group of health and education staff in York were supported to design a system to improve communication. The key findings were:

- Practice among health staff in passing information to teachers varied widely.
- Health staff experienced difficulties in communication with teachers and with health colleagues.
- Through working together, local health and education staff developed a joint model to improve health/school communication.
- The process of developing the model highlighted issues to take into account in inter-agency working to manage change, for example: having a realistic outcome and clear timescale; breaking down and sharing tasks; involving representatives from all relevant professions and agencies, including managers with power to take action; and early identification of any resource implications.

Background

Previous SPRU research with pupils, parents and teachers found that children with a chronic illness or physical disability have a range of support needs in school. For pupils needing support, it was crucial that teachers understood their health condition and its impact on school life. In practice, however, understanding among teachers varied widely, due largely to inconsistent communication between health and school staff.

Policy guidance in education on supporting pupils with 'special educational needs' provides a framework for inter-agency communication for pupils with a Statement of Special Educational Needs. However, the focus is on pupils with learning difficulties, and so excludes many children who have a chronic illness or physical disability. In the NHS, guidance exists on supporting pupils with 'medical needs', but is narrow in scope, has been shown to be poorly disseminated, and criticised for failing to identify responsibility for support.

Project objectives

- to add health staff's perspectives on communication to existing research evidence from pupils, parents and teachers;
- using the research evidence, to develop and implement an action plan for improved health/education communication in York;
- to make recommendations on the process of inter-agency working to help staff in other areas who want to make similar changes.

Findings

Health staff's communication with teachers

The first stage of the project was to complete the research picture by asking local health staff about their communication with teachers. Information and advice which health staff passed to teachers, and how they went about this, varied widely. The flow of information was most consistent where pupils had a Statement of Special Educational Needs, since there was an established system for passing on and reviewing information about the child's needs. However, pupils with an illness or disability will usually have a Statement only if they have accompanying learning difficulties. For pupils without a Statement, communication appeared to work best where a specialist nurse was in post (diabetes and epilepsy), or where there were agreed procedures for passing information to schools (diabetes and anaphylaxis) or, simply, where individual school staff had taken a keen interest in the pupil.

Health staff reported examples of good practice in working with teachers. These included: regular joint meetings (for example, for pupils with conditions difficult to diagnose and/or manage); agreed procedures for passing on information to schools (anaphylaxis); and shared documentation (being developed for pupils with epilepsy). Health staff valued efforts made by teachers who passed on health-related information to colleagues and eased arrangements for health staff visiting schools. However, not all teachers were thought to be supportive about health matters. Difficult experiences reported by health staff included apparent reluctance by some teachers to meet with them, and lack of distraction-free time and private space to talk in schools.

A particularly strong concern for health staff in sharing information with teachers was confidentiality:

> ***It's a minefield: on the one hand everything should be confidential and on the other we should all be working together.***
> *(School nurse)*

A key difficulty was that NHS staff saw codes of confidentiality in health as stricter than in the more 'open' environment of education.

Other difficulties in communication were practical: the lack of time for health staff and teachers to contact one another; and uncertainty about who in schools took responsibility for liaison in respect of this group of pupils. The views of health staff were consistent with our earlier findings from pupils, parents and teachers, and add weight to the need for a more systematic approach to health/school communication.

Communication difficulties among health staff

Health staff also experienced communication difficulties with their NHS colleagues which, in turn, affected the likelihood of information being passed to teachers. Practice varied widely with regard to transfer of information among health staff. What consultant paediatricians chose to do was crucial, since they were the primary source of much information. Although school doctors saw themselves as a key link with schools, lack of clarity among consultants about the school doctor role was contributing to variation among consultants in passing on information via school doctors.

A local model for health/school communication

To improve communication, health and education staff in York decided that they needed to introduce a system which clarified *who* was responsible for passing on information about this group of pupils, *what* information they were routinely expected to pass on, and to produce a *standard* set of documents for collecting information. The model they developed has five components *(see Box 1)* and has been written up as a set of guidelines on good practice for local health and education staff. Schools will be expected to use the guidelines from Autumn Term 2000 and an audit will be carried out in Spring 2001.

The named teacher will have designated responsibility for this group of pupils, including liaison with NHS and Local Education Authority staff. It will be for each school to decide who should take on this role. The named health professional will be a School Medical Officer in each case. In each school, the named teacher and the named health professional will be responsible for setting up a health register of all pupils with a medical condition or health support needs, and for reviewing this on at least an annual basis. The named health professional will take responsibility for writing, updating and reviewing health care plans for individual pupils, in conjunction with parents and the named teacher.

Box 1
A model for health/school communication in York

- A named teacher in every mainstream school with responsibility for pupils with medical/health needs
- A named health professional for every mainstream school
- A standard health care plan for pupils with an illness or disability
- A standard health register for all schools
- A *Smart card* for pupils with an illness or disability.

Overall, the model is designed to improve communication between staff about a pupil's health-related needs at school. The *Smart card* will be held by pupils and will contain any health information they might want to pass quickly and discreetly to teachers. Our research with pupils showed that, without such information, teachers sometimes refused pupils' health-related requests in the classroom, for example, asking to go to the toilet, or to take medication. The *Smart card* was proposed for inclusion in the model by pupils advising the York project.

Working together to develop the model

In line with existing evidence on managing change and our own experience, we took a staged approach to the development work. We began by making local health and education staff aware of the need for change by presenting the research evidence at a workshop. Delegates were then invited to form a working group which, with the assistance of the research team, planned the model for improved communication and prepared for its implementation. We also recruited local parents and pupils to advise and comment on the working group's plans. Over time we gradually withdrew our support, reducing our role from 'initiator' to 'facilitator' and then to 'monitor' as the group's work gained momentum. Staff said that, although this transition had been difficult, they thought that the overall approach had worked. Other factors which they thought had helped the project's success included: working in a small geographical area where relationships between some staff were already established; keeping the project resource-neutral; and having an external facilitator. The most difficult aspect of working together had been prioritising time for attending working group meetings.

Recommendations

Practice

Good communication between local health and school staff is important for ensuring that pupils receive the health-related support they need to get the most from school life. The York model for improved health/education communication is being implemented from Autumn 2000 and so it is too early to gauge its success. Having been developed in one area, it is one example of a possible approach, but may not be wholly transferable elsewhere. Staff on the inter-agency working group were asked to reflect on the *process* through which they had developed the model. They made the following recommendations for others wishing to do similar work:

Recommendations for joint working

Aims and ways of working

- keep to a realistic outcome
- have a time-limited end point
- break down big tasks to see progress
- share tasks among group members
- prioritise attending meetings
- avoid possible bias in the Chair: use an informed outsider or consider a shared role between agencies.

Group membership

- include senior staff who have power to take action
- draw representatives from all relevant professional areas, but
- try keep the group small (12 maximum), and
- guard against over-representation of one agency or professional group.

Resources

- resource-neutral projects are easier to run, since bidding for additional funds is unnecessary
- if additional funding is needed, consider this early.

In addition, from our own experience, we would encourage facilitators to:

- draw on existing evidence about group working and managing change
- be sufficiently flexible to work at the group's pace
- prepare groups for working independently
- ensure staff 'own' the work
- encourage staff to attend meetings.

Policy

The continuing policy drive for inclusive education means that growing numbers of pupils are likely to require support in mainstream schools to meet their health-related needs. Straddling the policy boundary between education and health, the support needs of this group remain largely hidden. Although mentioned in guidance in both education *and* health, there is a 'policy gap' in terms of identifying the range of needs of this group of pupils, clarifying who is responsible for supporting them, and advising health and education staff on how to work together to provide such support.

Methods

The project was funded by the NHS Executive Northern and Yorkshire Regional Research and Development programme. It was carried out in York between January 1999 and June 2000. There were two phases: research and development. In the research phase, twenty health professionals were interviewed about their experiences of and views on communication with education staff. Interviewees represented the range of local health staff involved with pupils who have a chronic illness or physical disability. These data added to findings from earlier research with pupils, parents and teachers in York and two other research sites. In the development phase, research findings on pupils' support needs and the need for improved communications were presented to local health and education staff, who then formed a multi-agency working group of 13 members (7 from health and 6 from education) to develop a model for more systematic communication in York. This process of change was facilitated and monitored by the researchers. The researchers also worked with 4 pupil and 5 parent advisors to the project, acting as intermediaries between these advisors and local staff. We asked staff to reflect on the process to help identify pointers for staff in other areas wishing to carry out similar work.

Further information

Copies of the full report *Improving communication between health and education for children with chronic illness or physical disability* by Suzanne Mukherjee, Jane Lightfoot and Patricia Sloper are available from the SPRU Publication Office, price £8.00.

Contact Ruth Dowling on
01904 433608 or
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Other relevant SPRU reports are:

Service support for children with a chronic illness or physical disability attending mainstream schools by Jane Lightfoot, Suzanne Mukherjee and Patricia Sloper. Available from the SPRU Publication Office, full report price £10.00; summary report free of charge.

Real change not rhetoric: putting research into practice in multi-agency services by Patricia Sloper, Suzanne Mukherjee, Bryony Beresford, Jane Lightfoot and Patricia Norris (ISBN 1861342071). Available from Biblios Publishers' Distribution Services Ltd, Customer orderline tel: 01403 710851, price £12.95 – please quote reference J06.

The Social Policy Research Unit is an independent research organisation at the University of York. Established in 1973, SPRU has an international reputation for excellence in key areas of social policy, including health and community care, and social security. Its Director is Professor Sally Baldwin. For further information about SPRU contact the Director or the Information Office, or visit our website at **http://www.york.ac.uk/inst/spru/**

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