



SCOTTISH EXECUTIVE
Education Department

GUIDANCE ON EDUCATION OF CHILDREN ABSENT FROM SCHOOL THROUGH ILL-HEALTH



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Making it work together



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Dear Sir or Madam

STANDARDS IN SCOTLAND'S SCHOOLS ETC. ACT 2000 EDUCATION OF CHILDREN ABSENT FROM SCHOOL THROUGH ILL-HEALTH

1. This circular offers guidance to education authorities to draw up policies in the light of their statutory duty to make special arrangements for children who, for health reasons, are unable to attend school.
2. Section 40 of the *Standards in Scotland's Schools etc. Act 2000* (see Annex A), amended section 14 of the Education (Scotland) Act 1980 so that education authorities are under a duty in relation to pupils unable to attend a suitable educational establishment as a result of their prolonged ill-health. In such circumstances, an education authority must make special arrangements for the pupil to receive education elsewhere than at an educational establishment.

Aims

3. The intention behind the new duty is to ensure that children, so far as possible within the constraints of their medical condition and the context in which they find themselves, receive education which is, as for all children, 'directed to the development of the personality, talents and mental and physical abilities of the child or young person to their fullest potential'. (Section 2(1) of the 2000 Act).

Children affected by the legislation

4. The population of children who are absent from school will include those who have a single prolonged block of absence and those who have several or many periods of absence of varying length. Normally, all will be receiving medical attention of some kind and should therefore be known to child health services as well as to their schools and education authorities.

Referrals

5. In practice, referral for, and management of, special arrangements outwith school may lie with children's own schools, although all such referrals and management should be undertaken in close co-operation with the education authority, regardless of whether delivery of provision is undertaken by the school or education authority specialist services or a combination of both.

6. The Act states that these special arrangements should be so organised as to come into effect "without undue delay". The main emphasis in the initial period of absence for children with ill-health will be on recovery of fitness and health and the time required for this will vary from child to child. However, wherever possible, absence should not lead to a deprivation of education which would have a detrimental effect on the pupil concerned. In general, therefore there should be an automatic referral by schools for education outwith school after 15 working days of continuous or 20 working days of intermittent, absence for verifiable medical reasons. Where, however, absence for verifiable medical reasons is known, or is reasonably thought, in advance of that period to be likely to extend to or beyond 15 or 20 days, then referral should proceed immediately.

7. Similarly, children who have received education in hospital and are discharged to go home to continue treatment or to recuperate should transfer automatically to home teaching if the total period of absence is likely to extend beyond 15 working days.

Planning

8. Children absent from school on the grounds of health will cover all age ranges and sectors of educational provision. A policy and management overview will be necessary and may be best obtained by co-ordination through the education authority officer responsible for Pupil Support Services or Special Educational Needs/Support for Learning.

9. The education authority should also appoint an appropriate member of staff to act as a key contact in order to facilitate referrals of children and to maintain the necessary links with families, specialist services and medical and paramedical personnel. Staff in schools and specialist services should receive appropriate staff development and have adequate and appropriate liaison time to address their responsibilities.

10. The education authority should establish referral systems for home-based and hospital education with appropriate referral forms and sufficient publicity to ensure that their statutory duties and provision are known to all possible sources of referral. These may include referrals from other education authorities, the School Health Service, Community and Paediatric Service, general practitioners, medical staff in NHS Trusts or specialist nurses. Referrals outside these routes may include referrals from school staff, educational psychologists, general practitioners, social workers, education welfare officers, other agencies, parents and, where appropriate, pupils themselves. Education authorities and schools should include information on these duties and on accessing provision routinely in all information packs given to parents when children enter or change school, in parents' and other professionals' briefing sessions, and on school notice boards.

11. With a small number of exceptions, children who are absent from school because of ill health will return to the school in which they are enrolled. Children should remain on their school roll and schools are expected to retain management responsibility for these children's education even when delivery is undertaken in part or wholly by specialist outreach services of the education authority or by hospital education services outwith the home authority. Schools' continuing involvement will enable optimum coherence and continuity in education and a smoother return to school.

12. Class and subject teachers should record missed work to ensure both effective education outwith school and to optimising continuity when any child returns to school.

13. Education authorities may wish to consider, in the case of children with extended absence, whether some educational provision should be made over holiday periods, particularly for those who are expected to be in-patients for more than 3 months. The hospital service teacher who has first hand knowledge of the needs of the child should advise on the provision.

Learning at home

14. Ill pupils are most likely to spend their period of absence at home (see paragraphs 36-39 for learning in hospital). Delivery of education at home by school staff is most likely to ensure curricular and social inclusion of absent children. The education authority and schools should consider if such delivery is feasible and how and when these duties might be undertaken. Where this is not feasible an education authority should provide education through specialist service or experienced home visiting teachers. In such cases, the school should still be overall managers, with responsibility for ensuring curricular coherence and continuity, for liaison with specialist service staff and for providing teaching and learning resources.

15. Parents' involvement and support for alternative educational arrangements should be sought. Parental support may take many forms, for example: encouragement, practical involvement in tasks such as listening to reading or checking through written work, or helping access additional resources for learning. However, it is important in planning provision to take account of the fact that families' capacities to provide a learning environment in their own homes will vary greatly. Education authorities should also ensure that schools and specialist services take account of those aspects of Child Protection and Health and Safety policies that have implications for staff and pupils involved in education at home (see also paragraph 23).

Provision

16. Education outwith school should involve the children concerned in some face-to-face contact with a teacher or teachers on a regular basis. It is suggested that three to seven hours per week may be an appropriate baseline from which to consider variation according to individual needs. Consideration should be given as to how fit the child is to benefit, with reference if need be to medical personnel involved. Children who are less well able to work on their own, children with pre-existing difficulties in learning, children working towards examinations and those whose families may be less able to support their learning, might be considered to have greater needs for direct teacher contact. In the case of older well-motivated pupils, some teacher time could be well spent on developing or accessing very specific resources for self-study.

17. Resources may take a variety of forms including: packaged ‘book and paper’ homework from school, telephone communication, faxed materials, video conferencing, ICT (e-mail and Internet resources), home tuition from own school, part-time education within a centre acting as a ‘half-way house’ in a pupil's own school or elsewhere, and home or hospital teaching by specialist service staff. While an education authority’s specialist teaching services are expected to have some basic resources, especially consumables and IT equipment and software, the main providers of resources for children should be children’s own schools. Key contacts in schools should assume responsibility for ensuring that resources can be, and are, provided.

Curricular issues

18. The same principles of a broad and balanced curriculum apply to children receiving education at home as to children in school but the constraints of children’s medical conditions and the contexts in which they are taught may impact on the degree to which these principles may be realised. In making educational provision outwith school, and on return to school, the focus should be on having challenging, but realistic, expectations.

19. The drawing up of a short-term learning plan, (or use of a Personal Learning Plan or Individualised Educational Programme (IEP) where these are already in place), will provide a framework for action and co-operation by all concerned. Targets should be shared and agreed with parents and, where possible, with children and young persons themselves. The education authority’s specialist teaching services should be involved from the beginning even when it is envisaged that the child’s own school might be the main or only provider of home teaching and resources. In the case of children with medical conditions, which impact directly on learning ability, medical advice should also be sought.

20. The education authority and school should endeavour to ensure that children are kept within the assessment and accreditation tracks of their peers and that work undertaken outwith school is considered for accreditation purposes. Where appropriate, hospital education services should consider seeking registration with the Scottish Qualifications Authority for assessment and examination purposes.

21. It is expected that the curriculum on offer in most circumstances outwith school will be based on the same frameworks as those within school, i.e. 5-14 Guidelines, Standard Grade and new National Qualifications. However, in the case of very ill or neurologically impaired children, and particularly in the case of children with deteriorating and terminal conditions, education may be child-led. In such cases children’s own interests, pressing questions and remaining abilities may suggest curricular routes and activities that are unique and satisfying to them. (See Annex B, Examples of good practice: Recommended reading)

Organisation and support of staff

22. All staff working with seriously ill children will need professional development and personal support on a planned basis. Steps should be taken to ensure that outreach staff, including those working with children with psychiatric conditions, are linked effectively to larger systems and resource bases that will meet these needs.

23. Staff should have professional credibility in terms of curricular knowledge and support for learning skills as well as a high level of inter-personal skills and empathy. In addition, they should operate within the guidance set out in “*Protecting Children a Shared Responsibility*” – *Guidance on Inter-Agency Co-operation* and “*Protecting Children a Shared Responsibility*” – *Guidance for Health Professionals in Scotland*.¹ They should take account of children’s and young persons’ rights to have their dignity and privacy respected. Staff must also be aware of aspects of Health and Safety policies that affect their work. Additionally, education authorities should take account, where appropriate, of Health and Safety procedures followed by the Health Care Trust.

24. Education authorities should ensure that, where appropriate, their teaching staff have sufficient additional skills and knowledge, to undertake hospital-based teaching with children from that authority, from other authorities and from the private sector who are in-patients.

Support for families/carers

25. Families with ill children experience considerable stress through additional caring duties and sometimes also through fear and uncertainty about children’s futures in terms of health and of education. Relationships between home, school/education services and child health services should be prioritised with adequate time for consultation with parents and, wherever possible, with children. Section 2 of the *Standards in Scotland’s Schools etc. Act 2000* includes a duty on education authorities to have regard to the views of children in decisions that significantly affect them. Awareness of and sensitivity to culture and religious beliefs and family circumstances, including the impact on brothers and sisters, are particularly important. At some times consultation may need to be intensive. Single named points of contact in education authorities, schools and in specialist services (as recommended in paragraph 9) will make for better communication.

Review arrangements

26. The education authority should ensure that there are appropriate review arrangements for pupils receiving education outwith school. Where a pupil has an IEP or a Personal Learning Plan, then a review for his/her absence through ill-health and the IEP or PLP review could be combined. Reviews may be straightforward informal education authority/school discussions with parents and children about evaluating progress to date and setting future targets. Or they may cover more formal multi-professional reviews. The latter should involve parents in discussing children who have been receiving education outwith school for significant periods of time (one term or more is suggested) and of children whose cases are particularly complex or problematic. Where possible, pupils should also be involved in these review discussions.

Child Health Services

27. The school health service and the NHS child health service are important sources of advice on medical conditions and their impact on accessing appropriate education. Sensitive confidential information about a pupil should only be shared with those who need to know, including parents or members of staff who are specifically involved with the pupil. The head teacher should agree with the pupil (where he/she has the capacity) or otherwise the parent, whom else should have access to health records or other information about a pupil. Close liaison at a senior level, in relation to general management issues and, where necessary, in relation to individual children, should ensure adequate and appropriate information to those charged with the responsibility of teaching affected children.

28. In some cases an education authority may need to jointly screen a new referral for education outwith school with the school health service paediatrician nominated for the child's school. This process should be effected ideally within one week of referral, although there may be a small number of more complex referrals that require more extended investigation. In the case of some children with chronic, recurrent or intermittent serious illness, or in the case of psychiatric emergency admissions, exemption from further screening and from 'initial qualification' periods of time may be arranged. This should be notified to parents, schools and education authority services, allowing these children direct and immediate access to special arrangements.

29. Education authorities should consult the school health service on problematic issues or areas of uncertainty. For example, advice may be sought on whether a particular child is well enough to return to school or to participate in a more demanding or extensive out of school programme. In specific cases, the school health service may be required to access a specialist opinion from the paediatric services, child health services, or child and adolescent mental health services.

30. It is expected that appropriate accommodation will be provided by the hospital concerned so that teachers can provide an educational service to children. Hospital managers should facilitate teachers' participation in relevant in-service opportunities and in multi-professional teams. Relevant medical in-service training days should count towards Continuing Professional Development.

31. Education authorities should work with the school health service to ensure effective liaison is established with appropriate personnel in relation to education outwith schools. This communication system should be made known to all schools and specialist education services. Education authorities that have not already done so may wish to establish liaison groups of key personnel from both education and health services.

32. Co-operation with school health services may be required to ensure relevant medication, medical treatment and appropriate and safe moving and handling of children. Such on-going arrangements for children in school are also critical in facilitating the return of absent children to school. The Scottish Executive has issued good practice guidance to education authorities, NHS Boards, NHS Trusts and other interested parties entitled "*The Administration of Medicines in Schools*". This guidance is intended to help local authorities, NHS Boards and schools draw up policies to manage health care in schools, develop effective management systems to help support pupils with health care needs and enable them to participate as fully as possible in mainstream education. The Guidance recommends that education staff meeting the healthcare needs of pupils should receive appropriate training, support and legal indemnification.

Reintegration of pupils who have been absent

33. For many children absence entails social dislocation from school, and from both staff and peers. This can result in very real fears about returning to school, especially after long-term absence, even where contact has been maintained. Difficulties may arise from the child's physical needs, continuing need for treatment or medication, reduced ability to sustain physical or mental effort, etc. or from social dislocation.

34. Class and group placement of children returning after absence should be the same as before, whenever possible. Children returning to school with changed physical appearance may be vulnerable to bullying. Schools should, therefore, make every effort to plan with teachers, fellow pupils, parents, specialist services, medical personnel and children themselves flexible and progressive arrangements to ensure successful reintegration. If the child wishes it the child's hospital teacher should accompany the child to their mainstream school to both support staff and the child in re-integration. Where appropriate a medical representative may also attend.

Transitional stages

35. Times of transition such as entry into primary or secondary school, or from stage to stage within a school, or from secondary to post-secondary provision should be addressed educationally and socially even where absence has been prolonged. Education authorities should consider the position in relation to children with significant health difficulties in pre-school and the 16–18 year old age groups. The latter may already have experienced substantial educational losses due to previous illness-related absence.

Hospital issues

36. There is a small but significant number of children who spend substantial periods of time in hospital, or who have recurrent shorter stays. Effective teaching in hospitals requires teamwork, trust and considerable understanding of the roles of medical and paramedical professionals, the demands of their work and the needs of patients and their families. It is suggested therefore that in-hospital teaching be undertaken by the teachers appointed, trained and supported for the sensitive work they undertake. This need not preclude the involvement of other teachers, for example, teachers from children's own schools or from the child's education authority specialist services. However, they should normally only be involved after prior negotiation and agreement with, and briefing by, the hospital's 'own' teaching service to ensure that children's paramount needs in hospital, for medical treatment and care, are safeguarded.

37. Teaching in hospital, including in any adult wards where children may be admitted, or hospice, should normally begin after five working days following admission, provided the child's state of health makes this desirable. Medical views, parental and, where appropriate, children's perspectives should be taken into account. As in home teaching, this period of time should not be a rigidly applied 'qualification period' for all children. If a child's in-patient stay is known, or reasonably thought, in advance of that period to be likely to extend to or beyond five days, then teaching should proceed immediately, provided this is otherwise appropriate. This will be particularly important in the case of children whose medical conditions require recurrent admission.

38. Internal referral procedures in children's hospitals, children's hospital units and wards should be established with medical, nursing and administrative staff and should be reinforced at intervals by education services hospital-based staff briefing new hospital staff about the existence, purpose and referrals systems for the education service. Referral procedures may require particular attention when children are admitted to adult wards. Referrals may also come from other sources such as families, general practitioners, schools etc. who may be aware in advance of a child's probable admission to hospital. An education authority's publicity and referrals forms (see paragraph 10) should cover all possible sources of referral.

39. All education authorities must secure adequate education for their area. This includes providing appropriate education for children in hospitals within their area. Where such provision is made for children whose parents ordinarily reside in the area of another authority, an education authority may, in terms of section 23(2) of the Education (Scotland) Act 1980, recover from that other authority such contributions as may be agreed between the authorities. In the event that agreement is not reached the Scottish Ministers can determine the amount of contribution to be recovered.

Deteriorating or life threatening conditions

40. There are very good reasons for continuing to provide education for children with deteriorating or life-threatening conditions even, with family wishes respected, towards the end of their lives. Such involvement with children requires particular human, imaginative and empathic qualities and teaching skills, found frequently but not uniquely in experienced hospital teachers and teachers who work in some special schools and services. At the same time, most parents and children wish to remain part of their own school community where staff and fellow pupils can play a very important part in supporting children with such conditions and their families.

41. Some children may spend time in hospices. Education in its broadest sense may be an appropriate part of a holistic approach to ensuring their well being while in the hospice. On-going contact with staff and peers from children's own schools, by means agreed with the family and the hospice, should be maintained. Most families welcome sustained contact when a very ill child is absent, even when he or she will not be returning to school.

42. A small number of school pupils die every year in Scotland from a range of causes including illness and accident. The death of a pupil is an event with which education authorities and schools should be prepared to deal with calmly and with respect and empathy, even when it is totally unexpected. In the case of children with a very serious or life-threatening medical condition there will have to be some time to consider the best ways of supporting the family and of helping the school community to cope. Sensitive support and contact may be appreciated around the time of the funeral and for some time afterwards. Parents/carers need to know that their child has been significant in the life of the school and will not be forgotten (see Annex B, Examples of good practice: Recommended reading).

43. Education authorities in which hospices are based may wish to discuss educational provision with the hospices or with the Children's Hospice Association Scotland, 18 Hanover Street, Edinburgh, EH2 2EN. (Telephone – 0131 226 4933)

Queries Concerning This Circular

44. Any queries concerning this circular should be directed to John Bissett, Pupil Support and Inclusion Division, 3-A (North) Victoria Quay, Edinburgh EH6 6QQ. Telephone: (0131) 244 0947

Yours sincerely

JOAN FRASER

Section 40 of Standards in Scotland's Schools Etc. Act 2000
Education outwith school

For section 14 of the 1980 Act there shall be substituted-

"14 Education for children unable to attend school etc.

(1) If an education authority are satisfied that, by reason of-

(a) any extraordinary circumstances (not being circumstances mentioned in paragraph (b), or subsection (2) or (3), below)-

(i) a pupil is unable; or

(ii) it would be unreasonable to expect a pupil,

to attend a suitable educational establishment for the purpose of receiving education, they may;

(b) a pupil's prolonged ill-health-

(i) the pupil is unable; or

(ii) it would be unreasonable to expect the pupil,

to attend such an establishment for that purpose, they shall, without undue delay after those circumstances become apparent to them,

make special arrangements for the pupil to receive education elsewhere than at an educational establishment.

(2) If an education authority have, under section 34(1) of this Act, granted a pupil exemption from the obligation to attend school, the exemption being to enable the pupil to give assistance at home in circumstances arising out of the illness or infirmity of a member of the pupil's family, they shall in so far as is practicable and without undue delay make such special arrangements as are mentioned in subsection (1) above.

(3) If a pupil withdraws, excluded by the education authority (or with the consent of the authority in circumstances where he would have been so excluded but for his withdrawal), from a public school in their area they shall, without undue delay-

(a) provide school education for him in a school managed by them;

(b) make arrangements for him to receive such education in any other school the managers of which are willing to receive him; or

(c) make such special arrangements as are mentioned in subsection (1) above."

EXAMPLES OF GOOD PRACTICE

The following case studies focus specifically on how local authorities and schools can make special arrangements for the education and social inclusion of children absent on the grounds of ill-health. To avoid identification of individual children, education authorities and schools, each example is a composite picture, created from the real experiences of several children.

They illustrate how educational continuity can be ensured during the absence from school of children with serious conditions, as well as how an education authority and school can do much to reduce unnecessary absence. The special arrangements are therefore practical extensions of the same basic principles of respect, care and planning that should be applied to the education of all children, including those with conditions that may not cause extended absence but are still unpleasant and debilitating.

In each case schools, families, education authorities and school health services worked together to ensure a flexible network of support. The emphasis in the examples is on the detail of additional arrangements made that ensured the optimal educational continuity and social inclusion of the particular children. These were the outcome of thought and understanding, mainly on the part of the four key partners involved in their individual contexts - education authority, school, school health services and family. The views of children were taken seriously and, wherever possible, they were included in discussion and in decision-making processes.

The case studies are organised according to the age of the children concerned. However, whilst some of the issues are specific to staff in a primary or secondary school there are also many generic issues. Accordingly, each case study has something to teach staff in both primary and secondary schools.

Jennie (6)

Jennie was very badly injured and burned in a car accident involving her family. All family members survived and eventually made good recoveries, but Jennie was the most severely affected with multiple fractures, some minor head and serious facial injuries and burns affecting the right side of her body. Jennie and her mother, who had broken both her legs and her pelvis, were patients in different parts of the same hospital and her mother was wheeled regularly to visit Jennie in the Burns Unit. Jennie's first period of in-patient treatment was likely to last over eight months, and it was envisaged that she would have to return to hospital for further plastic surgery and orthopaedic treatment throughout her childhood and adolescence.

The head of hospital and home teaching visited Jennie's mother whose immediate concern was for Jennie's physical recovery. She was surprised and even irritated at the suggestion of education. Taking account of the views of the Surgical Consultant she eventually agreed that a tentative start might be made by 'someone telling Jennie stories and singing to her'.

One of Jennie's two job-share teachers had already asked to go and see her and asked if she might be considered as a possible hospital teacher for Jennie. The head of the hospital and home teaching service accompanied the teacher for the first few weeks of her visits which were initially restricted to ten minutes a day. Over time Jennie was eventually receiving about six hours of educational contact per week once she was less in risk of infection and able to join small groups of other children. She found one-to-one teaching tiring and was happiest when this was restricted to short periods of 20 -30 minutes. The curriculum initially was largely 'Jennie-led' - with stories, talking and even singing about the things that concerned her most then, including her accident and treatment and her mother's broken legs. Later her programme paralleled that of her peers in school within the 5-14 curriculum framework.

Additional in-puts by the key partners

Education Authority

- The education authority agreed that the Home and Hospital Teaching service could co-opt another part-time teacher (one of Jennie's job-share class teachers) to ensure longer-term continuity and also agreed on-the-job induction and support by the head of service.
- Jennie has 'direct access' to hospital and home teaching without need to re-refer her.
- The education authority reviewed Jennie's education outwith school on a termly basis, involving the school's health service personnel, her hospital/school teacher, her school Headteacher and educational psychologist, and Jennie's parents. Jennie was asked to come to a meeting on her return to school but declined (her greatest wish was to be 'ordinary').
- The education authority provided computer hardware and software for the hospital teaching service and video equipment. These were important in Jennie's education as much of it could come to her bedside. A musical keyboard was also loaned to her.

School

- Ensuring sustainable support for Jennie and her family was important. It threatened initially to be excessive with children and parents of children in her class and throughout the school bringing mounds of toys, cards, flowers to school or sending them to the hospital for her. At a timely parents' evening, the Headteacher and the head of the hospital and home teaching

team explained to parents and older children that Jennie would need their encouragement and support over many years and that it would be best not to overwhelm the family at this time.

- On-going peer social contact could not be face-to-face because of potential infection. Jennie's teacher exchanged audio cassettes, drawings and messages between Jennie and her classmates and eventually there would be exchanged videos as part of a planned re-entry into ordinary school life
- The school involved all staff and pupils in a briefing about Jennie's return to school a month before the event. The Headteacher explained that Jennie's appearance would be altered but that she would still be 'the same Jennie' inside and that there should be a quiet welcome when she returned, not spoiling and not teasing. A video was shown of Jennie. A preliminary visit with her mother and her teacher was planned. Jennie wore a cap to cover the hair loss and scars on the right hand side of her head. Her desk in class had been kept for her beside the same children she had sat next to in the previous year.
- School staff ensured that any name-calling regarding Jennie in the playground or elsewhere in the school was dealt with firmly within the school's anti-bullying policy.
- The school has kept a watching brief for Jennie's older sister who sustained only minor injuries in the accident but then had four months of living without her mother and a further four months of both parents and other friends and relatives constantly visiting and discussing Jennie. She has seemed withdrawn at intervals and her classwork suffered but this is now picking up again.

School health services

- Jennie's physical abilities are impaired although there is hope that her right hand function and mobility will improve still further. She requires on-going skin-care where she had grafts to replace burned tissue. She has an Individual Healthcare Plan developed by hospital and school medical personnel, her class teacher and the school's early years auxiliary and Jennie's parents. Jennie also gave her views. She joins in sport and dance activities with care.
- The early years auxiliary assistant has a key role in supervising her physical care and has, along with Jennie's previous and new class teachers, received training for this from the paediatric physiotherapist and the charge nurse on the Burns Unit.
- The hospital and community based Occupational Therapists have also advised the school about facilitating her right hand grasp and providing left-handed resources.
- School staff have been informed about the extent to which Jennie can participate in normal school activities.

Family

- Jennie's parents and two siblings - one older, one younger - were also involved in the accident and the family has taken an understandably long time to recover its former stability. This is shaken, however, each time Jennie returns to hospital for further treatment when parents visit her alternately. Her mother does not plan to return to work. She is now beginning to take more interest in the children's education, hearing their reading and checking other homework and answering letters from school. One and a half years on, both parents began attending parents' evenings and other school occasions again.

Jennie has proved to be resilient against the odds, generally cheerful and an enthusiastic pupil. Learning and social acceptance currently, therefore, present no problems. Jennie's reading and writing - with her left hand - were well-ahead of those of her classmates and

her other work was comparable with theirs when she came back to school after her first stay in hospital. This may become more problematic as the curriculum becomes more complex. When she returns to school after her recurrent hospital stays, she tires easily but generally fits in well. However, school staff, educational psychologist and head of the hospital and home teaching team will continue to monitor her progress up to and through adolescence when her facial, body and limb scars may acquire a greater negative importance to Jennie that they currently seem to have.

Daniel (9)

Daniel is in P4 of his local primary school in a large city. Daniel is one of two children in the class with severe learning difficulties. He also has some physical impairments including a major heart abnormality which was due for surgery. His class of 23 children has an experienced class teacher with a full-time auxiliary helper because of the range of additional needs of four pupils in the class. The learning support teacher also works with the class four times a week.

Daniel enjoys school and has made a start on the very early stages of reading and number. He has a short attention span and is easily bored although not disruptive. His speech is immature and unclear although understood by his teacher, auxiliary and classmates. He still uses some Makaton signs, again, these are well understood by all in his class. A speech therapist works with the class teacher and auxiliary with four of the children, including Daniel, twice a week. He has a Record of Needs, an IEP and an IHP. As part of the Healthcare Plan, there is also an Emergency Plan for Daniel that covers resuscitation and emergency medical support in the event of heart failure. He has had frequent absences from school and sometimes has mobility problems when tired, because of his heart condition rather than the other physical impairments. The education authority and school therefore had to plan both for occasional shorter-term absences and for the longer block of absence for heart surgery, likely to include part of the summer holiday period.

Additional in-puts by the key partners

Education Authority

- The education authority continued to monitor and review Daniel's Record of Needs and ensure the provision of speech therapy during hospitalisation (once he was fit enough)
- It was agreed that Daniel should have immediate access to hospital and home teaching whenever absent.
- The Special Needs Adviser was responsible for planning and delivering some educational and play in-put over the summer holiday period when Daniel would normally join the summer club but was instead having his heart operation. The hospital already runs a play scheme and the temporary hospital teacher worked up to two half hour sessions, four days a week, with Daniel once he was well enough.

School

- Daniel's sister in P7 was assured of a listening ear by her own class teacher and by the class auxiliary who worked with Daniel, because of her own anxieties about Daniel and unavoidably reduced parental attention at this time

- The school welcomed visits by the hospital and home visiting staff to Daniel's class which allowed them to see him working in his normal context, discuss teaching resources and play activities. They also had a briefing with his class teacher, auxiliary and speech therapist and with Daniel's mother that covered Daniel's emotional and communication needs.
- The school prepared Daniel - and his class - for his coming stay in hospital by the hospital teacher's visit and talk with all the children, by the use of special hospital story books with Daniel and his class, by drama, and by planning in advance how they were all going to keep in touch (audio and video cassettes, drawings and, once he was fit enough, some visits from friends).
- Daniel's class auxiliary also paid a special visit with his mother and sister to the hospital ward where he would be. (Daniel was already familiar with the surgeon, nurses and ward where he had had several day patient investigations).
- Preparing for a possible failed operation or Daniel's death was difficult but necessary for the school staff. Daniel's parents had been very open about both possibilities although they found it too painful to discuss in detail. The head of the hospital and home visiting teacher service had been very supportive of the relevant school staff - head, class and learning support teachers and auxiliary assistants, and the school already had a well-established policy for dealing with crisis in terms of pupils, staff, parents and family of the child or children affected. Relevant reading was undertaken.
- Daniel's teacher and auxiliary were each allocated one hour weekly to visit Daniel, funded by the EA, and the auxiliary assistant's work programme allowed for gathering learning and play resources to renew the hospital teacher's supply on a weekly basis when she visited Daniel.
- Planning for a smooth and phased return - supportive but not indulgent - was very important as Daniel might have lost confidence or even forgotten a lot about school.
- Ensuring when Daniel needs to use his wheelchair that he has access to all relevant parts of the building, including suitable toilet facilities. Movement space in his own classroom has been arranged.

School health services

- A consultant community paediatrician with a specialism in children with multiple impairments worked with school staff to develop an Individual Healthcare Plan for Daniel that also included emergency plans
- A teacher with support for learning or special needs experience was co-opted from the peripatetic support for learning service and inducted into hospital teaching prior to Daniel's operation.
- The consultant along with nursing staff then carried out initial and refresher training to ensure school staff's ability to implement the Plan fully and calmly. The training included promoted staff, class teacher and all four school auxiliaries to ensure adequate cover and mutual support. (Attention to this plan, which included flexible hours of attendance, special transport provided by the Authority to and from school and the provision of rest facilities, had ensured that Daniel's absences had been kept to a minimum to date.)

Family

- Daniel's parents, after their joint vigil following the operation was over, alternated their visits and often carried on with work and play left by the visiting teacher and play worker.
- They also recycled his toys from a supply at home and provided his favourite videos and music cassettes.

- During the holidays Daniel's brother, sister, grandparents and club leaders also visited him often.
- The parents and older siblings help Daniel at home with his homework whether he is at school or absent.

In the event, Daniel's operation was a partial success and he even appeared to enjoy much of his hospital stay although he had regressed a little emotionally, clinging to his parents and siblings when he got home. He is less breathless and needs to use his wheelchair less frequently. The visits from his class teacher and auxiliary and from some classmates and friends from his clubs seemed to help continuity. His phased return to school ten weeks later was relatively uneventful, deliberately low-key but happy. He seemed initially to be rather less independent and orally communicative in the early weeks but the school and his family have more confidence that a second operation can be managed successfully.

Ben (11) and David (7)

Ben is one of 16 children in a composite P6/7 class of a rural primary school. His younger brother, David, is in Primary 1/2/3. Both children are 'bright-average' in terms of their potential school performance, sociable and with a wide range of interests.

Both boys have cystic fibrosis, a condition that is potentially life-threatening. However, health patterns are individual and Ben is worse affected than David, requiring physiotherapy three times a day while David copes well with twice a day. Both boys take a number of pills before eating, to facilitate absorption. David is occasionally absent for a few days but Ben has been in hospital three times in the current school year for several weeks of intravenous antibiotic treatment and intensive physiotherapy. He is often tired, coughs constantly and is very breathless. Climbing stairs is now difficult. He has a valve inserted in the back of his hand to enable antibiotics to be given intravenously and it is possible that he may have to have oxygen available in school soon. He has also developed secondary diabetes for which he must self-administer insulin using a simple 'pen' injector.

Both boys have so far mainly 'kept up' with their class-mates in school work, although Ben has needed additional help with Maths and Social Subjects. He was involved in the development of his IEP. This is implemented by his class teacher, the school's peripatetic Learning Support teacher and his Visiting Teacher who works with him both in hospital and at home when he is absent. Both parents are supportive of the boys' education but feel 'a bit out of their depth' in relation to Ben's work and are worried about his secondary education. Their part in the boys' physical care is very time and energy-consuming.

Additional in-puts by the key partners:

Education Authority

- Paying for travel to school by taxi for both boys. Ben has a Record of Needs.
- Arranging 'direct access' to home and hospital teaching for Ben so that he does not need re-referral each time he is absent.

- Ensuring that physical access to Ben's secondary school is improved prior to his transition. This has involved installing a lift between first and second floors as Ben might otherwise have had to go to a different school from his primary school classmates
- Ensuring counselling support through the Educational Psychology Service and School health services for Ben if/when he wants this.
- Bringing together hospital-based teachers and mainstream class teachers who teach pupils with a poor prognosis for some mutual support and training. Ben's class teacher, who is distressed by his health deterioration, has found this group very helpful (she is his chosen confidant in school). She and the Headteacher have already attended the Authority's course on 'Schools coping with crisis and loss'.

The school:

- Ensuring a safe environment for Ben through extension of the school's Inclusion and Anti-bullying policies (Ben was teased briefly about being a 'junkie' when he first had a valve for intravenous antibiotic injections and when he was also known to be giving himself insulin injections - this was addressed firmly and educationally by the Headteacher and the community specialist nurse)
- Elaborating Ben's transition to secondary school arrangements to include: the usual visits with classmates, an additional individual visit with his mother and his current learning support teacher to meet his future guidance teacher, the head of support for learning and the school auxiliary assistant
- Arranging meetings between primary and secondary staff towards end of P6 and throughout P7 to discuss Ben's transfer. Meetings took account of secondary school guidance, "Opening Doors" materials to allow suitable preparations for entry into S1 of pupils with physical disabilities.
- Providing Ben with a duplicate set of books at home so that unexpected absence is less problematic and so that he does not have to carry a heavy bag
- Maintaining social contact with the boys when absent. Both class teachers telephone the boys' home twice weekly with an update on work covered and on what has been happening in class. A class friend will also speak. During Ben's longer absences his class teacher visited him once in hospital and at home and Ben's class kept a weekly 'video diary' of happenings in class and personal messages which was taken home to him by David.
- Providing private space for the boys' medical treatment and rest, if needed
- Offering the parents' 'easy access' to discussion with the Headteacher and, through her, to the class teacher and school auxiliary.
- Providing safe storage of Ben's medication and that he has access to this at any time through contact with a range of identified staff. Recording of any medication administered in school.
- Enabling discussion between parents, Ben's health services and school meals service to ensure lunches meet with Ben's diabetes needs.

School health services

- The school medical officer and the specialist cystic fibrosis community nurse delivered relevant staff development in school that emphasised optimising the boys' abilities and health and their capacity to be self-managers of their healthcare regimes as far as possible.
- The paediatric physiotherapist trained the school auxiliary who had volunteered to help Ben with his mid-day physiotherapy session

- Liaising and collaborating with the School health services - paediatric specialist consultant, school doctor and nurse, cystic fibrosis and diabetes specialist community liaison nurses, to develop, implement and review Individualised Health Plans for both boys. David and Ben were actively involved in the process.

The family

- The boys' parents both work but carry mobile phones that can be used for urgent communications with the school.
- The family has ensured flexible child care arrangements to cover absences
- The boys and their parents have a 'pact' that school work at home should be done as well as possible and the parents encourage the boys and check work done.

Ben made a successful transition to secondary school despite increasing absence. He now works with three different outreach teachers to cover the secondary curriculum. The family has the loan of a fax machine from the Authority, used for home-school communications both for school work and for social contact. Ben's guidance teacher is the key link for his family and for other services making in-puts to support his education. He in turn liaises with the school's support for learning staff. David's school progress and his health, meantime, have been good.

Steven (14)

Steven is in S3 of a medium sized town high school. At primary school he was a rather withdrawn but quite able child, but who had occasional severe outbursts of temper that usually ended in prolonged sobbing. He also sometimes refused to go to school, complaining of stomach pains. By the time he transferred to secondary school his mother and father described him as 'emotionally disturbed and very angry'. He had obsessional worries and behaviour patterns and described a range of psychosomatic symptoms that he experienced, sometimes accompanying these with disturbing drawings of how he felt.

Steven was hospitalised following an overdose on painkillers. Immediate hospital treatment meant there were no lasting physical ill-effects and referral to the Adolescent Psychiatric Unit for day-patient support was swift. Weekly family and individual psychotherapy sessions proceeded and also some groupwork with fellow patients that were organised by the education authority Psychiatric Unit-based teachers. These had a broad personal and social education content and approach.

However, Steven now refused to attend school at all. The Principal Psychologist and Steven's guidance teacher were consulted by the Psychiatric Unit liaison teacher with a view to working with Steven and his family to develop an educational and psychological support strategy, the initial key aim being to get Steven back to school. The liaison teacher discussed Steven's fears, likes and dislikes about school with Steven and his mother during a series of home visits.

Later, Steven agreed that his school guidance teacher could visit him at home and, with his consent, join in discussions at the Psychiatric Unit. A phased return to school on a reduced timetable, avoiding three subject areas which gave rise to his fears, was negotiated with Steven

and formalised through his IEP. He himself suggested that he would work on his own in the Guidance Base on maths and art with resources provided from the classes he would otherwise have been attending. The school and Psychiatric Unit worked out a phased programme of accompanying Steven to school, initially involving the liaison teacher bringing him from home to the Guidance Base, but eventually Steven was able to come to the school gates on his own if he was met there either by his guidance teacher or by his Buddy (see *School*, below).

Additional in-puts by the key partners

Education Authority

- Outreach (home) teaching was considered but it was agreed that a return to school might not be helped by this provision at this time although it would be provided if other strategies did not work.
- Consideration was given to opening a Record of Needs for Steven but was not thought appropriate at that time. His case was discussed regularly by the School Liaison Group (SLG). The question of a Record would be revisited.
- Termly multi-professional reviews of Steven's progress, involving Steven and his family, would continue to be organised by the Principal Educational Psychologist acting for the EA.

School

- School staff, including senior managers, all guidance teachers, subject teachers who would be working with Steven and those from his 'feared' subjects undertook several development sessions on adolescent mental health, delivered by the Psychiatric Unit liaison teacher. This enabled some staff who had felt irritated and challenged by Steven's 'unreasonable' behaviour to adjust their thinking and responses
- A mature 6th year student member of the school's already established Peer Support system volunteered to be Steven's Buddy when he returned to school and was included in the staff development sessions
- Staff were particularly vigilant against bullying of Steven or any stigmatising of his younger brother.
- Steven knew he could contact his guidance teacher at any time and there were regular planned meetings to monitor his progress and to establish any difficulties which required to be addressed.

School health services

- Staff from the Young People's Mental Health Services were involved directly in therapeutic sessions with Steven and his family and supported their EA teacher colleagues in group-work and in home and school liaison
- The psychiatrist working with Steven and his family attended the termly reviews organised by the EA during the year that Steven attended the Psychiatric Unit.

Family

- Steven's parents supported all arrangements made but were still experiencing their own internal stresses and only gradually became more positive and participative in review meetings

- Steven's mother has suggested that she might undertake learning some French at home with Steven, using a television video series. Steven has not yet committed himself on this. Homework from school is well-supported.

Although Steven continues to be a troubled youngster who may well need long-term support, he is attending school and is achieving quite well, some of his obsessional behaviours have receded and the family stress level has been reduced. Three temporary set-backs were swiftly sorted out by the liaison teacher and Guidance teacher working with Steven and his parents, restoring some of the support 'scaffolding' until Steven was ready to progress again. Steven recently suggested that he would like to go back to Art classes rather than continue working on his own.

Susan (17)

Susan is in S5 in a large urban high school in a disadvantaged area. She lives near the school with her mother and three younger siblings. She was seen by school staff as a girl with low self-esteem and has had some difficulties with her school work, achieving no Standard Grades because her course work was not completed. The school had originally attributed this to 'unexplained' frequent absences over several years.

The educational welfare officer (EWO) attached to the school and Susan's guidance teacher worked closely with the family and Susan's mother eventually explained that Susan had 'internal problems' which meant that she was often not well enough or too embarrassed to go to school. Susan hated using the school toilets because of the lack of privacy.

The problems were eventually diagnosed as Crohn's disease, a serious chronic inflammation of the bowel. Susan would be unable to attend school regularly, even with the understanding and support now offered to her, and required intermittent hospitalisation - in an adult ward. She would have difficulty achieving her educational potential. The education authority, school health services and Susan herself planned a flexible package of support that included developing and implementing an Individualised Educational Programme and an Individual Healthcare Plan.

Additional in-puts by the key partners:

Education Authority

- Agreed to Susan's continuing education outwith school although she was beyond statutory schooling entitlement.
- Ensured that the EWO continued his supportive contact with the family.
- Paid for Susan to use a taxi to go to and from school when she felt unwell but able to go to school, even though she lived nearby. This was agreed even for very short periods of time.
- One of the outreach teachers who taught her in hospital worked three sessions weekly in the school alongside school Support Base staff to help Susan. This teacher also delivered some packaged work to her home when she was absent but did not undertake teaching.

The school:

- Support for Susan was channelled through its Support Base which is attended by pupils voluntarily for a range of reasons, for example, illness, behavioural or relationship difficulties, bereavement and anxiety. There is liaison between Base staff and subject teachers to ensure that class work is done in the Base and a return to timetabled classes planned for as soon as appropriate.
- Susan had ready access to her guidance teacher and there were regular planned meetings to review her progress and needs.
- Verbal bullying and rumours which had frightened Susan were dealt with firmly through established 'no blame' procedures.
- Susan was allowed to have access to the private toilet off the Medical Room and subject teachers were briefed about Susan's condition so that she could sit near the door and leave the room without first seeking permission.
- It was agreed that Susan could attend school as and when she was able to get there, in her timetabled classes or in the Base, depending on how well she was. When well enough, she stayed on for the homework club to help her make up lost ground.
- A modular programme of work offered Susan some vocational prospects. Base and learning support staff made special arrangements for assessment (individual room to allow for going to toilet, rest time if needed, some assessment of course work undertaken in hospital).
- Susan - at her own request - had both vocational/further educational advice from the schools/education authority's specialist careers service and personal counselling.
- She was allowed to use the Base to meet her friends, and to have breaks and lunch there if she was not well enough to go out. On the occasions when she was too ill at home to come into school at all, the Base staff and her friends maintained social contact by phone. They also visited her in hospital and sent cards.
- The school continued to send Susan's mother progress reports as usual with the Base staff reinforcing this with phone calls.

School health services

- The school medical officer (SMO) liaised with the consultant and ward charge nurse in Susan's (adult) hospital, arranging for the Outreach Teaching staff to work with Susan in a side room of the ward when she was an in-patient.
- The SMO helped Susan to monitor her Individual Health Plan and to become self-managing in her healthcare regime in school and at home.
- The SMO also helped Susan join a local Crohn's Disease support group.

Family

- Susan's home, despite intensive negotiation, was not sufficiently organised to allow effective home teaching. However, Susan's mother continued to accept visits from the EWO, gave Susan work packages delivered to the door by the visiting teacher and spoke readily to the Base staff by phone.

Susan was able to achieve some modular qualifications and enrolled for a part-time office technology course at FE College, referring herself to the College support staff. She was able to negotiate this for herself.

Recommended reading and other resources

- Brown, E. (1999) *Loss, Change and Grief: An Educational Perspective*. London: David Fulton Publishers.
- Closs, A. (2000) *The Education of Children with Medical Conditions*. London: David Fulton Publishers.
- Closs, A. and Burnett, A. (1995) 'Education for children with a poor prognosis: reflections on parental wishes and on an appropriate curriculum', *Child: Care, Health and Development* 21(6), 387-394.
- Irvine, S. (1997) *A Guide to Child Health in the Primary School*. Edinburgh: Health Education Board Scotland.
- Larcombe, I. (1995) *Reintegration to School after Hospital Treatment*. Aldershot: Avebury.
- Phillips, K. (1996) *What Do we Tell the Children? Books to Use with Children Affected by Illness and Bereavement*. Edinburgh: PARC, Dept of Child Life and Health, 20 Sylvan Place, Edinburgh EH9 1UW.
- Scottish Office Education and Industry Department (1999) *Helping Hands: Guidelines for Staff who provide Intimate Care for Children and Young People with Disabilities*. Edinburgh: The Scottish Executive.
- Sharp, S. and Cowie, H. (1998) *Counselling and Supporting Children in Distress*. London: Sage
- Yule, W. and Gould, A. (1993) *Wise Before the Event*. London: Gulbenkian Foundation.

Scent Network - This free UK e-mail network allows teachers working with children at home or in hospital to network and to propagate good ideas and software for teaching purposes. The procedure for joining the Network is as follows: send an email, without a subject, to majordomo@ngsl.gov.uk with the following two word message only: subscribe scent

Contact-a-Family (CaF) is concerned with children with special educational needs within the contexts of their families. It has a special interest in families of children with rare conditions. It aims to reduce the fear and isolation of families (and professionals) and to develop their knowledge and empowerment. They maintain a directory of conditions and linked medical and support networks. It may be purchased in ring binder form and is also available on the CaF Website, www.cafamily.org.uk

The office in Scotland is at Norton Park, 57 Albion Road, Edinburgh EH7 5QY, Tel. 0131 475 2608, e-mail Scotland@cafamily.org.uk.

The Mental Health Foundation website www.mentalhealth.org.uk has some information on peer support schemes for vulnerable young people.

YoungMinds is a national charity committed to improving the mental health of all children and young people. It publishes a magazine, has a range of leaflets on specific issues and policy matters and a telephone information service for parents, carers and professionals. Address: 102 Clerkenwell Road, London EC1M 5SA, Tel. 020 7336 8445. Helpline Tel. 0800 018 2138 e-mail: enquiries@youngminds.org.uk Website: www.youngminds.org.uk

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