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John Young & Kerstie Phillips
HIV/AIDS: Sharing the voice of young people

As teachers, how often do we actively consult our pupils on the content of our educational programmes? Not too often, we suspect. With HIV/AIDS, a sensitive topic dealing with sexuality, fear, prejudice and death, we feel that it is essential to consult and listen to the voice of young people. We hope in this article to explore how we as teachers have attempted to listen to young people and to develop an HIV project that takes note of that voice.

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The Unit 2 birthday and a farewell

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"I thought the workshop was successful because we were able to talk openly and ask questions that we wanted to know, rather than being lectured to."

One of the responses of Lothian Regional Council was to set up an education team consisting of teachers seconded from their present positions to the Lothian Region Education Department Advisory Service to develop and implement a comprehensive HIV/AIDS education programme for all young people in the primary and secondary sectors. Over the past five years, considerable effort has been made to provide schools with appropriate teaching resources so that this broad HIV/AIDS programme can be implemented.

Sharing the task
As secondary school teachers, with many years of experience working with pupils, we have a crucial role to play in disseminating information and actively encouraging debate about HIV and AIDS throughout the curriculum. Our programme, we would argue, is a development of the work carried out by teachers involved in personal and social education programmes throughout the school years and cannot in any way replace the necessity for long-term spiral curricular work developing self-esteem, negotiating skills, assertiveness and knowledge about human rela-
An opportunity for young people to talk openly and in confidence about HIV.

HIV/AIDS comes very near the top of the list of priorities in their education.

Choosing the group leaders

But which adults can pupils talk with? Our experience from listening to young people is that they should have the following qualities:

- They must not give the impression that they are 'controlling' the exercise.
- They must be knowledgeable and indeed be perceived as 'experts' in the field of HIV/AIDS.
- They must be comfortable in talking about sexuality.
- They must be non-intrusive and be able to encourage the members of a group to speak openly.
- They must be able to accept young people's views and not try to impose their own or someone else's value system.

At present, we employ about 20 trained facilitators on a sessional basis. These are people experienced in working with young people in a variety of settings. They are also people who are committed to working in the field of HIV/AIDS. They often work in other settings relevant to this topic, such as the Brook Advisory Service, Scottish AIDS Monitor, Milestone House (AIDS hospice), youth centres and drug agencies. Like other people in our community, many of our facilitators have been personally affected by HIV and AIDS.

As they often have other work commitments, the pool has to be large enough for us to be able to supply the numbers needed — sometimes up to 12 at a time, and four sessional per week. The sessional workers need to be able to work during normal working hours, and often at considerable distances from home.

Talking and listening

In the agenda-setting exercise that follows, the group is asked to split into pairs to write down the questions they want the group to discuss or the facilitator to answer. We make it clear that they can ask any question they want to do with HIV and AIDS in the broad context of human behaviour. Often, a variety of questions comes out of this exercise. These can be questions about drug behaviour, mythology concerning HIV/AIDS, sexual practices, current statistics, hopes of a cure, what it feels like to have AIDS, and so on. The facilitator then uses these questions to bring the group into a debate, adding the information which is appropriate. This leads on to discussion about how the facts affect lifestyle now and in the future, about choices, friendships, love and taking individual responsibility for our own health.

We believe that when young people start to touch each other's emotions we can get beyond what is merely factual information. They can often project the information into possible scenarios and start to discuss the emotional press-
It is not the end of the world when you are told that you are HIV+. The session was very successful because it was the first time my friends in our group were able to talk honestly about sex. The most interesting part was taking in the group where we concentrated all the embarrassing issues I would normally avoid. It changed my views and made me more aware.

Living with HIV

Our morning conference ends with a plenary session addressed by an experienced HIV+ speaker. The presentation is aimed at emphasizing that it is possible to live positively with HIV; that it is an infection worth avoiding but it is not the end of the world when you are told you have become infected. In Lothian we are constantly aware that in any school you visit there are pupils who have a relative or family friend who is HIV+, and that some of our pupils themselves may become infected.

This does not mean talking about the disease in general. The speaker talks about a close friend who was infected by the terminal period of his infection with AIDS. It is about pain, sadness and despair, but it is also balanced with an account of shared joy and companionship at the end. It is principally a talk about taking control of one's life and using the opportunities that all life affords.

This is often the first time that pupils have met someone who is talking openly about being infected with HIV and who is courageous enough to speak of personal feelings of fear of death, rage, love and acceptance. The pupils are then encouraged to ask questions. The impact is profound.

John Young is a development and training officer responsible for HIV/AIDS education in all of Lothian's secondary schools. Kerstin Phillips is a development officer responsible for HIV/AIDS education in secondary and special schools in Lothian. Further information about this work may be obtained by telephoning the authors (031 469 5855).

Problems and solutions

There have undoubtedly been difficulties over the last few years in developing this programme. We could never have foreseen the stresses that we personally face in dealing with HIV/AIDS. If we are being honest, we have had to face up to our own fears about death and dying while working closely with the HIV+ speakers, who have become personal friends. To deal with this we have had to share our vulnerabilities, sometimes our colleagues do not usually admit that they are expected to be in control all the time. We have had to support ouressional colleagues through similar experiences.

Many people involved in HIV education are working in isolation. We are concerned about this. It has been possible to develop our work because of the mutual support gained by working as a team. We have found it essential to bounce ideas off colleagues and to develop our ideas with them.

In the past we had to work on short-term secondments, making long-term planning impossible. Since August 1993, a permanent team of teachers has been established. This will permit continuity of work and long-term planning. We feel that the team has to be led by experienced teachers who understand, because of their long personal experience, that the demands faced by teaching staff are often stressed by their normal workload. We also feel that to do this work well, we need to be in constant contact with young people of different ages so that we hear the issues they are thinking of and talking about.

As we plan for the future, we must reflect upon our experiences in developing the programme so far. We need to take account of where we are in relation to our epidemic of HIV. As we approach the end of this decade, considerable numbers of young people will become directly affected by AIDS. At the time of writing (November 1993) it is estimated that 500 children and young people will be directly affected by AIDS, and that many will be orphaned. Our programme will need to take cognizance of that fact.

We have tried to explain in detail our rationale for working in this way. We hope that this article will stimulate those dedicated to working on HIV/AIDS with teenagers to consider our model as one of way of engaging young people. We recognize that this work has been possible only because of the response to HIV/AIDS in our community. Our teenagers and their parents know that they have to 'Take Care With Sex'. They read that massage every day as part of a Lothian Health-sponsored publicity campaign on our public buses. The community in Lothian knows that we have an HIV/AIDS problem, and that the infection is found within the heterosexual population. Unlike others, we no longer have to face reluctance or downright opposition to incorporating HIV education in the school curriculum.

There are, however, bridges to be built. We have not yet been able to take this programme into the Lothian Regional Catholic schools. We do not underestimate the difficulties that some community groups dealing with cultural and religious traditions face in opening up issues around HIV. We seek dialogue with community leaders in order to develop ways of working that are acceptable to them as well as responding to the needs of young people.

We also need to become more experienced in dealing sensitively with pupils that have been sexually abused; those who are in the process of coming to terms with a diagnosis of HIV, and with whom expression of sexuality is a frightening prospect; and those who are disaffected with school and may engage in high-risk behaviour. There is clearly much work to be done.

We continue in the belief that young people are valuable and that if we are really serious about facing up to the task of helping them to make informed decisions about their lives, we must always listen and be prepared to act upon what they say.

YOUNG PEOPLE

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