

"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."

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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.

But first, some background. In 1983, a massive upsurge of HIV infection spread amongst opiate injectors in Edinburgh. Most of them were young and predominantly of heterosexual orientation, living in some of the disadvantaged housing estates. Some of them were pupils in our classes. A decade later, HIV infection has spread out into the general heterosexual population, so that by the end of September 1993 1031 people in Lothian had tested positive for HIV. Given that Lothian has only 14% of Scotland's population but 51% of the country's known people living with HIV, it was clear that we had, and continue to have, the potential for considerable spread amongst the whole population.

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 know that class teachers 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.

tionships.

However, when it comes to working with young people on the sensitive and personal issues around sexual lifestyles and drugs, we feel that in a classroom setting the well-defined boundaries between class teacher and pupil can act as an inhibiting factor. For the work described in this article to be successful, there have to be different boundaries.

In 1990, as part of this comprehensive programme of HIV/AIDS education, our team set up a unique project targeted at all pupils in our secondary schools aged 15–16. The project's main aim was to try to establish an opportunity in the formal school setting for young people to talk openly and in confidence about HIV in the context of their lifestyle. We wanted to facilitate small-group discussion where friends could start to talk with each other about the possible impact of HIV in their own lives, now and in the future, in the presence of a knowledgeable and skilled adult.

The target groups

With limited resources in terms of staffing and money, we chose to target pupils aged 15–16. This has brought us criticism, mainly from pupils and staff who say that the project has come too late. We justify targeting this age range for the following reasons.

- This age group has been through puberty, so are able to relate personally to issues around HIV and sexual health.
- When we look at the cumulative HIV figures from Scotland, it is obvious that nearly 40% of those that have tested HIV positive became infected between the ages of 15 and 24.
- This is a critical period in a young person's life, when change, with all its excitement and activity, is on the agenda. Leaving school, seeking employment or further education, setting up in a flat, coming to terms with sexual orientation, living on the street, new relationships — it is not surprising that HIV infection is more likely when young people are struggling to put all these life experiences together.

Working in the formal school setting is not easy. Bustling noise, period bells and inappropriate classroom space do not provide an ideal atmosphere for sensitive small-group work. Trying to persuade schools to release senior

pupils in their main examination year for a whole morning to look at HIV in the context of sexual health may not appear to be a priority. Head teachers can be anxious about the content and delivery of the programme; principal subject teachers have deadlines to meet and courses to complete; class teachers can be resentful about their class base being usurped for the morning, and so on.

However, ask young people to list priorities in their education, and you are likely to find that HIV/AIDS comes very near to the top of the list. Bearing in mind that teenagers spend a lot of time thinking about sex, being given the opportunity to talk openly about it and ask questions is — not surprisingly — popular.

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 sessions per week. The sessional workers need to be able to work during normal working hours, and often at considerable distances from home.

Preparatory work before the visit to the school is essential.

Responsible management requires that our sessional workers are regularly updated with current information about HIV and AIDS. We have to offer regular training and support sessions as well as create opportunities to rediscover our group dynamic, so that the loyalty of team members continues and a professional approach is maintained. We use this team to deliver, through workshops, a conference on HIV/AIDS.

In the last two years we have worked directly with almost all S5 (pupils aged 15–16) in Lothian schools — about 8,000 pupils and a total of 120 conferences. A measure of the success of our work has been that schools now book the team well in advance.

Planning the visit

We know that preparatory work before the visit to the school is essential. Some months before the actual team visit, one of us visits the school to meet the teacher responsible for personal and social education and to plan the work. This involves deciding on a date that will cause the least disruption to the school, working out the accommodation needed for the different parts of the programme, and, most importantly, reassuring the management of the school that our team is capable of carrying out the conference in a professional manner.

A few weeks before the conference, one of us will meet the organising teacher and class representatives to explain the programme and ask their views on it. More often than not they agree to the programme in its entirety. As the pupils know the friendship patterns in the year group, we ask them to organise the workshop groups before the conference. We ask them to make sure that each pupil has at least a few friends in the group. These are friendship groups of no more than 12, and can be mixed or of the same sex.

By giving young people some ownership of the programme, something that does not usually happen, word spreads that this conference may actually be exciting. We come into school to work with pupils who are willing to suspend judgment on us and the topic, and thus many anticipate the conference positively.

Objectives and ground rules

The conference programme lasts for 3½ hours, and, if possible, we work in the mornings when pupils are more alert. There are a number of objectives to be achieved:

- To try to create an atmosphere in which young people can talk honestly, whether they are sexually active or not, about sexual behaviour.
- To check that the factual information about HIV that the young people bring to the group is accurate.
- To encourage pupils to perceive the relevance of their factual knowledge to their own lifestyle, now and in the near future. (Knowledge of facts is not sufficient if young people are going to develop strategies to protect themselves against HIV.)
- To challenge myths and prejudices about HIV and AIDS.

We establish two ground rules at the beginning, which is crucial to the work. The first is confidentiality within the group. Secondly, we say that we are going to explore issues around sexual behaviour that some people might find embarrassing and difficult to talk about, and that it is therefore acceptable to be a passive participant. The facilitator must try, in a very short period of time, to establish a friendly, conducive atmosphere so that discussion can take place. This is achieved by using an ice-breaking exercise.

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 factual information where 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-

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ures in relationships. Sometimes this is done through role-play using a written scenario, or else it follows naturally from the discussion following one of the questions brought up in the original agenda setting.

It is interesting to note the comments made by some of the pupils, taken from their written evaluation sheets:

- The session was very successful. I benefited most from the small-group discussion. The counsellor spoke with pupils 'on our level' — fairly informal — that was 'braw'.
- 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 talking in the group where we encountered 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 aim of this presentation is to emphasise 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 that you have become infected. In Lothian we are constantly aware that in any school we 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 talk does touch on endings. The speaker talks about nursing a close friend through the terminal period of his infection with AIDS. It is about pain, sadness and despair, but is also balanced with an account of shared joy and companionship to 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.

- I thought the most interesting part was when the whole fifth year was talked to by the guy who was HIV+. I don't think it really hit me how serious HIV is until I

listened and saw the guy in the flesh. I thought he was extremely brave and I admire him for his honesty.

- HIV and AIDS seemed all very far away but when Iain spoke to us it seemed real. It was the first time that I had knowingly come into contact with an HIV+ person and this dispelled all myths about 'them' being any different from the ordinary person in the street.
- Meeting the man with HIV was very moving. That made me realise what it was all about.

Before we disperse, the pupils are given the AVERT booklet *AIDS and Young People*, and asked to take it away and talk with parents and friends about the issues raised. There is also an information sheet on 'Sexual Health Services for Young People' which gives the telephone numbers and addresses of a variety of statutory and voluntary agencies, local and national, so that pupils can follow up any personal concerns raised during the conference.

Can we evaluate?

How can we evaluate the impact of this conference programme? We have an indicator of the success of the programme from the evaluation sheets filled in anonymously about a week after the conference and returned to us. They have been overwhelmingly positive. This gives us an opportunity to reflect on what we are doing, to plan ahead and modify the work in response to the suggestions from pupils.

It is difficult to evaluate in the long term the success of this way of working, as many of these young people will shortly move away from their original community. We wonder how one would measure the impact of our programme. There could be any number of influences affecting a young person's willingness to practise safer sex. Consider the impact of a friend becoming HIV+, or the realisation that one has been exposed to risk and needs to face up to one's own vulnerability and apparent irrational behaviour.

We believe that this model of working with small friendship groups creates a context within which young people can explore their feelings not only about the sensitive issues surrounding HIV/AIDS but also about crucial times in the future when informed decisions must be taken about relationships.

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, something teachers do not usually admit since they are expected to be in control all the time. We have had to support our sessional workers 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, the demands faced by teaching staff who 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.

The future

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 in Lothian are in relation to our epidemic of HIV. As we approach the end of this decade, considerable numbers of young people will be 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 way of engaging young people. We rec-

This work has been possible only because of the response to HIV/AIDS in our community.

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ognise 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 message 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 Region 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 out' as gay; those teenagers for whom expression of their 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.

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