

# **Listening to Children and Young People affected by Parental HIV**

Helen Kay

## **extract**

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## **2. Methods & Techniques of Data Collection**

### ***2.1 Sample***

From available statistics (SCIEH, 1999; Inglis & Morton, 1996) we knew that patients with HIV lived mainly in Dundee, Edinburgh and Glasgow: therefore it was agreed that we would try to make contact with children affected by parental HIV in these areas. As there is no obvious sampling frame that can be used, we started by listing people who might be able to provide a means of contact with affected families – health professionals who were treating patients with HIV, mainstream social workers working with families where parents had HIV and voluntary organisations providing services to people with HIV.

We found that none of the medical consultants were able to provide contact with families affected by HIV; initially because many consultants did not know if their patients had children. Later, consultants and nursing professionals were able to tell us that the majority of their patients had not told their children that they were suffering from HIV and therefore these parents did not want their children to participate in the project.

We also found that mainstream social workers were unable to provide contacts; although some knew several families affected by HIV, HIV was not the issue that had brought the families to ask for social work help nor was it the focus of their work, and therefore social workers felt that to bring up that issue would be an intrusion into family privacy. Some voluntary organisations providing services for adults with HIV offered to assist the research team in making contact but they found that those who were parents had not informed the children of their HIV status. Our only successful method of making contact with families affected by HIV was through voluntary organisations which provided services specifically for families affected by HIV and where disclosure was an issue that was being tackled.

An issue in the initial research design was to ensure that the sample would be representative of the population of children affected by parental HIV. However it was not possible to obtain an updated estimate of the numbers of children and young people affected by parental HIV, or their characteristics; and because of the necessity of working through two groups of gate-keeping adults, the parents and the professionals, it proved even more difficult to make contact with children and young people affected by HIV than we expected (for further discussion see Cree et al, 2002 p50).

## *2.2 Technique*

One of our research goals was to involve children and young people in the design and planning of the research but in order to achieve this, we found that first we had to negotiate with the two groups of gatekeepers, professionals and parents – and they wanted to have an outline of how we planned to undertake the research before they would cooperate. So we made several basic decisions about the research design before we consulted the young people. But we were able to consult a group of affected children about the logo for the project and the design of the information leaflet.

We knew that we wanted to explore the children's experiences of living in a family affected by HIV from their perspective and within the context of their framework of everyday life. As we knew very little about the children affected by parental HIV or the likely variation in their circumstances, we decided that we could not construct a questionnaire which would adequately reflect their interests or their circumstances. We considered using vignettes as a basis for the discussion but decided that we might then lose information on how children and young people framed the routine of their own everyday experiences. We decided to use personal face-to-face interviews which would be as informal and child-led as possible, and would vary in length and design according to the age and stage and preoccupations of each participant. We designed a topic list to guide the interview conversation and adapted several simple games as tools to facilitate communication. The interview plan incorporated some writing, some drawing, a simple game for younger children, a set of topic cards for older children to choose, and a group of hand puppets.

These interview sessions were tape-recorded to capture the vibrancy of children's language. It is difficult to assess how much participants were constrained by the use of the tape recorder: they were certainly aware of it. (I discuss routines of consent below.) On one occasion when the recorder had been inadvertently placed in her line of vision, a young person asked for it to be moved, and we had a few children who wanted to listen to some of their tape at the 'end' of the interview.