‘I Want to be Like the Others’

Citation for published version:
Cree, V & Sidhva, D 2009, ‘I Want to be Like the Others’: : A Cross-Sector Needs Assessment of Children Infected and Affected by HIV in Scotland. Waverly Care.

Link:
Link to publication record in Edinburgh Research Explorer

Document Version:
Publisher final version (usually the publisher pdf)

‘I Want to be Like the Others’: A Cross-Sector Needs Assessment of Children Infected and Affected by HIV in Scotland

Funded by Elton John AIDS Foundation

By Viviene Cree and Dina Sidhva
The University of Edinburgh

September 2009

© Cree, V.E. and Sidhva, D. (2009) *'I Want to be Like the Others': A Cross-Sector Needs Assessment of Children Infected and Affected by HIV in Scotland*, Edinburgh: Waverley Care and The University of Edinburgh.

School of Social & Political Science
Chrystal Macmillan Building
15A George Square
Edinburgh EH8 9LD
0131 650 3927
www.socialwork.ed.ac.uk/

© Cree, V.E. and Sidhva, D. (2009) *'I Want to be Like the Others': A Cross-Sector Needs Assessment of Children Infected and Affected by HIV in Scotland*, Edinburgh: Waverley Care and The University of Edinburgh.

(Further copies of report and executive summary are available from www.waverleycare.org/)

© Cree, V.E. and Sidhva, D. (2009) *'I Want to be Like the Others': A Cross-Sector Needs Assessment of Children Infected and Affected by HIV in Scotland*, Edinburgh: Waverley Care and The University of Edinburgh.

Contents

© Cree, V.E. and Sidhva, D. (2009) *'I Want to be Like the Others': A Cross-Sector Needs Assessment of Children Infected and Affected by HIV in Scotland*, Edinburgh: Waverley Care and The University of Edinburgh.

Acknowledgements

We would like to thank the members of our Steering Group without whom this study would not have been possible. Special thanks go to the following people who also contributed to the study in significant ways: Martha Baillie, Anne Cameron, Anne Chiswick, Glenn Codere, Brenda Colligan, Aileen Davies, Peter Davies, Dr Conor Doherty, Francis Emmerson, Babs Evans, Nichola Frith, Linda Hutton, Roger Irwin, David Johnson, Helen Kay, Roy Kilpatrick, Alison Lord, Dr Gordon McKenna, Janet Masters, Dr Jacqueline Mok, Sarah Morton, Neil Munro, Betty Offerman, Jean Petrie, Jacqui Pollock, Eunice Sinyemu, Neil Squires, Ailsa Spindler, Maureen Thompson, Rachel Thompson, Margaret Totten, Lynne Williamson, Fiona Jane Wright, Mildred Zimunya. Last but by no means least, thanks must go to all the children, parents and carers who gave us their time and insights so generously. We have not been able to name them in the report because of the need for confidentiality, but it is their stories that this report seeks to tell.

Steering group members

David Johnson (Chair)	Waverley Care
Babs Evans	Elton John AIDS Foundation
Roy Kilpatrick	HIV Scotland
Jacqueline Mok	Royal Hospital for Sick Children, Edinburgh
Jacqui Pollock	HIV-AIDS Carers & Family Service Provider, Scotland
Ailsa Spindler	Terrence Higgins Trust, Scotland

Glossary of terms used in this report

AIDS	Acquired Immunodeficiency Syndrome
ART/ARVs	Anti Retroviral Therapy/ Antiretroviral drugs(combination of drugs of different classes to inhibit viral replication)
BHIVA	British Human Immunodeficiency Virus Association
CD4	Cluster of Differentiation 4 (a glycoprotein which is important in assessing the immune system of people with HIV)
ECS	European Collaborative Study
GUM	Genitourinary medicine
HAART	Highly Active Anti Retroviral Therapy
HIV	Human Immunodeficiency Virus
HPA	Health Protection Agency
HPS	Health Protection Scotland
ICH	Institute of Child Health
NHS	National Health Service
NSHPC	National Study of HIV in Pregnancy and Childhood
SCIEH	Scottish Centre for Infection and Environmental Health

© Cree, V.E. and Sidhva, D. (2009) *'I Want to be Like the Others': A Cross-Sector Needs Assessment of Children Infected and Affected by HIV in Scotland*, Edinburgh: Waverley Care and The University of Edinburgh.

Foreword

This publication is a timely reminder that, whatever stated aspirations we have for our children and young people to be the highest priority, some children remain invisible. The children infected and affected by HIV in Scotland can be described as such, yet I am confident their needs will not be ignored. My confidence comes from the clear presentation of the information and analysis in this report, and the stubborn dedication of the staff working with children in the HIV field.

The combination of the epidemiological survey and the qualitative study are important additions to our understanding of the changing prevalence and characteristics of HIV in Scotland. The issues and recommendations highlighted in the report are crucial to improving our response to needs of children and young people infected and affected by HIV. There is a clear resonance with the UN Convention on the Rights of the Child (UNCRC) and I am particularly impressed by the link to Article 12, which states that children have the right to say what they think should happen when adults making decisions that affect them, and to have their opinions taken into account.

As Children's Commissioner I am pleased that the voices and experiences of children and young people have been captured in the report as they are important influences to improving our services. And what I hear is a call for them to be treated like any other child, but for that to be complemented by an acknowledgement of their particular circumstances. For those of us who have worked with children there are no surprises here. What could be more normal than for us to treat all children and young people as individuals, special in their own right, regardless of their HIV or any other status? Yet the experiences from children and young people consistently remind us of the extraordinary stigma associated with HIV, challenging their basic human right to dignity in all aspects of their lives. They tell us that they need support, but that it has to be at a time and nature that suits their individual needs. Above all, the messages they convey, remind us that they are children who need fun and activities – just like all children. They are entitled to all of the rights of the UNCRC and we have a duty to listen and act on their message.

I am greatly encouraged that these messages will be heeded by the professionals already working in the field as the well-informed range of issues and recommendations demonstrates. As always, the real challenge is to have a wider understanding and adoption of these. The fact that they are informed by children and young people, make them all the more powerful.

I do hope that the key messages of the report are acted upon at all levels, and that we afford a higher profile for the needs, and most importantly, the realisation of the rights of these children and young people.

Tam Baillie, Scotland's Commissioner for Children and Young People

© Cree, V.E. and Sidhva, D. (2009) *'I Want to be Like the Others': A Cross-Sector Needs Assessment of Children Infected and Affected by HIV in Scotland*, Edinburgh: Waverley Care and The University of Edinburgh.

Executive Summary

This report outlines findings from a Cross-Sector Needs Assessment of children infected with, and affected by, HIV in a changed and changing Scotland. New treatments and better support for HIV positive women in pregnancy and childbirth have led to a dramatic decline in the number of deaths from HIV; at the same time, new reports of HIV are on the increase, particularly amongst those whose infections have been acquired overseas (HPS, 2008). The end-result is that more people are living with HIV today, and many more are predicted to do so in the future. And as more adults are living with HIV, so, inevitably, are more children.

The motivation behind this study was the desire of HIV agencies in Scotland to find out more about how HIV is impacting on children in Scotland today; and to develop a deeper understanding of the needs of children affected or infected by HIV. The aim of the Cross-Sector Needs Assessment was therefore to investigate children and HIV from different perspectives: from research and policy documents, from health and statistical services, from a range of practitioners, from parents and carers, and from children infected and affected by HIV. This was achieved through a methodology which encompassed three different strategies: a scoping study, an epidemiological survey, and a qualitative study.

Scoping study

The scoping study identified three different sources of evidence in relation to children and HIV.

- Searches uncovered a considerable body of research which explored epidemiological and psychological factors in relation to children infected with HIV. Notable examples include the European Collaborative Study, which began in 1987 and has continued to provide useful data on infected children ever since, and the Collaborative HIV Paediatric Study and National Study of HIV in Pregnancy and Childhood, which started some years later in 1996.
- There is also extensive 'grey' literature, including government reports, policy papers and agency documents which provides additional information about those infected with, and affected by, HIV, as well as the views of practitioners and those working in the field.
- The views and experiences of children affected by parental HIV have been investigated through a number of illuminative, though relatively small-scale,

research projects. Significant examples include the 'Listening to Children in Scotland' study, conducted between 1999 and 2002 (Cree *et al*, 2002; 2004a; 2004b; 2006; Kay *et al*, 2003; Tisdall *et al*, 2004; Wallace *et al*, 2006); and 'Afraid to Care', on children living with their families in supported housing in London (Lewis, 2001). Additionally, cross-country comparisons of young carers in developed and developing countries (Becker, 2007) and young carers in the context of HIV/AIDS (Evans and Becker, 2007 and 2009) offer further information.

Research on children and HIV demonstrates that, in spite of advances in improved prognosis and treatment, HIV remains a highly troubling and stigmatised illness which impacts negatively on the lives of both infected and affected children. Furthermore, a recent consensus report raises another area of concern, that is, that some 'affected' children may, as yet, be undiagnosed, but infected all the same. Although it may seem that the experiences of children in the UK pale into insignificance as set against the devastation caused by HIV in parts of the developing world,[1] this report demonstrates that the upset which HIV brings to young lives in the UK is real, and its effects cannot, and should not, be ignored.

The scoping study concludes that at a time when the focus of attention is increasingly on the targeted prevention of HIV, and when HIV itself is increasingly being treated as a 'manageable', long-term illness like any other, so the needs of children infected and affected by HIV may become sidelined. This is an area of major concern, not least because HIV, unlike any other serious illness or social issue, remains a secret, uniquely stigmatised and stigmatising condition.

Epidemiological Survey

Infected Children

Evidence from statistical sources and clinicians indicates that numbers of infected children in Scotland are low – between 35 and 47, depending on the method of data collection. Particular issues emerge:

- Thanks to the introduction of HIV testing for pregnant women and successful treatment before and after pregnancy, there have been no children born with HIV in Scotland since 2001.
- It is not known, however, what long-term adverse effects may arise for children of medication taken to prevent mother-to-child transmission of HIV.

- There are now two distinct groups of children infected with HIV in Scotland: younger children (born abroad) and British-born children who are older; born before routine testing and preventive treatment.
- There are special pressures on parts of Scotland in relation to HIV today, with NHS Greater Glasgow & Clyde and NHS Lothian treating the largest number of HIV infected people and young people.

Affected children

Reaching an accurate estimate of children affected by HIV is difficult, because there is no routine data collection. Using methods first employed by Inglis and Morton (1996), questionnaires were sent to key HIV agencies (statutory and voluntary) in Scotland. Overall, 13 agencies provided data about children and young people whom they knew to be affected by parental HIV, and this figure was used to extrapolate for Scotland as a whole. The total number of affected children in Scotland was found to be around 833. Again, mirroring the findings in relation to infected children, specific issues come to light:

- The total number of affected children in Scotland was estimated to be lower than in 1996: 833 as compared with 911 in 1996.
- There has been a shift in pressure on Health Board areas. Tayside today has many fewer affected children than in 1996, as does Lothian (though Lothian continues to have the second largest number of affected children in Scotland). Greater Glasgow & Clyde has many more affected children than in 1996.
- There has been a shift in the age distribution of children, with a much greater number of under-5s in both Lothian and Greater Glasgow & Clyde. There are also many more older teenagers in Greater Glasgow & Clyde, whilst the number in Tayside has fallen. Research suggests that the very young children affected by HIV are largely children of black African mothers, who (it is already known) are living with severe hardships, economically and socially, as well as with HIV (Crusaid/Waverley Care, 2007).
- Most affected children in this survey were not accessing any services in their own right; but were simply known to exist by the agency which was supporting their HIV-positive parent/s. Where services were provided, children made use of them; a small number of affected children were known across three or four agencies.

Qualitative Study

The study identified a range of stakeholders with knowledge and insight into the needs of children infected and affected by HIV in Scotland. Those included:

- Practitioners from health and voluntary sector HIV agencies
- Parents and carers
- Children and young people infected with HIV
- Children and young people affected by parental HIV

In total, 48 people contributed to the qualitative part of the study: 20 practitioners from voluntary sector HIV agencies and NHS services in Edinburgh, Glasgow, Dundee and Aberdeen, as well as 28 adults and children in Edinburgh and Glasgow. Of these, 16 were parents and carers, five were children and young people infected with HIV and seven were children and young people affected by parental HIV. Most interviews were with individuals or occasionally with two practitioners together. One group interview was also held in Glasgow with parents and carers.

Key findings from practitioners

- With the exception of health services, HIV agencies in Scotland are focused on adults; where services for children exist, these have to be accessed through adults first. Furthermore, targeted services for children infected with, and affected by, HIV are scarce across Scotland.
- All the agencies currently working with children and HIV would like to be able to do more for children. Additionally, two high profile children's charities (Barnardo's and Children in Scotland) which had been active in the field of children and HIV in the past are no longer involved in this area, because of difficulties in funding this work. Both would like to offer services again in the future.
- Agencies work a great deal with others in the field, and with external voluntary and statutory agencies. However, practitioners noted that inter-agency collaboration was made difficult by pressures on agencies, particularly health-care agencies. Concern for confidentiality may also impede collaboration: service users from one agency may not want to be referred to another for specialist support due to fear of stigma.
- Practitioners identified the importance of offering safe, non-threatening services to children infected and affected by HIV, particularly given the stigma which surrounds HIV.

- They also felt that more needs to be done across-the-board to highlight the issues faced by children in relation to HIV (e.g. in schools and in health boards, especially those with low numbers of infected adults).
- A few practitioners spoke about the differences between the needs of young people differing from those of younger children, and the need for a transitional service from paediatric to adult care.

Key findings from parents and carers

- Parents and carers were most concerned about how best to support their child, and a principal issue here was disclosure: how, when and what to tell their child and who else could and should be told what, and when. They asked for help to be able to discuss HIV more easily with their children
- Parents and carers spoke about the negative impact of stigma 'by association', and the fear this places on their children. The connection with drug misuse remains a prominent feature here.
- They were also all concerned about the lack of services for children infected and affected by HIV, as well as for HIV positive women. It was stressed that giving support to parents may also lead to improvements in children's lives.

Key findings from infected children and young people

- The infected children and young people were at pains to present themselves, their lives and HIV as 'normal'. This was in spite of their very troubled backgrounds and current hardships. Being 'normal' is a major preoccupation in adolescence; it is also, however, an indication of the wish to avoid stigma.
- For some children with HIV, medication is the one reminder that they have the virus; medication also makes them feel ill at times. Because of this, non-compliance to medication in teenage years is not unexpected. The children and young people displayed a very knowledgeable and mature approach to their illness, as well as more typically rebellious teenage attitudes at times.
- None of the children was able to talk about their HIV outside a very small, strictly defined zone of safety, for fear of prejudice or reprisal. One child spoke about being unable to talk even to the one person who knew about their HIV (the mother), because the child did not wish to upset her.
- The children and young people showed ambivalence towards support services. Some did not wish to be singled out for specialist services, because of the need

to see themselves as 'normal'. One young person felt that talking about her worries made things worse. All wanted opportunities to have fun and forget their worries, and sport played an important role here. But all also acknowledged that it was good to be able to talk to others in the same position as themselves.

- One youth highlighted the unsatisfactory nature of health provision for teenagers who do not feel comfortable in either children or adult services.

Key findings from affected children and young people

- It was clear from the interviews that parental HIV is something which affects children's lives over and above the difficulties and worries which are common-place in childhood and adolescence, and over and above any hardships which may also arise out of issues such as poverty, poor housing and insecure immigration status.
- In the same way as infected children, affected children live with fear and uncertainty, never sure when a parent will become ill or die, yet they want to be seen as 'normal' children living with 'normal' parents'.
- All the children could identify someone they could talk to: usually a parent, but also a teacher, youth worker, befriender and social worker were mentioned. But they were very aware of the dangers of disclosing a parent's HIV status.
- None of the affected children and young people in Glasgow was in touch with any support services; all those in Edinburgh were. Again, in common with infected children, they expressed caution about whether additional services would help. They said that support should be available to all children, but they also called for more specialised services so that they could be free to talk about HIV in a safe environment.

Conclusions

1) All children and young people affected by HIV (infected and affected children) are 'children in need' under the Children (Scotland) Act of 1995. They have special needs, physically, psychologically and socially. Yet they are barely mentioned in the Scottish Government's draft HIV Action Plan. Moreover, their needs are currently invisible in mainstream, universal, integrated children's services plans.
2) Children infected with and affected by HIV do not want to be singled out as different from other children. They want opportunities for education, fun and play like all children, but would also like the chance to meet others in the same

situation as themselves, so that they can receive information and support in a safe and secure environment.

3) Parents find it difficult to disclose their own HIV status to their children. They also find it difficult to tell their children that they are infected with HIV. Disclosure needs to be handled sensitively; it is not a single event, but is a gradual process which happens over time, and parents need expert help to support their children better.
4) Children infected with HIV are living longer. They have particular needs in terms of health-care and support once they reach teenage years as well as guidance on sex education and relationships.
5) The stigma which HIV carries remains extraordinarily high; no other terminal or chronic illness carries such stigma. The cost of this is high for individuals who carry the burden of shame and are unable to share their worries with others. It is also high for society, as those who are afraid to disclose their HIV status may put others at risk, both adults and children.
6) HIV in Scotland disproportionately affects families of black African origin who also experience high levels of poverty, discrimination and hardship. Stigma is known to be a particular concern for African people in Scotland, who have little alternative but to keep HIV a secret from others.
7) Lothian and Greater Glasgow and Clyde Health Board areas experience high levels of demand generally in relation to infected and affected children, and with particular pressure due to the rise in under-5s affected by HIV.
8) There are also small pockets of children affected by HIV throughout Scotland.
9) There is currently little opportunity for collaboration across and within Scotland between agencies providing services for infected and affected children.
10) There is no routine collection of data in relation to children affected by HIV in Scotland. Moreover, some children may remain undiagnosed and significantly at risk. Government and NHS agencies collect data on infected children in different ways, using different ages as the dividing line between children and adults.

Recommendations

1) Scottish Government should re-examine its HIV Action Plan and/or related guidance and implementation to take account of the experiences of infected and affected children.

2) Local Authorities should, in turn, be asked to give special consideration to children infected with, and affected by, HIV and ensure their inclusion in their integrated children's plans.
3) Financial support should be made available (from central and local government) to voluntary and other agencies to allow them to maintain and extend their specialist provision to children and young people infected and affected by HIV.
4) HIV agencies should be funded to provide HIV training and support to practitioners in all agencies which work with parents and infected and affected children.
5) NHS Boards should re-examine the provision they currently have for teenagers with HIV, and explore whether an adolescent clinic should be provided in their area.
6) There should be a new public health education campaign on HIV. This should stress the reality that HIV can affect anyone, straight or gay; white or black; adult or child.
7) More targeted support should be made available to all black African families in Scotland (not only to those where there is known to be HIV), through funding of voluntary and other agencies to carry out this work.
8) Additional funding should be made available to areas under greatest pressure from, e.g. dispersal programmes or increased incidence to support their work in this area; at the same time, training on the specific needs of these families living with HIV should be delivered to health visitors and children and young people's workers.
9) All Health Boards and statutory children's services should look to see whether more might be done to support children in communities where there are only small numbers of affected children.
10) A small sum should be set aside each year to enable one service provider (from a key voluntary HIV or children's agency) to bring agencies together and to act as a national coordinator and champion for HIV and children in Scotland. This could be spearheaded and managed by Scotland's Commissioner for Children and Young People (SCCYP).
11) All adults should be asked in a sensitive and supportive way about their parental status (numbers and ages of children) when they are diagnosed with HIV and protocols for testing the children of HIV-positive parents must be worked out in collaboration with patients' and service users' groups

12) Government and NHS agencies should reconcile their differences in approaches to data collection in relation to infected children.

1. Introduction and Overview

1.1 Context and purpose

HIV in Scotland has changed and is changing. There has been a significant reduction in HIV-related deaths in recent years, thanks mainly to the success of antiretroviral treatments. But there has also been an increase in new reports of HIV: more new HIV cases were reported in 2007 than at any time since reporting began in 1981 (HPS, 2008). Some of the increase in new HIV cases has been attributed to policy changes in testing in GUM clinics, antenatal testing and recent guidance to clinicians to 'be alert to the circumstances in which it is appropriate to offer and recommend an HIV test' (Johnman, 2009). The increase is also, however, explained by the rise in reports of heterosexually-acquired infection of people from sub-Saharan Africa now resident in Scotland. Because people are living longer with HIV, and more new HIV cases are coming forward for treatment, the total number of patients attending HIV treatment and care services in Scotland has risen from 1,307 in 2000 to 2,674 in 2007, and this figure is predicted to rise still further in the years ahead (HPS, 2008).[1] Put simply, more people in Scotland are infected with, and affected by, HIV than at any time in the past, and more will be so in the future. And if more people are living with HIV, what implications does this have for children and young people in Scotland?

This research study arises out of a perceived gap in knowledge and understanding about children and young people infected with, and affected by, HIV in Scotland. Agencies and practitioners working in the field of HIV in Scotland identified that while much is known about adults and HIV in Scotland, there was little current information about infected and affected children, even at the simple level of numbers – how many children are there, and what are the issues that face them? The Elton John AIDS Foundation convened a meeting of 10 Scottish based HIV agencies in June 2008 where it was agreed that Waverley Care should apply to the Foundation, on

---

[1] Projections for Scotland developed by Health Protection Scotland (HPS) suggest that there could be between an increase of between 42% and 85% in the number of people attending HIV treatment and care services for CD4 monitoring by 2012 (based on 2006 figures and using three different modelling methods). This will mean an increase of between 150 and 350 persons per year. The biggest increase is expected to be in the NHS Greater Glasgow & Clyde and NHS Lothian board areas (HPS, 2008).

behalf of all the agencies, for funding to undertake a cross-sector needs assessment of children infected and affected by HIV in Scotland. Funding was received in August 2008 and a Steering Group was set up to oversee the project, consisting of representatives from Waverley Care, HIV Scotland, the Terrence Higgins Trust, HIV-AIDS Carers & Family Service Provider Scotland and NHS Lothian.

1.2 Scope

The initial grant application stated that the cross-sector needs assessment would compile up-to-date information on the numbers of children affected and infected by HIV in Scotland and find out about their needs and available services. It was believed that this information would be useful in a variety of ways, such as setting goals, developing action plans, allocating resources, developing effective programmes and policies, and determining the direction for services for children infected and affected by HIV.

In January 2009, the Steering Group commissioned two researchers with experience in carrying out research on HIV in Scotland (Professor Viviene Cree and Dr Dina Sidhva from the University of Edinburgh) to undertake the study between February and July 2009. It was acknowledged at this start that the aspirations of the project were ambitious, given the time-scale and resources available. Two courses of action were therefore agreed at the first meeting: that Steering Group members would play an active part in supporting the data collection; and that the researchers' main priority should be to speak directly to key stakeholders, that is, practitioners currently providing HIV services for adults and children, parents and carers, and children themselves.

1.3 Method

The Steering Group met on a regular basis throughout the period of the cross-sector needs assessment, and members played an active role in the shaping and implementation of the project's work. The needs assessment used three methods of data collection:

- A scoping study of literature and reports, focusing on findings from studies conducted in the last 10 years;

- An epidemiological survey of infected and affected children, to be based on published statistics on infected children and to replicate the methodology used in an earlier study of affected children in Scotland;
- Interviews with practitioners, parents, infected and affected children and young people.

Ethical approval was sought and granted by the University of Edinburgh's School of Social & Political Science Research Ethics Committee.

1.4 Structure

This report will begin with findings of a scoping study which examines what is known about children and HIV from research literature and information from government and voluntary agency sources, focusing on the last 10 years. It will then present and analyse data drawn from the quantitative surveys of infected and affected children, providing clarification about the scale and nature of the children touched by HIV in Scotland. This is followed by discussion and analysis of the qualitative aspects of the study: that is, the interviews with stakeholders. The report ends by identifying key issues and makes recommendations for taking these forward.

1.5 Terminology

Three points merit attention here. Firstly, the term 'children and young people' has been used throughout the report to refer to all those up to the age of 18 years, in line with the United Nations Convention on the Rights of the Child and legislation which concerns children in Scotland. This is not, however, the age used by Health Protection Scotland in its analysis, as will be discussed in Section 3.

Secondly, the terms 'infected' and 'affected' children and young people are used in the report in a particular way. The term 'infected children' is used to refer to all those children and young people who have been born to mothers with HIV infection and are themselves subsequently found to be infected with HIV. (Adults infected with HIV are often referred to as 'HIV positive', but this term is not accurate in the case of all children infected with HIV.[2]) We have used the term 'affected children' by way of contrast, to refer to children and young people who have a parent, carer or family member who is HIV positive, but are not infected with HIV themselves. This is, of course, an artificial distinction, because all infected children are also *affected* by HIV, because they too are likely to live in families where someone is infected with the virus. At the same time, some children who are thought to be 'uninfected' with HIV may, more accurately, be undiagnosed, as the recent BHIVA/CHIVA/BASHH consensus document (2009) makes clear (see Section 2.4.1).

Thirdly, it must be acknowledged that none of the terms ('infected', 'affected', 'HIV positive'), is value free; each carries its own meaning and signifier to self and others. Some of those who are HIV positive prefer to describe themselves as 'living with HIV' (Sidhva, 2004). Although this might have seemed to offer a helpful way forward, on reflection, this term was not adopted in case it led to a lack of clarity about whether or not an informant had HIV. In consequence, where appropriate, the less appealing, more medical terms, 'infected' and 'affected', have been used throughout the report, meanwhile recognising that HIV is not the only important aspect of an individual person's humanity.

---

[2] Adults who are infected with the virus are usually described as 'HIV positive' because they test positive for HIV antibody. Diagnosis of blood-borne infections in young children is complicated because the passage of maternal antibodies through the placenta means that all babies born to women with HIV are 'HIV positive'. The presence of antibodies in a child under 18 months therefore does not necessarily signify HIV infection in the child. In addition, there have been rare cases of infants who test negative for HIV antibody but are shown to be infected on PCR (polymerase chain reaction – a test which detects the presence of the virus itself in the blood). These cases occur when mothers have been infected in late pregnancy and consequently have not built up an antibody response to transfer maternal antibodies to the baby. Therefore, if maternal status is unknown in a child under 18 months, both an antibody test and PCR test for HIV need to be performed. For children over 18 months, HIV infection is identified with an antibody test, as is the case with adults. By this age the child will have lost maternal antibodies and therefore any antibody identified will signify that the child is infected. For the above reasons, clinicians have used the following classification to describe children born to mothers with HIV infection: Indeterminate: when a child is under follow-up and insufficient tests have been carried out for a diagnosis, or when a child born to a mother with HIV has never been tested; Infected with HIV: when the criteria are met for a diagnosis of infection, ie the detection of virus by PCR on 2 separate samples taken at different times; Uninfected: when all the appropriate HIV tests have been done and are found to be negative. (Information supplied by Dr Mok, NHS Lothian).

2. Scoping Study

2.1 Introduction

The purpose of the scoping study was to find out what information was already in the public domain about children and young people infected and affected by HIV. The focus was on recent literature and policy papers, for two main reasons, scholarly and pragmatic. Firstly, it was recognised that the context of HIV had changed, and so much of the previous body of research and knowledge may have had little relevance to today's situation. Secondly, with a short timescale and limited budget, it was agreed that a more extended review of literature was not feasible.

The scoping study will begin by examining research evidence in relation to children infected with HIV, before going on to explore what is known about affected children and young people. It will focus on recent UK studies which have been identified as having particular interest for this topic, but it will also mention, where thought to be pertinent, key studies from the United States. Research on the experiences of infected and affected children in the developing world has not been included in this literature review except where the research is part of a cross-national study. This is because the issues facing children and young people in countries without routine access to medical and health care (where infant mortality is high and life expectation low) are too different to be able to provide sufficient comparable evidence for a needs analysis of children with HIV in Scotland.[3]

2.2 Method

Searches of electronic citation and journal databases were undertaken, using the key words 'children', HIV' and 'UK', and covering the period from 1999 to 2009. A deliberate decision was made to examine both health and social science sources, hence the following databases were searched: ASSIA, Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (Cinahl Plus), Ingenta, International Bibliography of Social Sciences, JSTOR, Sociological Abstracts, Social Service Abstracts, Web of Knowledge. All potentially useful papers were read and their

---

[3] This view is supported by Wigersma, Singh and van der Boom (1998). See also Schafer (2005) writing more recently about children and uneven globality.

references were examined for other relevant papers. These were then followed up using the same criteria as above, and, where necessary, this led to further articles and papers. In addition, a web search was undertaken using Google and Google Scholar, throwing up a wider selection of 'grey' literature (including unpublished papers, government and voluntary agency reports, newspaper articles etc.) The formal search strategy was supported by a targeted examination of policy and statistical data identified by members of the Steering Group, and by following up specific suggestions made by informants over the process of the study.

The searches revealed a surprising scarcity of current research in the UK on children and HIV, most specifically on children affected by HIV. The focus of attention in research, policy and practice has been fairly consistently on those who are infected with the virus: gay men, intravenous drug-using adults, children with HIV, and, more recently, heterosexual adults. This conclusion is supported by the findings of a systematic review reported in the Cochrane Library in 2009 which states that there have been no studies of interventions for improving the psycho-social well-being of children affected by HIV. 'Available knowledge', the authors assert, 'consists of "lessons learned", child psychological theory and other related research in the adult population' (King *et al*, 2009). This is not to suggest, however, that there has been no research on children and HIV in the UK. On the contrary, a considerable body of research has explored epidemiological and psychological factors in relation to children infected with HIV. There is also extensive 'grey' literature which provides additional information as well as the views of practitioners and those working in the field. Most of the knowledge about affected children arises, as we will demonstrate, from a number of illuminative, though relatively small-scale, research projects which have explored the views and experiences of parents and children who are affected by parental HIV.

2.3 Children infected with HIV

2.3.1 Evidence from research and literature

One of the primary sources of knowledge on children infected with HIV for over 20 years has been the European Collaborative Study (ECS). This prospective cohort study began in 1987 with the objective of exploring issues relating to HIV infection in pregnancy and childhood across Europe. In its early years, the study was primarily concerned with tracing the impact of HIV infection on children, and sharing good practice in minimising vertical (mother to child) transmission of HIV.[4] More recently, it has turned its attention to new areas, as well as maintaining its original interest in pregnancy and childbirth. Writing in 2002, Thorne *et al* highlight the increase in numbers of perinatally infected children who now survive into adulthood; although this trend had been seen before the widespread use of highly active antiretroviral therapy (HAART), earlier and increasing use of HAART has allowed survival rates to improve further (Thorne *et al*, 2002). ECS publications from 2003 onwards demonstrate extensive research into the consequences of the use of HAART in pregnancy on infected and uninfected children, as well as examining a range of other issues, including possible gender, race and age differences, East-West differences across Europe, and the additional impact of co-infection (Hepatitis B or Hepatitis C) on pregnant women with HIV.

Research evidence from the Collaborative HIV Paediatric Study and National Study of HIV in Pregnancy and Childhood provide support for the epidemiological findings of the ECS. Gibb *et al* (2003) identify reductions of 80% in mortality and 50% in progression to AIDS amongst children perinatally infected with HIV in the UK and Ireland between 1997 and 2002. The authors also note an 80% decrease in hospital admission rates, although they go on to point out that the actual number of admissions decreased by only 25%, suggesting that the increasing number of HIV infected children requiring care has implications for services in the UK and Ireland. Judd *et al* (2006) similarly report on 10 years of paediatric care for children infected perinatally from 1996 to 2006. Judd *et al* state that the characteristics of this group of children have changed in recent years. Many children now present with HIV at an older age, and a large proportion are coming from abroad; this picture is also said to be found in other European countries. The numbers of children with new diagnoses and children receiving care continue to increase each year, and most new arrivals have not previously received antiretroviral treatment. Looking ahead, Judd *et al* predict that more children will be presenting who have been taking simple, fixed-dose combinations of generic drugs, and more children may have resistance to drugs.

---

[4] Historically, the vast majority of HIV infections in children were due to vertical (mother to child) transmission; children acquired HIV from their mothers during pregnancy, around the time of birth or through breast feeding.

More encouragingly, they note that initial decreases in overall rates of progression to AIDS and death after the introduction of HAART in 1997 have been sustained, with further decreases between 2002 and 2006. One of the repercussions of this is that hospital admission rates have continued to decline, and care has shifted from paediatric wards to outpatient clinics. There has also, they note, been an increase in geographical dispersal within the UK of families from countries where the prevalence of HIV is high. This observation has particular relevance to the current needs assessment of children and HIV in Scotland.

Recent research has explored the potentially negative, as well as positive, effects of HAART. Studies show that increased survival has brought additional implications for infected children and their families. Not only are infected children now living with a chronic childhood illness, but interventions to reduce the risk of mother-to-child transmission may have long-term adverse physical effects, in particular for uninfected children who were exposed to antiretroviral therapy in utero or early in life. Considerable research has been undertaken in recent years which seeks to assess the neurological and developmental effects of HAART (for example, ECS publications, Chiriboga *et al*, 2005; Foster *et al*, 2006; and Shanbhag *et al*, 2005). A recent survey confirms there is widespread unease amongst parents and health professionals about the impact of HAART. Almost all 180 respondents in Hankin *et al*'s (2007) survey said that they were anxious about the possible side-effects from exposure to HAART on children. This survey also asked parents and professionals about disclosure in relation to possible health risks; who were thought to be the best people to tell children about any health risks. Interestingly, almost three quarters of the parents surveyed (n=102) felt that *they* should be the ones to tell their children of any health risks, even when the child had grown up.

Parents' disquiet about who should tell their children about potential side-effects of HAART is, of course, wholly connected with their more general fear of telling them about HIV. Much of the early, practice-based literature on HIV focused on this, examining when and how parents should disclose their HIV status to their children (for example, McClory, 1996; Melvin, 1997). HIV was, and remains, a highly stigmatised and stimatising illness (c.f. Sontag, 1988; Malcolm *et al*, 1998; Green and Sobo, 2000; Carlisle, 2001; Cree *et al*, 2004b). An Ipsos MORI survey of young people aged between 14 and 25 found high levels of stigma (and, indeed, ignorance) around HIV. Although 84% of the British young people who took part in the survey said that they would remain friends with someone with HIV, 45% said they would not buy food from a shopkeeper who has HIV, and only 32% said they were willing to receive treatment from a doctor who has HIV (British Red Cross, 2007). A recent investigation of the needs of HIV infected 'looked after' children in the UK suggests that fear of rejection and loss of control over their diagnosis may lead many young people to decide against disclosing their HIV status to a partner or friend (Ely, 2008).

The European Collaborative Study identifies that whilst telling children about their HIV status has *always* been difficult for parents and for children, HAART may encourage parents to disclose at an earlier stage, in an attempt to improve adherence to treatment and in answer to questions from the child (Thorne *et al*, 2002). Non-compliance to medical treatment is known to be a common problem for children with chronic illness, particularly when they reach the potentially rebellious teenage years (c.f. Drotar, 2000; Logan *et al*, 2003). Ely's (2008) study of 'looked after' children suggests that adherence to medication is likely to be particularly poor during adolescence, as young people at this time make active choices about not wanting to take their medication, or they find it difficult to maintain the strict regime as their lifestyles become less predictable. Looking ahead, it is not clear whether earlier disclosure will lead to more or less psychological and psycho-social difficulties for children and young people. The evidence from other studies of disclosure, for example in relation to adoption in childhood, indicate that children who grow up knowing are less likely to experience extreme upset during adolescence (Triseliotis, 1973; Triseliotis, Shireman and Hundleby, 1997). It remains to be seen whether the same will be true of children with HIV.

We have touched here on another key area of research attention, that is, the effects of HIV on children's psychological and psycho-social functioning. It is known that childhood and adolescence is a time of major change in children's lives, psychologically, socially and emotionally (Rutter and Taylor, 2002). Moreover, it is widely documented that chronic illness is a risk factor for children's psychological adjustment (e.g. Eiser, 1990). The additional impact which HIV brings is less certain. An early study from the United States suggested that HIV-infected children were likely to have learning and language difficulties, indicating that they required special educational provision (Papola *et al*, 1994). Eight years later and in marked contrast, Thorne *et al* (2002) found that most of the children in their European cohort were in mainstream school, with only a small minority having special educational needs. They suggest that this may be explained by the very different social background of the children in each research project, [5] confirming that the socio-economic background in which HIV is located is critical to children's development. A longitudinal study of adaptive and cognitive functioning of children with HIV in the UK notes wide variability in children's functioning; some were functioning much better than others. But the study also uncovered a high prevalence of behavioural and attention difficulties in the children in the study (Gosling *et al*, 2004). The authors conclude that children infected with HIV contend with multiple risks for their development and psychological well-being. Such findings lead clinicians such as Melvin and Biggs (2007) to urge for more routine developmental monitoring of children infected with HIV. They assert that in order to plan service provision at both a specialist and local level better, there is a need for basic reporting of indices of developmental difficulties across HIV centres and services, including those where developmental screening may be limited.

Conway (2006a) picks up the issues facing children and young people in a handbook for service providers. She highlights that HIV-infected young people can suffer from a poor sense of self and body image. The virus may delay puberty and the drugs regimes can cause physical symptoms. She asserts that many HIV-infected young people struggle with this, because adolescence is also a time when awareness of body image is at its peak. These young people may struggle to maintain friendships and relationships, leaving them feeling isolated, introverted and different; periods of ill-health can also impact upon their confidence and result in time out of school, which then impacts on building and maintaining peer relationships. This rather discouraging picture emerges again in Melvin *et al*'s (2007) survey which set out to measure parents' and carers' concerns about behavioural or emotional difficulties in a group of HIV-infected school-age children attending London clinics. In this survey, 14% of the total (n=107) respondents said that their children had behavioural and emotional

---

[5] Research evidence in relation to adults' experiences confirms this. Anderson and Weatherburn (2004) conducted a large-scale survey of 1,821 people living with HIV in the UK. This identified that although some people with HIV were coping well with minimum unmet need (about a quarter of all respondents), the overall picture for the rest was dominated by personal, social and economic concerns.

difficulties in the 'abnormal' range; this figure is similar to that reported for other chronic childhood illnesses and slightly higher than in the general child population. This finding will be returned to later when we look at research on children affected by parental HIV.

The greater longevity of children with HIV has a further, inevitable, outcome which is explored in the research literature. As infected children move into adolescence, so matters relating to sexual health and sex education become pressing for both parents and children, and again this raises questions about who can, and should, be told (and not told) about a young person's HIV status. Thorne *et al* urge that service planners and providers 'need to take into account the changing needs of this growing group of young people living with HIV infection' (2002: 401). Prime *et al* (2004) pick this up in the *British Medical Journal*, where they describe the setting up of the first adolescent-only outpatient service in the UK. They contend that there is a need for dedicated adolescent services for three reasons: to minimise loss to follow-up; to encourage adherence to treatment with antiretrovirals; and to prevent transmission of drug resistant virus. They also call for the creation of comprehensive guidelines to ensure best practice, given that individual HIV units may see only a small number of adolescents. This echoes earlier results from Mok and Cooper's (1997) review of 120 case records of 86 HIV positive mothers and 120 children. Here they highlight the multiple needs of children living with maternal HIV infection, who, they argue, require dedicated resources and commitment from health, education, and social work agencies and the voluntary sector. They go on to propose the model of chronic illness as the standard of care for these children, with professionals from different agencies in the hospital and community working together. This is again a point of special interest for an assessment of current needs in Scotland.

Adolescence brings another implication for service providers. Research has consistently shown that the transition from paediatric to adult services can be problematic for young people, *whatever* their condition (Altschuler, 1997). Adolescents can be 'caught in the cleft between paediatrics and adults'; their experiences can be 'overlooked, underestimated or ignored' (Melvin, 1997). This issue is picked up more broadly in a recent Scottish review of health service provision for children and young people. One of the recommendations here is that 'The Scottish Executive Health Department, Regional Planning Groups and NHS

Boards should address the lack of provision of age sensitive services in Scotland especially for young people who find themselves caught in the existing fault line between paediatric and adult services' (Child Health Support Group, 2004: 34). This issue appears again in 2006, when researchers call for the creation of transition pathways to adolescent and adult services, alongside monitoring of the effects of prolonged exposure to both HIV and HAART (Judd *et al*, 2006).

There is one final area of concern which is of particular relevance to the Scottish context today. We have already noted that children infected with HIV are presenting at an older age, and that these children are largely from the developing world (Judd *et al,* 2006). Miller and Murray discuss the issues facing those from sub-Saharan Africa who attended the counselling, social care and HIV prevention service at an inner London hospital between 1985 and 1999. They point out that most African people presenting with HIV at their clinic were acutely ill at the time of diagnosis; they did not usually seek testing until a medical problem emerges. They had not seen themselves as at risk, and were afraid of the consequences of others (including their children) knowing about their condition, because HIV is so tied up with stigma and shame in their countries of origin. (These findings are replicated in studies by Chinouya-Mudari and O'Brien, 1999; Burns *et al*, 2001, and in Sethi *et al*, 2004, writing about patients from South Asia.) They were also, of course, facing additional pressures arising out of poverty, discrimination and their uncertain immigration status (e.g. Conway, 2006b; Crusaid/Waverley Care, 2007). Miller and Murray recommend that the best way forward for giving children the help they need is to support their parents and provide a relationship with them and their families over time. These findings re-emerge in more recent Scottish studies. In their enquiry into the experiences of Africans living in Edinburgh and Glasgow, Sinyemu and Baillie (2005) note that HIV is still a very 'silent' illness among African communities, and because of this, it is not unusual for an African person to receive an AIDS diagnosis when they were tested for the first time. Stigma and discrimination were found to be common-place for HIV positive Africans living in Scotland. In Cree's (2008) study in Glasgow, the focus was an evaluation of an HIV testing campaign targeted at adults. Here she learned that about the risks adults faced in sharing their diagnosis with others, even family members. She also discovered that many of the adults living with HIV in Glasgow are parents who have children at home in Africa, bringing additional distress for both children and parents alike.

2.3.2 Discussion

Although current epidemiological studies demonstrate that more children are living with HIV, the picture which emerges is not wholly encouraging. Children are living into adulthood with high levels of uncertainty, both about their illness and about their treatment; HAART is not a simple 'cure-all' for HIV. Moreover, it is found that the prognosis for children and young people who have come to the UK from developing countries is likely to be much less positive than for those born here. Evidence suggests that HIV remains a stigmatised and stigmatising illness. This affects parents' willingness to disclose HIV status, and affects children and young people as they grow up, impacting on all aspects of their lives. Research suggests that HIV can be accompanied by psychological and psycho-social difficulties in childhood, and that particular issues are likely to emerge in adolescence in relation to puberty, sexual health and sex education. For those coming to the UK from developing countries, HIV can carry additionally heavy burdens in relation to health and social issues. On a more positive note, there is clear evidence that some health and social care practitioners have shown long-standing commitment over a 20-year period to working with families affected by HIV. Likewise, voluntary organisations have come together to develop good practice in supporting children and their families, demonstrated in recent agency-based studies by Sinyemu and Baillie (2005), Miah (2006) and Cree (2008).

2.4 Children Affected with HIV

2.4.1 Evidence from research and literature

There has been little systematic study of affected children in the UK There is, however, a growing body of knowledge based on a series of agency reports and small-scale research projects conducted over the last 15 years. There is also relevant information from parallel research into children living with parental ill-health, including studies of young carers (for example, Aldridge and Becker, 1993; Cree, 2003; Hindle, 1998; Becker, 2007).

Publications from the early 1990s (for example, Melvin and Sherr, 1993) drew attention to the reality that HIV, perhaps unlike any other, is a family illness which has an adverse impact on all family members, not just on those who have the virus. The mid-1990s marked the beginnings of attempts to quantify the number of children affected by parental HIV. In a ground-breaking quantitative study, Imrie and Coombes (1995) estimated that over 4,000 children in the UK in 1993 had a parent or primary care-giver who was HIV positive. Of these, 626 were said to be living in Scotland, mainly in the three cities of Edinburgh, Glasgow and Dundee. The Scottish figure was projected to rise to 724 by 1996. The researchers acknowledged that their statistics were likely to be under-estimated, because they based their information-gathering only on children born to infected mothers, thus excluding all children born to an HIV positive father (and negative mother), and all those born to haemophiliacs infected with HIV. In a Scottish study published the following year, Inglis and Morton (1996) confirmed the view that it was essential to get accurate numbers of children affected by parental HIV, because, as they explained, children affected by HIV were 'children in need' under the Children (Scotland) Act 1995, and local authorities therefore had a duty to plan, provide and review services for them. Inglis and Morton proposed that Imrie and Coombes' Scottish estimate should be substantially higher. From their own investigation, they claimed that 741 affected children were living in Edinburgh, Dundee and Glasgow in 1996. From this, they estimated that there were 911 children affected by HIV in Scotland as a whole. Of the total number for the three cities, just over half (52%) were said to be of primary school age; 52% lived in Edinburgh; and 29% had experienced the death of a parent or carer. Inglis and Morton concluded that data on children affected by HIV should be centrally and regularly collected; one way to do this would be to ask infected adults to indicate their parental status. (This recommendation has never been put into practice, hence the current attempt to make an estimate of affected numbers in Scotland.)

Alongside the attempts to measure the scale of the problem, a number of reports published by voluntary agencies in the early to mid 1990s sought to draw public (and potential funders') attention to what they saw as the nature of the problem. Accounts written by professionals and practitioners working with children and families in the field of HIV, in hospital settings, drug projects, statutory social work services, and voluntary HIV day-centres and hospices were published (Alexander, 1995; Batty, 1993; Claxton and Harrison, 1991; Honigsbaum, 1991; Morton and Johnson, 1996). These publications (which often draw on research findings from the United States) suggested that children affected by HIV experienced a range of issues in their lives, including poverty and poor accommodation, social stigma and exclusion, discrimination and oppression, parental drug abuse, separation and loss and the ever-present fear of loss. One of the first examples of research undertaken in Scotland to consider the position of affected children was Mok and Cooper's (1997) investigation of 86 case-records of HIV positive mothers and their 120 children. This research detailed the experiences of both infected and affected children, and revealed considerable social and behavioural problems amongst uninfected (that is, affected) children. A key finding which was greeted with some surprise at the time the study was published was that the affected children in the sample were more likely than the infected children to be demonstrating problems at school. Some received special education because of behavioural problems; two were in special schools and one was educated at home, after being excluded from school because of disruptive and aggressive behaviour. In contrast, none of the HIV-infected children was in a special school, and all nine who received extra educational support did so because of learning or physical difficulty, not a behavioural problem (1997: 485).

The 'Listening to Children in Scotland' study took research with affected children in a new direction, by setting out to talk to children themselves about their experiences of living with a parent or carer with HIV (Cree *et al*, 2002; Cree *et al*, 2004a, 2004b, 2006; Kay *et al*, 2003; Tisdall *et al*, 2004; Wallace *et al*, 2006). This study had three elements: a postal survey of health and social work agencies in Scotland; interviews with 28 children and young people in Dundee, Edinburgh and Glasgow; and a postal survey of schools in the same cities. The study found little recognition from statutory agencies of the needs of affected children, whether in health, education or social work; the small number of support services which existed at this time for affected children were all provided by the voluntary sector (Tisdall *et al*, 2004). The researchers report considerable difficulty in accessing affected children in Scotland, because of the high levels of secrecy which surround HIV, for adults and children alike, and because they had taken a decision only to speak with children who were believed to know and understand about their parents' HIV status. In the event, the children and young people who took part in the study were found to be carrying a heavy burden in terms of stigma, family disruption and loss. Their greatest wish was to be seen as 'normal' children with 'normal' parents, but the lives which they described were far from 'normal' for most children, largely because of the stigma attached to HIV (Cree at al, 2004a). A picture emerges of several stages in parental illness, some of which recur: 'not really ill' (with few chronic symptoms); chronic conditions; diagnostic operations; episodes of acute infection and illness; steady and substantial deterioration; and death (Cree *et al*, 2006). These stages each had an impact on children in different (and often unpredictable) ways, at home, at school and in the wider community. For example, many children had missed significant parts of their schooling, either through staying at home with a parent or through tiredness in class. The focus on HIV prevention at school made them feel bad, reinforcing the message that only 'foolish' people who indulged in 'risky behaviour' were at risk of infection (Wallace *et al*, 2006). Only a few children felt able to talk to their parents about their fears or ask questions about the illness, and extended family members could find it too painful to discuss, even though they provided practical or emotional support to the parent (Kay *et al*, 2004). Most children had been told to keep HIV a 'family secret'. This meant that when they did manage to share their concerns with a friend, they risked being ostracised by their peers, and punished by their parent (Cree *et al*, 2006). The theme of stigma is picked up again in a recent research study on African American adolescents affected by HIV in the United States (Mason *et al*, 2009). This study reports that 'stigma by association' is a common experience for adolescents whose mothers have HIV. It is argued that interventions should 'empower teens to manage stigma situations, with mothers as their coaches and supports' (2009: 8).

At the same time as the 'Listening to Children in Scotland' study was conducted, another research project was carried out on affected and infected children and their parents living in supported housing in London (Lewis, 2001). Thirty children and young people (seven infected and 23 affected by HIV) took part in interviews, along with 35 parents. Most children (80%) were described as black African; only two were white British. Lewis notes that she had problems in accessing potential respondents. Some people were afraid to be interviewed, and, given their shared background of persecution in their country of origin, this was understandable. At other times, people who had agreed to be interviewed were ill and interviews had to be cancelled. Controversially, although all the children and young people gave their consent to take part in the study, not all had been told that their parent/s had HIV. Twenty-one were said to have only 'partial knowledge'; they had been told that a parent was ill, but not that this illness was HIV (2001: 13). In fact, it is stated that only three affected children had 'full knowledge' about parental HIV (2001: 27). One of the main findings to emerge from this study is that children 'know a lot more than parents sometimes would imagine' (2001: 30). Lewis concludes that 'knowing and not knowing' is a linear process rather than a fixed point in time.

The idea of 'knowing and not knowing' becomes even more perturbing when it is realised that some affected children may themselves be infected with HIV, but not know, because they have never been tested. The British HIV Association, Children's HIV Association and British Association for Sexual Health and HIV's consensus document, 'Don't Forget the Children' (2009) identifies the significant health risks for affected children who are undiagnosed. The Report recommends that all HIV services must have protocols and procedures in place for testing affected children and young people. Further, it recommends that information about children should be sought from all new patients or service users, and in the case of patients, they should be educated that existing protocols require that their children be tested, and that this is recorded on their confidential reports.

Studies of 'young carers' provide further illumination on the subject of affected children, although it must be acknowledged that the question of how to define a young carer is a contested one. Although there has been considerable research into young carers in the UK beginning with the work of Aldridge & Becker (1993), there is no agreed definition of a young carer, and organisations vary in the definition they adopt. In a study of the mental health needs of 61 young carers in Scotland, Cree (2003) found that the young carers who attended a community-based support project identified significant 'worries and problems' in relation to their well-being. Additionally, these were portrayed as over and above what might be thought to be 'normal' adolescent difficulties. More specifically, the number and extent of problems and worries identified by young carers were influenced greatly by the length of time they had been caring for a family member, and by the nature of their parent's illness or condition. So, for example, almost all categories of problems were found to increase according to length of time caring; meanwhile, caring for a parent with a stigmatised condition such as a drug or alcohol problem led to many more worries for young people than a more socially acceptable condition such as physical disability.

Cross-national research on young carers in the UK, Australia, the United States and Sub-Saharan Africa suggests that children's informal caring roles in both developing and developed countries can be located along a 'caregiving continuum' (Becker, 2007: 32). Becker concludes that there is a need in all countries for young carers to be recognised, identified, analysed and supported as a distinct group of 'vulnerable children' (2007: 43). More recently, Evans and Becker (2007 and 2009) have focused on children caring for a parent with HIV/AIDS, again cross-nationally, this time in the context of the UK and Tanzania. In this study, interviews were conducted with children, parents/relatives and professionals; in total, 22 children and young people took part in Tanzania and 11 in England (in Greater London, the South-East, East and West Midlands). The researchers argue that in spite of very different socio-economic, cultural and policy contexts, children caring for parents with HIV in Tanzania and the UK share experiences in terms of their everyday caring responsibilities, needs and aspirations. They find that caregiving has negative effects on children's emotional well-being, health, school attendance and academic performance, engagement in leisure and social activities with their peers, relationships with family members and others in the wider community. But all is not totally negative. Many children said they felt they had gained from their caring responsibilities in terms of closer relationships with their parent/relative with HIV, siblings and other family members. Moreover, they felt that they had become more independent, mature and had developed greater emotional resilience and knowledge and understanding about HIV/AIDS (2007: 3).

2.4.2 Discussion

This section began with an acknowledgement that there has been little systematic or large-scale investigation of affected children in the UK. Beyond attempts to estimate numbers of affected children in the mid 1990s, most studies have been qualitative, small-scale studies. Nevertheless, these studies provide extensive information about the difficulties at home, at school and in the community which HIV presents to children affected by HIV at home, at school and in the community. Whilst some studies have highlighted young carers within this, others draw attention to the very special nature of stigma around HIV, and the ways in which this impacts on the lived experiences of affected children. Furthermore, the recent consensus document highlights the worrying fact that the difference between affected and infected children may be a matter of testing, not reality.

2.5 Summary and postscript

The main finding from the scoping study of research and 'grey' literature on infected and affected children is that HIV continues to carry considerable risks and challenges for both infected and affected children. Although infected children inevitably experience additional issues arising out of their own health and well-being, HIV brings stress and disruption to the relationships and childhoods of infected and affected children alike, not least because of the all-pervasive nature of HIV stigma. Looking ahead, it seems likely that as parents and children live longer with HIV, so HIV may increasingly become perceived by government agencies and service providers as a manageable, long-term illness like any other and financial support to organisations which work with families with HIV may be reduced. This would be an extremely unfortunate outcome, given the identified and increasing needs of children and young people living with HIV.

At the time of writing this research report, two government-backed policy documents have emerged on HIV in Scotland. The first is a needs assessment of treatment and care services required for people with HIV, conducted by the Scottish Public Health Network (ScotPHN), at the request of the Chief Medical Officer. The aims of the project are stated as follows: to look at epidemiological data (number of people living with HIV etc), comparative data (what happens in other areas/countries) and corporate views (mainly views of those involved with the delivery of services) to ascertain what services are currently available and to look at what services will be required in the future. The needs assessment has now been made available as a draft for stakeholders' review (Johnman, 2009) and patients' views have already been sought and published (Health Scotland, 2009).

The draft review is extremely informative, as are the views of the patient scrutiny panel. Section 3.5 is devoted to children living with HIV (that is, infected with HIV) in Scotland. It suggests that the treatment and care of children living with HIV is extremely complex and needs to reflect the involvement of the whole family (2009: 85). Further, it argues that management of HIV may be complicated by concurrent infection in family members including parents and siblings, and as children survive longer, planning transition to adult clinics is an important issue which will place new demands on services. The review highlights stigma as a real issue for young people, and suggests that young people must be:'(1) well educated about their condition and its treatment; (2) confident in their ability to talk about HIV with those who they want to know about their condition; (3) have a support system, so they know where to get help and advice when they need it.' (2009: 86). The review acknowledges the key role played by the voluntary sector in HIV in Scotland, whilst also observing that access to support provided by the voluntary sector to people living with HIV varies throughout Scotland, as do levels of collaboration between NHS services and the voluntary sector. Amongst its 24 recommendations, the following have particular relevance to children and young people infected and affected by HIV:

20. Paediatric services should have access to appropriately skilled personnel to provide a multidisciplinary service and appropriate support for children, young people and their families, affected by HIV.
21. Protocols should be developed to ensure smooth transition of children to adult services (in keeping with CHIVA guidelines).
22. Support for voluntary and community sector provision and cross-sectoral collaboration with Local Authorities, should be part of the provision made at national and health board level to ensure that the social and psychological needs of people living with HIV are met.
23. There should be improved collaboration between NHS staff and the voluntary sector.
24. All People living with HIV should have access, both directly and via HIV treatment and care services, to voluntary sector provision.

The scrutiny panel members, all of whom are individuals living with HIV, begin their report with a challenge to the notion that HIV is regarded as a 'manageable condition', either by health service staff or by the general public. They stress the impact of stigma, and call for trained counsellors (from health or social work) to be available to help parents who wish to disclose their HIV status to their children, or tell the child that s/he has HIV. They draw attention to the need for support services for affected children and for African families living with HIV. The panel members also give substance to the call for better transition services, by drawing attention to the fact that children with HIV have to move from the familiar setting of a children's hospital to the GUM clinic: a very different ('daunting') experience. The panel members highlight the contribution of Waverley Care in providing the only dedicated children and families' HIV service in Scotland.[6]

---

[6] As will be discussed later in the report, HIV-AIDS Carers & Family Service Provider, Scotland also provides support to families and Positive Help offers a befriending service to children in Edinburgh.

Disappointingly, the considerable attention given to children and young people in this needs assessment is not reflected in either of the early drafts of the government's 'Action Plan for HIV from 2009 to 2011'. The main proposal of the first draft, published in February 2009 (Scottish Government, 2009a), is to establish three Managed Prevention and Care Networks (MPCN) in Scotland, with a focus on prevention of HIV transmission; the role of care and treatment services is given as follows: 'to contribute to a reduction in the transmission of HIV and longer survival rates for those living with HIV'. There is no mention of children or young people in this draft. A final draft, published in August 2009 (Scottish Government, 2009b) retains the emphasis on prevention, but now mentions 'young people' twice. Firstly, it is stated that MPCNs 'will access the support of statutory and voluntary organisations as appropriate and will facilitate multiagency and professional disciplinary working at local, regional and national levels: for example, through supporting a national "network" of individuals involved in the care of infected young people' (2009: 10). Secondly, in a discussion of the importance of 'education and HIV awareness-raising', it is stated that 'Young people, particularly those at risk of HIV infection, such as young MSM [men who have sex with men], also need to be informed and updated on risks associated with HIV transmission' (2009: 14). It is to be hoped that the final version of the HIV Action Plan (currently awaited) might refer more strongly to the needs of children and young people.

Much of the inspiration for the plan seems to derive from an earlier policy initiative introduced by Scottish Executive in 2005. 'Respect and Responsibility: Strategy and Action for Improving Sexual Health' was launched with the aim of enhancing the provision and accessibility of sexual health services in Scotland (Scottish Executive, 2005). Funding was extended within the 'Better Health, Better Care: Action Plan (2007), which, interestingly, makes no mention of HIV or AIDS. A review of 'Respect and Responsibility' published by Health Scotland (2008) claims that most of the actions taken to enhance sexual health promotion, education and service provision 'have now been delivered, and will continue to be delivered, thanks to the joint working of agencies across Scotland' (2008: 1) Although it is not specifically interested in HIV, this review does contain some possibilities for support for families with HIV through universal services. For example, the early years' strategy makes a commitment to give 'Support for parents to achieve the best outcomes for their children is a key strand of the strategy which will contribute in the long term to better health outcomes for children and young people' (2008: 2). Furthermore, the section of education recognises that relationships, sexual health and parenthood education is 'an important part of every young person's personal and social development' (2008: 3).

Reviewing the government's approach as a whole (as demonstrated in the HIV Action Plan and in the 'Respect and Responsibility' initiative), it is difficult to see how this, as it is currently set out, will lead to any real improvements in the lives of children in Scotland who are already infected with, and affected by, HIV. This issue will be discussed further in the conclusion and recommendations, following on from the findings from our own epidemiological survey and qualitative study.

3. Epidemiological Survey

3.1 Introduction

Knowledge of the current epidemiology of HIV among children and young people who are infected with HIV is of key importance in developing a deeper understanding of their needs. Equally, there is a need to know the incidence/numbers of children and young people who are affected by HIV. Current and accurate data of numbers of infected and affected children and young people is essential in the assessment of needs and for the planning and provision of appropriate and adequate services. The survey of infected and affected children in this study is designed to report the most up-to date picture in Scotland today.

3.2 Infected Children and Young People

3.2.1 Method

Data in relation to the number of children and young people infected by HIV were obtained from two main published sources: Health Protection Scotland (HPS), (previously known as the Scottish Centre for Infection and Environmental Health (SCIEH) and the Institute of Child Health (ICH) (London).

Health Protection Scotland (HPS) regularly gathers information on numbers of infected children and young people through an extensive surveillance network, comprising of general practitioners, local authority departments, hospitals, NHS health boards and other surveillance centres. This information is then recorded on its website.[7] The Institute of Child Health (London) also undertakes extensive research into HIV infection in children and young people in the UK and Ireland through the National Study of HIV in Pregnancy and Childhood (NSHPC).

The presentation of data is informed by discussions with HPS's Information Manager Mr Glenn Codere and Dr Conor Doherty, Consultant in Paediatric Infectious Diseases at Yorkhill Hospital, Glasgow.

---

[7] See www.hps.scot.nhs.uk/surveillance/index.aspx/

3.2.2 Findings

Identifying the total number of children who are infected with HIV has proved more difficult than might have been anticipated. Agencies collect slightly different kinds of data and hence come up with different numbers of infected children.

According to the main government statistical collection agency in Scotland, Health Protection Scotland (HPS), the total number of infected children and young people known to be living with HIV in Scotland (under age 15) as at 31st March 2009 was 35.[8] This includes 17 males and 18 females, who were all infected via perinatal transmission (HPS, March 2009). HPS figures also provide information about the ethnic background of these children and young people. Table 3.1 suggests that that the vast majority (84 per cent) of children and young people living with HIV in Scotland are of black African origin.

Table 3.1: Ethnic Origins of HIV Infected Children (under age 15) living in Scotland (as at 31st March 2009)

Ethnicity	*Number of Cases*
White (Scottish)	3
White (Other British)	1
White (Other)	1
Black-African	24
Mixed	4
Unknown	1
Total	35

(Source: HPS data, as at 31st March 2009.)

The Institute of Child Health (ICL) based in London also provides data which throw light on numbers of children infected by HIV. ICL hosts the National Study of HIV in Pregnancy and Childhood (NSHPC) which is a confidential national (UK and Ireland) active reporting scheme for pregnancies in HIV-infected women; babies born to HIV-

---

[8] HPS defines children as those under 15 years of age because of a view that those over 15 may be sexually active, and therefore may become infected with HIV through sexual intercourse. HPS (2009) notes that the total figure may include cases of young people who have been lost to follow-up (i.e. unreported death, left the country, etc.).

infected women; and other children with HIV infection and AIDS. [9] Its figures suggest that there were 43 infected children attending paediatric clinics in Scotland in 2008. Table 3.2 demonstrates that over half of those (58%) were born outside the UK. NSHPC further reports that all seven children born in the UK between 2001 and 2008 were born to women who were undiagnosed with HIV by the time of delivery.[10]

Table 3.2: Infected children (born after 1990) attending clinics in Scotland

Age group and place of birth			
Year of birth	*Born UK*	*Born abroad*	*Total*
1991 - 1995	6	9	15
1996 – 2000	5	9	14
2001 – 2008	7	7	14
Total	18	25	43

(Source: NSHPC data, UCL Institute of Child Health, Data to end 2008.)

NSHPC also provides information on children born to women who were known to be HIV positive. Table 3.3 demonstrates that although there was an increase in the number of children born to diagnosed HIV positive women in Scotland between 1996 and 2008, no new infections have been reported in children born since 2001.[11] While the infection status of some children is still to be confirmed, it is suggested that it is unlikely that they will be infected, because the majority of women will have received appropriate treatment to reduce the risk of transmission.

Table 3.3: Infants born to diagnosed HIV positive women in Scotland, 1996-2008

Year of birth	*Infection status of infants*	*Number of*

---

[9] NSHPC is based in the Centre for Paediatric Epidemiology and Biostatistics at the Institute of Child Health, London. Since 1989, pregnant women with diagnosed HIV infection have been reported through a quarterly reporting scheme administered under the auspices of the Royal College of Obstetricians and Gynaecologists. Paediatric reporting started in 1986, and is mainly carried out through the British Paediatric Surveillance Unit's monthly 'orange card', which is routinely sent to all consultant paediatricians registered with the Royal College of Paediatrics and Child Health. Some clinicians looking after large numbers of children report directly to the NSHPC. Laboratory sources also contribute data. See www.nshpc.ucl.ac.uk/

[10] It should be noted that we have no information about where in the UK these children were born, and so this may have no relevance to Scotland.

[11] Only eight children were reported to be infected in the early years of HIV infection in Scotland, that is, between 1996 and 2000 (NSHPC, 2008).

				infants
	*Infected***	*Uninfected*	*Not yet reported**	
1996	17%	58%	25%	12
1997	25%	63%	13%	8
1998	25%	63%	13%	8
1999	0%	100%	0%	10
2000	13%	81%	6%	16
2001	0%	100%	0%	14
2002	0%	100%	0%	21
2003	0%	93%	7%	14
2004	0%	93%	7%	27
2005	0%	100%	0%	31
2006	0%	100%	0%	35
2007	0%	74%	26%	42
2008	0%	61%	39%	36
*11% died, lost to follow up or known to have gone abroad before their infection status was established				
** only 8 children in total				

(Source: NSHPC data, UCL Institute of Child Health, Data to end 2008.)

Paediatric clinicians working with infected children in Scotland suggest that the total number of infected children in Scotland is neither 35 nor 43, but 47 (Draft Proposal for Managed Clinical Network in Paediatric Immune Deficiency, 2009).[12] This discrepancy is, in part, explained simply: paediatric services include children up to the age of 18 years, whereas HPS only counts those up to 15 years of age. But another complicating factor in predicting numbers accurately is that there is a window of uncertainty in establishing whether children are infected, and in many cases, maternal HIV infection is only recognised when the child becomes ill. There may also be a delay or failure to report HIV-infected children by paediatricians to either HPS or NSHPC. Hence the data regarding the number of infected children may not reflect the true proportion of births to HIV infected mothers which result in the child being infected. [13]

---

[12] This information was presented to the second meeting of the Scottish Paediatric HIV Group held in Perth (Scotland) on 5th May, 2009.

[13] The 'window of uncertainty' used to be 18 months, but with the use of more sensitive tests, a diagnosis of HIV infection in a child can be made with a certainty of about 95% by 6 months of age. There should rarely be a 'window of uncertainty' of 18 months unless inappropriate tests have been done or the child continues to be exposed to risks, for example, is breast-fed. (Information supplied by Dr Mok, NHS Lothian).

It is informative to place these figures in the national and local picture of HIV infection across Scotland. As previously stated, statistics demonstrate that there has been a significant rise in the number of people receiving treatment for HIV in Scotland (HPS, 2007; Scottish Government, 2009). This rise is not evenly spread across Scotland, however, with some areas experiencing significantly more pressure than others.[14] Table 3.4 shows this graphically:

Table 3.4: CD4 Monitoring & treatment by NHS Board, 2007

NHS Board	*Total attendees*	*Attending for first time in 2007*
Ayrshire & Annan	31	2
Borders	2	0
Dumfries & Galloway	37	7
Fife	69	8
Forth Valley	43	3
Grampian	202	45
Greater Glasgow & Clyde	891	160
Highland	35	7
Lanarkshire	103	21
Lothian	1,066	120
Orkney	0	0
Shetland	0	0
Tayside	195	25
Western Isles	0	0
Scotland	2,674	398

(Source: HPS figures reported in Johnman, 2009: 38.)

3.2.3 Discussion

Available information would seem to suggest that the number of infected children in Scotland overall is relatively small: either 35, 43 or 47, depending on the question that is asked, and the ways that data are collected. But the low numbers should not deceive us into thinking that the problems which these children face are also small. The scoping study has already demonstrated that children with HIV face very real problems, both physically and psycho-socially, and these will be further reflected in the findings from the qualitative component in our research.

---

[14] It is known that some patients travel across NHS Boards to receive HIV treatment and care. This is particularly the case in NHS Greater Glasgow and Clyde and NHS Lothian health board areas (see Johnman, 2009: 38).

The data also highlight differences across Scotland as well as the sharp divide in the numbers, expectations and prognosis for children born inside and outside the UK. HPS figures suggest that 24 of the 35 children under the age of 15 who are infected with HIV are black African children. This is a highly significant fact in its own right. Over and above this, it is known from 'whole Scotland' figures (Table 3.4) that Health Boards experience uneven demands on their services. Although the cross-sector needs assessment was not set up to look specifically at needs on the basis of ethnicity, it must be acknowledged that issues such as poverty, immigration and discrimination based on 'race' and ethnicity have a major impact on psycho-social factors and other health-related quality of life issues and, to that extent, are vital in understanding needs and planning services. This will also be explored further in the interviews with practitioners, parents and children.

3.3 Affected Children and Young People

Repeating Inglis and Morton's (1996) methodology, the needs assessment set out to count, as accurately as possible, the number of children and young people currently living in Scotland who are affected by parental HIV. It was known from the outset that it would only ever be possible to come up with a rough approximation of total figures, because there has never been any official record kept of children affected by HIV, and because HIV has always been such a secret illness, as the scoping study has demonstrated. It made sense, however, to re-use the approach adopted by Inglis and Morton, firstly, so that a figure could be reached by similar means, and secondly, so that comparisons could then be made over time.

3.3.1 Method

Questionnaires were sent to all HIV service providers in Lothian, Greater Glasgow & Clyde and Tayside Health Board areas, asking for details of the children with whom they had contact (see Appendices 7.1). Additionally, given the known increase in the number of reports of HIV infections from areas such as Fife, Lanarkshire, Grampian and Highland during 2007 (Scottish Government, 2009), the study was broadened to include these areas. Steering Group members provided the information and contacts to agencies and practitioners working with children and young people affected by HIV in each area.

The questionnaire was designed to be as simple as possible. Practitioners were asked to identify each child/young person that they knew to be affected by HIV or AIDS, by their two initials, age and sex as well as details of whom they lived with. This ensured confidentiality and allowed key characteristics to be established, through which duplicate cases could be deleted. The questionnaire also provided information on the HIV status of their parent, sibling and any other family member living with HIV and the death of a parent, sibling or other family member.

A total of 13 agencies participated in the number-counting exercise:

- 4 agencies from Edinburgh: the Royal Hospital for Sick Children, Waverley Care, Positive Help and the Regional Infectious Diseases Unit at the Western General Hospital.
- 5 from Glasgow: HIV-AIDS Carers and Family Service Provider Scotland, the Brownlee Clinic, Royal Hospital for Sick Children (Yorkhill Hospital), Terrence Higgins Trust and Waverley Care's African Health Project;
- 4 others agencies, namely Terrence Higgins Trust (Aberdeen), Ninewells Hospital (Dundee) and Grampian and Highland Health Boards.

3.3.2 Findings

The data provided counted 711 children and young people affected by HIV across the NHS board areas in Scotland. This number excludes the 70 duplicate cases (15 from NHS Lothian and 55 from Greater Glasgow & Clyde) and an additional 50 unconfirmed numbers from Fife.[15] The numbers reported from the NHS board areas were as follows:

- 251 in Lothian
- 336 in Greater Glasgow & Clyde
- 90 in Tayside
- 23 in Grampian
- 11 in Highland

Using the formula previously employed by Inglis and Morton (1996), these figures are placed in the Scottish-wide context. As of 31st December 2008 (HPS, 2009), it was

---

[15] Although our named contact in Fife spoke with us on a number of occasions, no completed form was returned to us.

known that there were 3,524 HIV infected adults in the Health Boards covering Lothian (1,499), Greater Glasgow and Clyde (1,217) Tayside (326), Grampian (330) and Highland (98). The number of children and young people found by this study to be affected by HIV living in these areas represents one affected child for every five infected adults (20.17%). Applying this ratio to all infected adults throughout Scotland (n= 4,164),[16] we can extrapolate that there are an estimated 833 children and young people affected by HIV in Scotland.

Beyond the big picture, the returns provided interesting additional information about the gender and ages of affected children in the three Health Board areas with highest reported numbers, that is, Lothian, Greater Glasgow & Clyde and Tayside. The numbers for the other areas were thought to be too small to offer any further scope for analysis.

Gender

No notable differences were found in the gender of the children across the three areas. Of the affected children identified in Lothian, a comparable numbers of girls (119) and boys (129) were counted. Of the affected children identified in Greater Glasgow & Clyde, the numbers of girls (156) and boys (158) were almost the same. Of the affected children identified in Tayside, the number of boys counted (51) was slightly larger than the number of girls (39), but figures here are too small to suggest any further analysis.

Age

Overall, the age distribution of the affected children in the three geographical areas was towards the younger end of the scale. The highest percentage of children (41% of the total sample) was found to be of primary school age, that is, between 5 and 11 years. The next largest group (27%) was children aged between 0 and 4 years. Table 3.5 provides a breakdown of affected children's ages across the three areas. This shows that the age distribution in Lothian and Greater Glasgow & Clyde was very similar for children up to 15 years, but that Greater Glasgow & Clyde had proportionately more older teenagers than Lothian. The picture looks quite different in

---

[16] That is, cases not known to be dead and who are aged 15 years or over as at 31st December 2008.

Tayside, however. Here we find a lower percentage of 0 to 4 year olds, and a much higher proportion of children aged between 12 and 15 years.

Table 3.5: Ages of Children Affected by HIV

Age	*Lothian*	*Gr. Glasgow & Clyde*	*Tayside*	*Total*
0-4	78 (31%)	93 (28%)	13 (14%)	184 (27%)
5-11	107 (43%)	131 (39%)	38 (42%)	276 (41%)
12-15	48 (19%)	55 (16%)	25 (28%)	128 (19%)
16-18	16 (6%)	47 (14%)	14 (16%)	77 (11%)
Unknown	2 (1%)	10 (3%)	0	12 (2%)
Total	251 (37%)	336 (50%)	90 (13%)	677 (100%)

The survey provides a rather inconclusive picture of the patterns of use of voluntary sector agencies and services by those affected by HIV. Most children were identified by one agency (this was often the hospital clinic offering support to HIV positive parents); only 70 children and young people were known by more than one agency. There was, however, marked geographical variation in this. So, for example, in Lothian, 15 children were known to more than one agency, two of whom were known to two agencies and 13 to three agencies. In Greater Glasgow & Clyde, 55 children and young people were known to more than one service: 32 to two services, 20 to three services, and three to four services. This suggests that where services are provided, families do make use of them.

Comparing the 2009 findings with those of 13 years earlier (Inglis and Morton, 1996),[17] interesting patterns emerge, as shown in Table 3.5. Here it is demonstrated that there has been an overall decrease in the number of affected children across the three Health Board areas (the children affected in 1996 have now grown up and so disappeared from the statistics, and fewer new cases have replaced them). But there are marked differences between areas, most especially, decreases in numbers in Lothian and Tayside, but a large increase in numbers of affected children across all age-groups in Greater Glasgow & Clyde. Interestingly, just over half the affected children in the 1996 survey (52%) were of primary school age. This group remains

---

[17] It should be noted that although Inglis and Morton's (1996) survey describes itself as a study of children in Glasgow, Dundee and Edinburgh, the figures used were in fact those for the Health Board areas covering Glasgow, Edinburgh and Dundee, as used again in the 2009 survey.

the highest overall percentage (at 41%), but numbers of under-5s have risen considerably in Lothian and Greater Glasgow & Clyde. There are also many more older teenagers in Greater Glasgow & Clyde, whilst the number in Tayside has fallen. The survey did not ask about ethnicity, because this did not appear as a question in the 1996 survey. Nevertheless, issues of ethnicity, age and HIV do intersect across the years. So, for example, it seems reasonable to suggest that the (predominantly white) Tayside drug-using population of the 1990s has grown up and is no longer of child-bearing age; hence the fall in affected numbers in Tayside. At the same time, although drug-users in Greater Glasgow & Clyde and Lothian have similarly grown older, they have been replaced in HIV terms by a (predominantly black) asylum seeking and refugee population which is younger, and more likely to be having children; hence the increased number of under-5s in these areas.

Table 3.6 Comparisons between 2009 and 1996 figures (1996 figures in brackets)

Age	*Lothian*		*Greater Glasgow & Clyde*		*Tayside*		*Total*	
	2009	*(1996)*	*2009*	*(1996)*	*2009*	*(1996)*	*2009*	*(1996)*
0-4	78	(59)	93	(22)	13	(37)	27%	(16%)
5-11	107	(229)	131	(47)	38	(107)	41%	(52%)
12-15	48	(63)	55	(32)	25	(69)	19%	(22%)
16-18	16	(15)	47	(8)	14	(32)	11%	(7%)
Unknown	2	(18)	10	(2)	0	(1)	2%	(4%)
Total	251	(384)	336	(111)	90	(246)	100%	(100%)

UK statistics add to the overall picture. It has been estimated that the total number of affected children in the UK may be somewhere between 15,000 to 20,000 (Conway, 2006a). Scotland has a population of approximately one-tenth of the UK population: 5 million as compared with around 50 million.[18] This might suggest that we should expect to see a population of 1,500 to 2,000 children affected by HIV in Scotland. Our estimate is, self-evidently, significantly lower than this.

3.3.3 Discussion

Reflecting on the process of data collection, it should be stated that this was found to be a time-consuming and onerous task, for researchers and agency staff alike. Although the plan had been to collect the minimum of data necessary to ensure lack

---

[18] See www.gro-scotland.gov.uk/

of duplication (and, of course, to replicate the earlier study), the process of gathering information which is not already available was difficult, especially given the short time-scale of the study. Most agencies said that they were short-staffed and under-resourced, and providing detailed information about children and families required time and careful deliberation. Because of this, the research project was obliged to pay for extra secretarial hours to one agency so that it could supply the required data. In another, a Health Board representative was unable to provide data beyond a total figure, and so this area could not be included in the more detailed analysis.

The overall picture which emerges is one of a decline in the number of affected children in Scotland, providing some comfort to government and health agencies which have sought to make prevention of HIV a priority (see Scottish Government, 2009). However, this broad statement masks key issues which emerge in the demographic characteristics that are related to the considerable variation across Scotland.

- Most critically, our survey has shown a consistent increase in the impact of HIV on families in Greater Glasgow & Clyde, suggesting a likely increase in pressure on health, education and social services in the city.
- We have also demonstrated an increase in affected children under the age of five years in both Greater Glasgow & Clyde and Lothian (171 as compared with 81 thirteen years earlier), suggesting possible increased pressure on health visiting and pre-school services in those areas.
- This needs to be connected with what has already been discussed in relation to HIV and ethnicity. Whilst the early generation of (white) affected children has, in the main, grown up, they have been replaced in the affected figures by children of (black) African parents, again suggesting additional needs in relation to poverty, insecure immigration status and discrimination (Crusaid/Waverley Care, 2009).
- The data have shown that most affected children do not have access to services (they were only named by one agency, usually their parent's clinic), but when these are available, families will use a range of services. This point will be explored further in the qualitative findings.

3.4 Summary

The evidence from the data relating to infected and affected children suggests a rather mixed picture The 'headline news' is that the number of children infected and affected by HIV in Scotland is low and has fallen over the last 13 years, demonstrating that public health initiatives such as needle-exchange programmes, routine antenatal screening and interventions to reduce vertical transmission of HIV have been successful in achieving their wider health goals.

But underneath this success story, new factors have come onto the scene, including the impact of age and ethnicity on HIV and children. Most of the women being diagnosed with HIV today are infected heterosexually, not through intravenous drug use. Black and immigrant women are more likely to be young, sexually active, and so at risk of HIV. A recent evaluation of a health education programme in Glasgow (Cree, 2008) identified that much more needs to be done to encourage sexually active people (white and black) to go for an HIV test. There are important implications here for service providers across Scotland.

The survey has also drawn attention to wide geographical variation across Health Boards. There is serious pressure on a small number of Health Board areas. But there are also small pockets of affected children across a wide part of Scotland, suggesting that the needs of those children may be even less likely to be met unless there is a policy shift towards offering them more support.

4. Qualitative Study

4.1 Introduction

In total, 48 adults and children contributed to the qualitative part of the cross-sector needs assessment. Twenty practitioners took part in interviews in Edinburgh, Glasgow, Dundee and Aberdeen, alongside 28 adults and children in Edinburgh and Glasgow. Of these, 16 were parents and carers, five were HIV-infected children and young people and seven were children and young people affected by parental HIV.

4.2 Method

The cross-sector needs assessment identified from the outset a range of stakeholders with knowledge and insight into the needs of children infected and affected by HIV in Scotland. Those included:

- Practitioners (from health and voluntary sector HIV agencies)
- Parents and carers (both HIV positive and not HIV positive)
- Children and young people infected with, and affected by, parental HIV

The main method of data collection used was individual, semi-structured interviews. Three interviews also met two practitioners together. Interview schedules (see Appendices 7.2) were devised in cooperation with Steering Group members who are listed at the beginning of this report. One group interview took place with parents and carers in Glasgow, and operated along the lines of a focus group. (This had not been part of the original plan for the study, but when the Glasgow Women's Group invited the interviewer to come to talk to them, this proved to be an extremely useful opportunity not just to get feedback but also to access interviewees for the study.) All interviews were recorded using an MP3 digital recorder and transcribed for future analysis.

The choice of a semi-structured format was a pragmatic response to the need to get specific information in relation to existing services and identified needs; a more non-directive or narrative approach might have failed to address the central questions of the study (see Bechhofer and Paterson, 2000). However, the interviews were, in practice, not rigidly structured. On the contrary, the interviewer (Dina) adopted an open, reflective approach which allowed her to step away from the interview schedule if, for example, an informant became distressed, or had a lot to say in relation to a particular topic. She also, on two occasions, agreed to stop the interview and to pick up with the informant on another occasion. This was, without doubt, 'research in the real world' (Gray, 2009), and that meant being flexible and being respectful of the wishes and needs of informants.

Great care was taken to ensure that informants understood the purpose of the interview, and felt able to give their informed consent to take part. All the interviews were conducted by one interviewer, who took time with people before the interviews, giving information about the study and building a relationship of trust, and then carrying out the interviews in such a way that the informants did not experience them as, at best, an intrusion in their lives, or, at worst, a violation (McLaughlin, 2007). Dina met many of the parents, carers and children on more than one occasion, and each time, allowed for preparation before, and debriefing after, any formal 'interview' discussion. Substantial amounts of time were also spent with the facilitator of the women's group in Glasgow, and with the child care and adult workers in Edinburgh and Glasgow. Each made a considerable commitment to the study, and encouraged others to take part in the interviews (as outlined further below).

4.2.1 Practitioner interviews

The focus of the practitioner interviews was, as the schedule indicates, to find out which agencies and services currently exist, whether there are any significant areas of overlap between them, and what identified needs are not being met, if any. Practitioners were also invited to add anything else they wished (see Appendices 7.2).

All those who were interviewed were either Steering Group members, or were recommended by a Steering Group member or other informant, using a mixture of purposive and snowball sampling (Grey, 2009). In total, 20 practitioners were interviewed from agencies based in Edinburgh, Glasgow, Dundee and Aberdeen, with equal numbers coming from the voluntary sector and statutory sectors (in this case, the National Health Service). The practitioners held varying responsibilities in their agencies, from direct practice to policy and management posts. Some worked with adults with HIV while others worked with children who were infected with and affected by HIV. The final practitioner interview was conducted with someone whose agency had been centrally involved in providing support services for affected children in the past, but no longer does so.

4.2.2 Interviews with parents and carers

Interviews with parents and carers sought to explore three main areas: general questions about the family, neighbourhood, and work/study; more specific questions about HIV in the family; and questions which related to support services currently used, and ideas about what support might be provided in the future. Parents and carers were also asked to add anything else at the end (see Appendices 7.2).

Sixteen parents and carers contributed to the study. Nine were interviewed individually (four in Edinburgh and five in Glasgow); two women who were interviewed on their own also took part in a group interview with another seven women held in Glasgow. All the parents and carers had been invited to do so by a clinician or voluntary agency worker. They were not, in consequence, a random or representative group of people. Moreover, not all the parents and carers who were approached by practitioners agreed to be interviewed. Those who did clearly had something they wished to get across, and given the highly secret and sensitive nature of the topic, they were also the people who felt most able to talk about their HIV status, or the HIV status of the child whom they cared for (Lee, 1993).

All the Edinburgh informants (n=4) were white and Scottish (one was a parent and three were carers). Seven of the Glasgow informants were white and Scottish (all were parents); five Glasgow informants were black African women (one of whom was a carer) (n=12 in Glasgow). Only one man was interviewed; he was one of the carers in Edinburgh. Fourteen of those interviewed were HIV positive women; two carers (one grandparent and one sibling) did not have HIV. All but three of those interviewed were parents; one was a sibling and carer; one was a parent's sibling and carer; and the third was a grandparent and carer. The parents and carers were bringing up families of different sizes, as Table 4.1 demonstrates.

Table 4.1: Number of children cared for

Number of Children	*Edinburgh*	*Glasgow*	*Total*
1		7	7

2	3	4	7
3		1	1
4	1		1
Total	4	12	16

4.2.3 Interviews with children and young people

The interviews with children and young people covered very similar ground as the interviews with parents and carers. Children were asked to speak about their family, neighbourhood, and school; and about HIV in the family; and about support services they used, and might like to use in the future. They were also given the opportunity to add anything else (see Appendices 7.2).

Following the approach used in the earlier 'Listening to Children' study, practitioners approached parents to ask if they would be willing to talk to their children about taking part in the study. It was hoped that their 'sponsorship' would facilitate access in what was known would be a difficult area to engage potential informants (Cree *et al*, 2002; Kay *et al*, 2003). Once parents had given their initial agreement to be contacted, this was followed up by the interviewer sharing further information with them before going on to conduct interviews. This methodology drew on the researchers' previous experience of conducting research with children, as well as a considerable body of literature which has emerged in recent years on this topic (see for example, Alderson, 1995; Cree *et al*, 2002; Tisdall *et al*, 2008).

At the outset, Steering Group members were relatively confident that they would be able to find sufficient numbers for the study: it was felt that they were working with significant numbers of adults and children, and those adults and children had strong views about the need for support services for children and HIV. In the event, however, it was extraordinarily difficult to get people to take part in the study. Parents and carers were (understandably) reluctant to upset their children by talking to them about the study. Perhaps more surprisingly, some agencies were themselves concerned that their service users might be distressed by being asked to take part in the study. With so much 'gate-keeping' going on, our original estimates of numbers we wished to interview were reassessed downwards at each Steering Group meeting. Nevertheless, the 12 interviews with children and young people provided extremely important information for the needs assessment.

Five infected children took part in individual interviews in Edinburgh and Glasgow. The Edinburgh-based informants were two young people (one white Scottish and one who was born in Eastern Europe but raised in Scotland). All three Glasgow informants were black African children, two girls and one boy. One of these girls (aged 11) was not fluent in English, so her aunt remained throughout the interview and translated where necessary. The children's age distribution is presented below in Table 4.2.

Table 4.2: Age and location of informants who were infected children

Age	*Edinburgh*		*Glasgow*		*Total*
	F	*M*	*F*	*M*	
9-11			1		1
12-15		1	1	1	3
16 +	1				1
Total	1	1	2	1	5

Seven children and young people affected by parental HIV took part in individual interviews in Edinburgh and Glasgow. All but one (a black African boy aged 11 years) were white and Scottish. Their ages are shown in Table 4.3.

Table 4.3: Age and location of informants who were affected children

Age	*Edinburgh*		*Glasgow*		*Total*
	F	*M*	*F*	*M*	
9-11				1	1
12-15	2	1			3
16 +	1		2		3
Total	3	1	2	1	7

4.3 Findings

4.3.1 Practitioners

The 20 practitioners who were interviewed were asked to comment on the strengths and weaknesses of their own agency, and of other agencies with which they have worked (both statutory health and voluntary HIV agencies). Most agencies had been working with HIV in Scotland since the late 1980s; one had opened a Scottish branch in recent years; another had ceased to offer HIV support services to children in Glasgow in 2008. The agencies' work ranged from influencing HIV-related policies to clinical and counselling work (antenatal counselling for women with HIV and testing of infants after birth; testing, diagnosis and treatment of people infected with HIV or living with AIDS); to more community based interventions (including health promotion and community support; children's befriending service, domiciliary assistance for HIV positive parents; respite care (including residential respite), child care; end of life services, child and family advocacy; support groups; African Health Project, gay men's programme, buddy project etc).

The main finding to emerge from the practitioner interviews is that with the exception of health services, HIV agencies in Scotland are focused on adults; where services for children exist, these have to be accessed through adults first. Moreover, targeted services for children infected with, and affected by, HIV are scarce across Scotland. Whilst Edinburgh has been fortunate enough to have had the benefit of children's services through Waverley Care and Positive Help for many years, there is little in the way of any other dedicated service for children across Scotland, with the one exception being the medical help offered to infected children through clinics and hospitals. One agency in Glasgow (HIV-AIDS Carers & Family Service Provider Scotland) offered some trips to children in the past but is not able currently to fund this. Identifying a huge unmet need there, Waverley Care has recently extended its provision to African people in Glasgow by sending one of its Children and Young People's Project Workers to Glasgow on a part-time basis. The worker, however, is currently only working with infected children and young people.

Significantly, two high profile children's charities which had been extremely active in the field of HIV and children in Scotland in the past are no longer involved in this area. Barnardo's in Scotland formerly ran projects for children in Edinburgh, Glasgow and Dundee, under the name of Riverside Project. Meanwhile, Children in Scotland had acted as co-ordinator to a Children & HIV/AIDS Network for practitioners in Scotland, and had been the host agency for the Inglis and Morton (1996) needs assessment and for the 1999-2002 'Listening to Children' study. In interview, the Barnardo's representative expressed his regret that the agency was not providing services for affected children any more. The retrenchment had come about because of financial and organisational pressures, rather than because of any lack of commitment on the agency's part to this work. Likewise, Children in Scotland could not continue to support the network without external funding, and was forced to give this up. This will be returned to later in the report.

Identified strengths of agencies

Voluntary sector staff saw their strengths as follows:

- consistency and flexibility to adapt to the needs of service users
- practical help including support with benefit claims
- continuity of befriending
- provision of holistic, person centred care and a user friendly service
- ability to provide culturally sensitive services
- ability to work with service users across different stages of HIV – from pre-diagnosis, to living with HIV and AIDS and loss and bereavement
- a workforce which includes HIV positive people was seen as a strength.

Statutory/NHS staff highlighted other features:

- high quality care to sick children and adults in a non-judgemental and safe environment
- provision of antiretroviral drugs and promoting the health of the family
- provision of a multidisciplinary approach and liaison with other services in the hospital and the community e.g. social services and schools

Limitations of agencies

Financial constraints and lack of resources were the main issues facing voluntary sector practitioners. Lack of adequate funding has led to:

- cuts in volunteer support services, including training new volunteers to support children
- limited geographical breadth of operation
- restrictions on facilities and transport
- limited human resources to manage huge demands.

This was mirrored by limitations identified by statutory/NHS staff:

- lack of community nursing home services for younger individuals
- lack of local resources for respite care
- lack of housing
- lack of resources for specialized nursing care, dietetics, pharmacy, psychology, or social work support to deal with non-medical problems.

Barriers to accessing services

All but one of the practitioners talked extensively about the barriers which people face in accessing services because of stigma. Despite years of education and advances in the care and treatment of people with HIV, stigma and discrimination around HIV is still felt to be strong, and is particularly so amongst members of the African community. Fear of stigma and societal reprisal play a key determining factor in service users accessing services. It was also pointed out that practitioners in mainstream settings who are the first point of contact for service users (for example, those in health, education, housing and social work services) may not themselves be knowledgeable about HIV and may show some of the same prejudices as found in the general public; this, not surprisingly, can also put people off from asking for help.

Language difficulties were felt to impact on service use. While increased provision of interpreter services might seem to provide an answer here, it was acknowledged that it is not always easy for HIV positive service users to use such a service, because of the need for confidentiality and trust.

The fragmented nature of services was also identified as a barrier to service use. Services tend to be geared towards a particular segment of the population (either adults or children, for example), and this limits their ability to reach out to those who are outside their remit. This leads into the importance of inter-agency working.

Strengths and weaknesses in inter-agency collaboration

All staff said that their agencies promoted a strong inter-agency culture. This was said to be vitally important because agencies have their own specialist areas of expertise, and rely on each other to ensure that service users are given the best possible health and social care support. It is therefore routine practice for voluntary agencies to seek support from NHS-based clinics for their service users and vice-versa, and for cross-referrals to be made within the voluntary sector. [19]

Informants noted that inter-agency collaboration was impeded, at times, by the pressures and demands placed on agencies. Clinics were often busy and hospital staff did not always have the time they might wish to spend with patients. Further, inter-agency work was made more difficult by a fear of breaches in confidentiality; by lack of access to settings outside normal working hours; and by lack of outreach programmes and support. Sometimes service users from one agency did not actually want to be referred to another agency for specialist support due to fear of stigma, especially if the agency had 'HIV' in its title. Difficulties in inter-agency working may also have been a reflection of the barriers that organisations (as well as service users) still encounter when working across different agencies. Despite the policy underpinnings and political commitment to joint working, ideological/professional as well as the organisational barriers may stand in the way of smooth inter-agency collaboration to promote the welfare of the service users (Morris, 2008).

Services for children and young people provided by agencies

All the agencies expressed a view that they would like to extend their services and reach out to as many children as possible, but lack of financial resources and appropriate staff at times proved a considerable hindrance to achieving these aspirations. This proved to be a major barrier in children accessing HIV-related services when they felt a need to do so. Other barriers included parents' reluctance to let children use services due to their fear of children finding out about parents' HIV status; geographical distance and hence children's inability to access support from a distance.

Practitioners said they found it difficult to gauge how children felt about the services they use. Almost invariably, younger children were unaware of their HIV status and older children sometimes found it difficult to talk about the issue directly with agency

---

[19] The following voluntary agencies were seen as particularly helpful for families affected by HIV: Waverley Care, the Scottish Refugee Council, the Red Cross, the Ethnic Minority Law Centre, Immigrant Advisory Service, Positive Action for Housing, Rock Trust, Sunflower Garden project, Richmond Hope, Elton John AIDS Foundation, Children's HIV Association of UK and Ireland (CHIVA), and Children with AIDS Charity (CWAC).

staff. Most often, it was the parents who provided feedback to the agency staff. Parents reported that children really enjoy activities, workshops and playgroups, particularly the residential outings; they loved being out with peers, and being in a children-friendly environment.

Many practitioners felt that children need to have 'somewhere to go to, to find out about HIV and talk safely about their experiences without fear of disclosure or stigma'. The need for age appropriate information and activities, particularly where the stigma of HIV keeps them from getting the kind of support that a child whose parent has cancer or multiple sclerosis might receive. Other priorities included reaching out to children with HIV, especially from cross-cultural families. It was stated that having HIV is a lonely experience, and more so for children from black and minority ethnic (BME) backgrounds who experience a great deal of social isolation and exclusion. Developing a more holistic package of services with cultural links, support services, and specialist nurses was identified as a key priority for children from BME backgrounds.

Some identified the need to provide support for young people as they transition to adult services as a key priority. Others felt that as children get older, they display challenging behaviour that leads to school refusal, expulsion etc and there is a lack of specific services to support these vulnerable children and their families. These children often go through a stage of confusion and anxiety and psychological counselling and psychiatric support were identified as other priority areas for development.

The issue of stigma and discrimination was generally still perceived by practitioners as widespread and the need for prevention work in schools and creating better awareness to combat stigma such that people affected/infected are able to access services without the fear of reprisal was suggested. Another priority area for affected families was the need for health visitors to focus on specific child rearing issues.

Gaps in services for children and young people

As already indicated, services are currently extremely limited and unevenly spread geographically across Scotland. Specific gaps which were identified by practitioners included: respite care for children or adults with HIV and AIDS; parenting skills programmes; mother and toddler programmes; lack of funding for public education and information on sexual health; lack of services during the transition period between children and adult care; and lack of specialist services (for example, pharmacists, dieticians, psychologists, and support services and social workers who specialise in work with children with HIV and their parents). Another issue cited was the gap between public health and immigration policies. Asylum seekers get six months in the UK; but if their application for asylum fails, they have to return to their country of origin. In this situation, there is no way of ensuring that their treatment continues. Coupled with this, some parents who are in Scotland and receiving medical treatment have to live with the knowledge that if they have children residing in Africa or elsewhere they may not be getting any medical help.

How should services be delivered in the future?

- Practitioners reported that without exception, children want the 'same things as normal children', just as parents 'want a better life for their children, a life without stigma'. This was felt to be particularly true for black African parents who experience discrimination on all fronts; they want their children to be 'proud of their heritage and culture'.
- They also emphasised that parents and children appreciate the opportunity to speak to someone who is seen as neutral and non-statutory, non-threatening and safe. Most therefore saw the benefits for children of receiving support from specialist agencies in the health and voluntary sectors.
- Practitioners felt that services should be developed that promote awareness of the needs and issues of infected and affected children across Scotland, not just in the areas of historical high demand.

4.3.2 Parents and carers

As already indicated, the 16 parents and carers who took part in the study were an extremely varied group of people. Four lived in Edinburgh and the rest lived in and around Glasgow; but beyond this, there were differences in their age, gender, ethnicity, social background, whether they were parents or not, and even whether they themselves were HIV positive or not. This shows that probably the only thing which they had in common was that they were caring for a child who was affected by HIV, and in that respect, their accounts have clear similarities. One parent said in a few words what many others spoke about during the interviews:

> 'HIV is an illness of uncertainty and hardship and that's bound to affect our children in every which way'.

Interestingly, parents in Glasgow spoke about their surprise that someone was taking the time to speak to them about their lives. They had a lot of experience in being 'interviewed' by clinicians, social workers and other authority figures. But this felt like the first time anyone had shown any real interest in them and in their children. One said:

> 'It's like someone is interested in listening to our story too - not just asking about medication, but about the struggle we go through'.

A common refrain from a large number of parents and carers from in and around Glasgow was: 'We don't want anything for ourselves; we just want something for our children'.

Disclosure

A key issue faced by all parents and carers was how best to support their child, and for all of the informants, this included the extremely thorny issue of disclosure: how, when and what to tell their child, and who else could and should be told what and when. The women in the Glasgow women's group talked about the continuing need to maintain secrecy regarding their HIV status. One woman expressed concern about her daughter's innocent comments regarding the recurrent blood tests that both of them had to have. She said that her daughter tells people: 'Me and mum's got bad blood,' and she (with some justification) fears the consequences of this disclosure. The stigma which surrounds HIV means that another parent said that she had found it much easier to disclose her own HIV status to her teenager who is not infected, than to tell her other child who has HIV. She was inevitably afraid that her HIV-infected child would blame and even reject her because of her responsibility for her child's HIV infection.

This touches again on stigma and HIV. Parents spoke about the negative impact of stigma 'by association with HIV' and the fear of the impact of this on their children. In particular, some parents/carers spoke about the unhelpful association of HIV with drug misuse. One parent/carer said: 'HIV is still like – huh - HIV - you're a druggie'. Another echoed this sentiment, saying: 'they ken you're a junkie', whether or not you have ever used drugs. One carer stressed that the stigma associated with HIV was still very much alive. She said:

> 'It's still very much there, you have to keep it secret, it's a constant, it's as strong as it ever was.'

Support services

Several of the HIV positive women who were interviewed expressed the wish that their children could have an opportunity to get to know other affected children while they are still young, so that when they get older and learn about their parent's HIV status, they would have someone to talk to about it. One carer suggested that it would be useful to have residential weekends or conferences where young people could meet with other young people and have an opportunity to discuss issues related to HIV and how it affects them. She felt strongly that awareness among children and young people was important in helping children and young people to understand that: 'it's more widespread than they think, and they're not the only ones in this predicament'.

One woman noted that children in families marked by other health conditions get this kind of help, such as in the case of ADHD or depression. One woman suggested that a youth worker could coordinate support and services for affected children. Another mentioned the need for a buddy service that would provide people who would get to know the child over time and provide ongoing support. Yet another idea was a drop-in facility where you could take children for play and activities. Activities such as a drama group or a dance workshop would be welcome. These would provide opportunities for children to make contact with other affected children in the context of fun activities that weren't necessarily focused on their parents' HIV status. All of the women expressed wishes for opportunities to give their children experiences such as travel or participation in special activities, while still recognising the special needs of children affected by HIV. One parent also spoke about the importance of transition services for young people between the ages of fifteen and eighteen, an 'in-between service', where medication and counselling could be provided.

One parent from Edinburgh pointed out that it was crucial that services for children and young people continue to be provided free. She said: 'not having to pay for services that are there makes them more accessible and less stressful'.

Finally, one woman pointed out the lack of services targeted to the unique needs of HIV positive women. She could think of no services that targeted women as women and as mothers, and she noted that women are often focused on issues related to children. Thus, she argued, the lack of services aimed at women also impacts on their children, and similarly, services that help women as mothers would help their children as well.

4.3.3 Infected children and young people

The infected children and young people who were interviewed are noteworthy for a number of reasons. Firstly, although only five were interviewed, given that there are only 47 affected children and young people known to clinicians in Scotland, this accounts for over 10% of the total population of infected children. Secondly, amongst the five, there was remarkable diversity. This means that in spite of the small numbers, a wide variety of lifestyles, social backgrounds, class, age and ethnicity is demonstrated in this group. We cannot, of course, claim that any child or young person's story is representative of any other child. In many ways, a key finding is the unique experience of each young person, because they each had their own combination of supports and pressures which characterised their lives. Nevertheless, there were recurring themes which came up throughout the interviews, and these were often reproduced to some degree by the children affected by HIV, as will be discussed below.

Everything is 'normal'

Some children and young people struggled to present themselves, their lives and HIV as 'normal'. One 11-year old black African child/young person recently arrived in Scotland said poignantly:

> ''I want to be like the others in my class, same well like them, same well like other childrens.'

Sometimes, this seemed like wishful thinking rather than a reality. One 15-year old black African young person expressed this vividly:

> 'People just try to make the world so complicated, but everything is normal if you want it to be. […] HIV is just normal, you don't have to make a fuss about it - like on TV when they talk about HIV, they just try to make out as if it's the end of the world, but it isn't.'

Looked at from the outside, there is, in truth, little that is 'normal' about this young person's life or illness. The young person has been looked after by an elder sibling since they came to the UK two years ago. The young person has very few friends in the area and does not like the new school. The young person's father died when the person was very young and mother died two years ago. The young person has known about his/her HIV status since he/she was 11 or 12, and has felt quite unwell recently, not because of HIV, but because of new, stronger medication. The wish to be seen as 'normal' is, of course, part-and-parcel of adolescence. Research has consistently shown that adolescents will do anything not to be seen as different from their peers (see Coleman and Hendry, 1999). The need to be seen as 'normal' is also a strong indicator of the presence of stigma, as Cree *et al* (2003) have discussed in relation to children affected by parental HIV, and as will be illustrated again below.

Non-compliance to medication in teenage years

The scoping study has already identified that it is common to find young people with chronic illness (including HIV) refusing to take their medication in their teenage years. This might, from the outside, be understood as an illustration of familiar adolescent rebellious behaviour. Talking to HIV-infected children, however, the reasons become both more complex and also more understandable. It becomes clear that HIV is invisible to infected young people; it is the medication which reminds them that they have HIV, and it is (often) the medication which makes them feel ill. One 15-year old said:

> 'I got tired of taking medication because I had been taking it for a long time. I could not see any difference between taking the medicines or not taking it, so I decided to stop taking it.'

This does not mean that the young people who took part in the study did not experience adolescence too. One 17-year old was extremely insightful about this. She described having 'good and bad days…:

> '… teenage rebellion and things like that. It all sort of adds up and makes it difficult at home – they'll argue "white", I'll argue "black", just things like that, normal things. Things are not brilliant at the moment, but I am hopeful that things will sort out eventually.'

Some children and young people demonstrated considerable maturity as well as knowledge about their condition far beyond what might be expected of their years. One 13-year old said he was having a difficult time with his medication, which sometimes gives him 'an upset tummy' and makes him feel sick. But he said he is willing to stick with it for now. Another youth (aged 15) said that he had heard from another young person whom he met on an outing with a befriender about the advantage of having a gastronomy tube fitted so that medicine could go straight into the stomach. He raised this with his doctor who agreed to arrange this for him, and although the operation was painful and to start with he was afraid to do certain things, he is now able 'to do everything that I usually do'.

Disclosure: who knows about HIV?

None of the children and young people who were interviewed felt able to talk about their HIV outside a very small, strictly defined zone of safety, usually their home and the hospital or clinic they attend. One 15-year old girl said she could only talk about HIV with her brothers; even her cousin has not been told, and she said she felt unable to talk to her GP or nurse about any problems she might have. In another situation, a boy of 13 lives with his mother, and she is the only person who knows he has the virus. Yet he cannot talk to her about HIV, because, as he explains, 'I don't want to worry her'. One 15-year old youth from Edinburgh has been able to be a little more open about HIV, in the family and at school, where the guidance teacher knows about the illness, but again the line is sharply drawn here, and no-one else has been told.

Fear of disclosing HIV status is an ever-present theme in the HIV research literature, and is demonstrated again in the interviews with affected children. It is widely accepted that HIV carries stigma unlike any other chronic or terminal illness, because of its shared association with sexual behaviour and drug-taking. This makes disclosure of HIV such a risky activity for those infected and affected by the virus (Bor and Elford, 1998; Cree *et a*l, 2003; Green and Sobo, 2000; Mason *et al*, 2009).

Support services

The children and young people showed marked ambivalence to support services, and demonstrated a range of emotions in relation to the support they received and would like to receive in the future. Some said that they did not want to be singled out for specialist services, for the same reasons already explored in relation to the need to be 'normal':

> 'I don't think there should be something to separate people from, like, other people, cos that's going to make them feel like a bit selected or something else, so I'm fine the way I am.'

This young woman went on to say that she would like to do things which took her mind off her HIV – 'talking about it gets you worse and worse!' So she would like opportunities to make friends and have fun. This was echoed by an 11-year old girl who would like to go on a trip, to the countryside, out of the city, or to the cinema.

Both boys in the study talked animatedly about sport as their refuge from HIV. One 13-year old youth from Glasgow plays basketball and football, and goes to an after-school club which he enjoys. He said he would love to go camping in the future, but he also appreciates the opportunity now given to him by Waverley Care in Glasgow to talk to others in his situation. As he said: 'It brings out your emotions to other people who have the same illness as you.' The other young person (aged 15, living in Edinburgh) also loves playing football, but likes to go to Waverley Care where the children and young people's project worker 'is good at listening to stuff about HIV'.

This young person also raised another issue in relation to support services which emerged in the scoping study, that is, transition to adult services. He outlined his views about this clearly:

> 'The hospital [a children's hospital] - when I go for my check-ups, I don't like it, it's, how? – it's a bit *babyish*, but the adult hospital is a bit too adult. I want one just in-between.'

4.3.4 Affected children and young people

Many of the themes which came up in the infected children's interviews were reflected in the conversations with the children and young people who were affected by parental HIV. These themes also connect strongly with previous research in affected children in the 'Listening to Children' study. Seven children and young people affected by parental HIV spoke to us, aged between 'nearly 12' and 22 years of age. Most critically, what emerges is that there has been little improvement in the lives of children living with HIV in Scotland in the last 10 years since the first study of affected children began. In fact, there are fewer support services today than there were in 1999.

Childhood and adolescence plus parental HIV

A striking feature to emerge in all the interviews is that HIV is something which affects children's lives over and above the difficulties and worries which are part and parcel of most childhoods and adolescence. The children to whom we spoke told us about the good times in their lives: about playing with friends and going to youth clubs, about looking after their pets and marching with Majorettes. They also spoke about being bullied because of their body-size or red hair, and one young person talked about racist graffiti being daubed on the front door of his flat. The young people also described lives which were full of disruption and loss. They had experienced many changes of school, neighbourhood and friends, as well as parental separation and the loss of grandparent, parent and even, on two occasions, both parents. One young person also spoke about lack of money as his mother's greatest need. HIV was, for those children and young people, not simply an added burden; it was one which has to be kept secret and which never went away, even after a parent had died. One 16-year old told us that she cannot tell people about the cause of her mother's death even now, two years later; she always says that her mum died of 'liver failure'. She went on to explain further:

> '[My life] was quite different to other children. I mean, everybody's got their problems. I just feel that because mines was such a big secret, I couldn't tell anyone about it.'

This demonstrates not only the stigma that surrounds HIV (well documented in previous studies) but also the longevity of HIV's impact. HIV is part of affected children's childhoods, taking on greater and lesser significance at different times. Hence some of the children and young people said that they worried less, now that they were older and understood more, and perhaps because they had become accustomed to living with parental HIV. But, irrespective of their age, they still had to live with uncertainty and fear: fear that a parent might be taken ill and fear that they might die suddenly. Again, this picks up a major theme in the earlier study. In both studies, and in common with infected children (as already discussed) children wanted to see themselves as 'normal' children living with 'normal' parents', but HIV is a constant thread throughout their lives.

Disclosure

When asked about whom they talk to when they are worried, all the children and young people whom we met were able to identify someone they could talk to: usually a parent, but also a teacher, youth worker, befriender and social worker were mentioned. Children shared the dangers of disclosing a parent's HIV status. One young person described telling a friend about her mother's illness. Later they fell out and her former friend 'pure used it this against me, so I never told anybody after that'. Another young woman, now aged 17 years, expressed openly her mixed feelings about talking to our interviewer about her parent's HIV:

> 'It's weird talking to someone, because I've never really talked to anyone about my mum's HIV, or my feelings about it. It's like if you've never driven a bike and someone suddenly gives you a bike to ride. It's a bit weird.'

Support services

None of the affected children and young people who were interviewed in Glasgow was in touch with any support services; all those in Edinburgh were, mirroring the parents' findings. Looking ahead, the children and young people, again in common with those from the earlier study, expressed caution about whether additional services would help. They said that they felt that support should be available to all children, and they recognised that well-being is strongly related to activities such as football, sport, youth clubs, music and dancing. But they also called for more specialised services so that children and young people could be free to talk about HIV in a safe environment.

4.3.4 Discussion

Across all the interviews with parents and carers and children, themes emerge which centre on living with HIV, disclosure of HIV status to others, and support services. In addition, the interviews with practitioners provided important additional information about service provision, now, in the past, and in the future.

These findings mirror most of the issues which have already been touched on in the scoping study. The interviews also give substance to the 'facts' which emerged in the epidemiological survey. The reality of HIV as a family illness comes out prominently throughout the interviews, as does the impact of stigma on infected and affected children alike. The study has also thrown light on the reasons why teenagers' might be reluctant to take their medication. All the interviews emphasise the special situation of African people in Scotland (both adults and children), as well as drawing attention to the need for adolescent services; areas which again were highlighted in the scoping study.

The interviews leave us with a paradox. Practitioners, parents and children all stressed that children need to be treated as 'normal children', the same as every other child. But they also valued specialist services, and urged that these be extended across Scotland. The call to treat children 'the same' speaks very much to the current policy thrust of the Scottish Government in its focus on universal services for children, demonstrated in 'Getting it Right for Every Child' (GiRfEC), first launched in 2004. Guidance about the programme states that it is a 'national programme that aims to change the way adults think and act, to help all children and young people grow, develop and reach their full potential'. It aims to 'remove the obstacles that can block children's paths on their journey from birth to adulthood'. It will do this by adopting 'a common, coordinated approach across all agencies that supports the delivery of appropriate, proportionate and timely help to all children as they need it' (Scottish Parliament, 2008). GiRfEC has been put into practice across Scotland through the introduction of Local Authorities' Integrated Children's Services Plans. Interestingly, and perhaps not unexpectedly, these plans make little or no mention of HIV. Edinburgh City's Integrated Children and Young People's Plan (2008-2011), whilst making no mention of HIV, acknowledges that 'parents' misuse of alcohol and drugs is central in this', reflecting the historically high incidence of drug use in the capital. Glasgow City's Plan (2005-2008), currently being revised, does mention HIV. Encouragingly, it states:

> 'While there is a continuing expectation that there will be overall improvements in service quality across universal and specialist services, the above strategic objectives are aimed at ensuring improvements for children, young people, their families / carers whose access to mainstream services can be difficult, where they need additional supports or where these services do not best meet their needs. This includes children and young people [a long list continues here]….. who are affected by HIV/ AIDS; from refugee families; from Asylum Seeking families / who are seeking asylum.'

This gives hope for the future, although we have to wait and see what the revised plan holds. Overall, the GiRfEC programme is both inspirational and aspirational. But given the information which practitioners, parents and children have given us in this needs assessment, how confident can we be that mainstream agencies in health and social care will have enough knowledge and experience, and enough lack of prejudice, to be able to adequately support infected and affected children in universal services? Furthermore, if children are advised by their parents not to tell anyone about HIV, how will they be able to access the help they need from mainstream services? These questions remain critical for the conclusion and recommendations.

4.4 Summary

The qualitative study has highlighted the challenges for children infected and affected by HIV in living with the virus. Although children who are infected face extra physical and psychological difficulties related to their status, both infected and affected children have to live with what remains a secret and highly stigmatised illness. This comes over and above the normal childhood and adolescent challenges of growing up in Scotland, and over and above the additional issues of poverty, poor housing, and possibly insecure immigration status and discrimination. The children and young people who took part in this study showed themselves to be knowledgeable, reflective and resilient, but living with HIV undoubtedly brings additional needs which are not currently being met.

It has been acknowledged that children want to be treated as 'normal' children. The study has shown that this is especially difficult for black African families living in Scotland, where there is additional stress and where return to their country of origin might mean the loss of access to treatment such as ART and other medical care required for viral suppression of the infection. Our final assessment is that it is likely that there will continue to be specific needs for infected and affected children in Scotland in the years ahead: needs for social support from specialist HIV agencies (children and family workers, befrienders, buddies etc.), as well as intensive medical/clinical support. These are likely to exist over and above the provision of universal health, education and social work services.

5. Conclusions and Recommendations

This cross-sector needs assessment has identified a number of key issues facing children in Scotland who are infected with, and affected by, HIV. These will now be addressed in turn, and recommendations offered in each instance.

Issue 1

Whether children are infected with HIV or live with a parent or carer with HIV, they are all affected by HIV and, as such, are 'children in need' under the Children (Scotland) Act of 1995. These children are known to have special needs (physically, psychologically and socially). Yet they are barely mentioned in the Scottish Government's draft HIV Action Plan. Moreover, their needs are currently invisible in mainstream, universal, integrated children's services plans.

Recommendations

i) Scottish Government should re-examine its HIV Action Plan to take account of the experiences of infected and affected children.

ii) Local Authorities should, in turn, be asked to give special consideration to children infected with, and affected by, HIV in their integrated children's plans.

Issue 2

Children infected with and affected by HIV do not want to be singled out as different from other children. They want opportunities for education, fun and play like all children, but would also like the chance to meet others in the same situation as themselves, so that they can receive information and support in a safe and secure environment.

Recommendation

iii) Financial support should be made available (from central and local government) to voluntary agencies to allow them to maintain and extend their specialist provision to children and young people infected and affected by HIV.

Issue 3

Parents find it difficult to disclose their own HIV status to their children. They also find it difficult to tell their children that they are infected with HIV. Disclosure needs to be handled sensitively; it is not a single event, but is a gradual process which happens over time, and parents need expert help and support to cope with this and with their own issues around HIV in the family.

Recommendation

iv) HIV agencies should be funded to provide HIV training and support to practitioners in all agencies which work with parents and infected and affected children.

Issue 4

Children infected with HIV are living longer. They have particular needs in terms of health-care and support once they reach teenage years as well as guidance on sex education and relationships.

Recommendation

v) NHS Boards should review the provision they currently have for teenagers with HIV, and explore whether an adolescent clinic should be provided in their area.

Issue 5

The stigma which HIV carries remains extraordinarily high; no other terminal or chronic illness carries such stigma. The cost of this is high for individuals who carry the burden of shame and are unable to share their worries with others. It is also high for society, as those who are afraid to disclose their HIV status may put others at risk, both adults and children.

Recommendation

vi) There should be a new public health education campaign on HIV. This should stress the reality that HIV can affect anyone, straight or gay; white or black; adult or child.

Issue 6

HIV in Scotland disproportionately affects families of black African origin who also experience high levels of poverty, discrimination and hardship. Stigma is known to be a particular concern for African people in Scotland, who have little alternative but to keep HIV a secret from others.

Recommendation

vii) More targeted support should be made available to all black African families in Scotland (not only to those where there is known to be HIV), through funding of voluntary agencies to carry out this work.

Issue 7

Lothian and Greater Glasgow and Clyde Health Board areas experience high levels of demand in relation to infected and affected children, as well as new pressures connected with the rise in HIV-infection rates of children under 5 years affected by HIV.

Recommendation

viii) Additional funding should be made available from government to areas under greatest pressure to support their work in this area, at the same time, training must be delivered to health visitors and child care workers on HIV.

Issue 8

There are small pockets of children affected by HIV throughout Scotland.

Recommendation

ix) All Health Boards and statutory children's services should review their support to children in communities where there are small numbers of affected children, and explore funding voluntary HIV or children's charities to work with these children and families.

Issue 9

There is currently little opportunity for collaboration across and within Scotland between agencies providing services for infected and affected children.

Recommendation

x) A small sum should be set aside each year to enable one service provider (from a key voluntary HIV or children's agency) to bring agencies together and to act as a national coordinator and champion for HIV and children in Scotland. This could be spearheaded and managed by Scotland's Commissioner for Children and Young People (SCCYP).

Issue 10

There is no routine collection of data in relation to children affected by HIV in Scotland. Moreover, some children may remain undiagnosed and significantly at risk. Government and NHS agencies collect data on infected children in different ways, using different ages as the dividing line between children and adults.

Recommendations

xi) All adults should be asked in a sensitive and supportive way about their parental status (numbers and ages of children) when they are diagnosed with HIV and protocols for testing the children of HIV-positive parents must be worked out in collaboration with patients' and service users' groups .

xii) Government and NHS agencies should reconcile their differences in approaches to data collection in relation to infected children.

6. References

Alderson, P. (1995) *Listening to Children. Children and Social Research Ethics,* London: Barnardo's.

Aldridge, J. & Becker, S. (1993) *Children who Care: Inside the World of Young Carers*. Department of Social Science, Loughborough: Loughborough University.

Alexander, H. (1995) *Young Carers and HIV*, Edinburgh: Children in Scotland.

Altschuler, J. (1997) *Working with Chronic Illness*, Basingstoke: Macmillan.

Anderson, W.J. and Weatherburn, P. (2003) 'The needs of people with HIV in the UK: findings from a national survey', *International Journal of STD & AIDS,* 15 (12): 793-796.

Batty, D. (Ed.) (1993) *HIV Infection and Children in Need*, London: BAAF*.*

Bechhofer, F. and Paterson, L. (2000) *Principles of Research Design in the Social* Sciences, London: Routeldge.

Becker, S. (2007) 'Global Perspectives on Children's Unpaid Caregiving in the Family', *Global Social Policy*, 7 (1): 23-50.

BHIVA/CHIVA /BASHH (2009) '*Don't Forget the Children'. Guidance for the HIV Testing of Children with HIV-Positive Parents,* Available at: www.bhiva.org/

British Red Cross (2007) *HIV: What's the Story?* Available at: www.redcrosshiv.org/

Bor, R. and Elford, J. (1998) *The Family and HIV Today. Recent Research and Practice*, London: Cassell.

Brown, L.K., Lourie, K.J. and Pao, M. (2000) 'Children and Adolescents Living with HIV and AIDS: a Review', *Journal of Child Psychology and Psychiatry*, 41 (1): 81-96.

Burns, F.M., Fakoya, A.O., Copas, A.J. and French, P.D. (2001) 'Africans in London continue to present with advanced HIV disease in the era of highly active antiretroviral therapy', *AIDS*, 15 (18): 2453-2455.

Carlisle, C. (2001) 'HIV and AIDS', in Mason, T., Carlisle, C., Watkins, C., and Whitehead, E. (eds) *Stigma and Social Exclusion in Healthcare*, London: Routledge.

Child Health Support Group (2004) Review of Tertiary Paediatric Services in Scotland Draft Report 9th November 2004, Available at: www.sehd.scot.nhs.uk/cyphsg/documents/

Chinouya-Mudari, M. and O'Brien, M. (1999) 'African Refugee Children and HIV/AIDS in London', in Aggleton, P., Hart, G. and Davies, P. (eds) *Families and Communities Responding to AIDS*, London: UCL Press.

Chiriboga, C.A., Fleishman, S., Champion, S., Gaye-Robinson, L., Abrams, E.J. (2005) Incidence and prevalence of HIV encephalopathy in children with HIV infection receiving highly active anti-retroviral therapy (HAART), *Journal of Pediatrics,* 146 (3): 402-407.

Claxton, R. and Harrison, T. (eds) (1991) *Caring for Children with HIV and AIDS*, Sevenoaks: Edward Arnold.

Coleman, J. and Hendry, L.B. (1999) *The Nature of Adolescence*, 3rd edition, London: Routledge.

Conway, M. (2006a) *Developing Support Services for Children, Young People and Families Living with HIV*, London: National Children's Bureau.

Conway, M. (2006b) *Children, HIV, Asylum and Immigration*, London: National Children's Bureau.

Cree, V.E., Kay, H. and Tisdall, K. (2002) 'Research with children: sharing the dilemmas', *Child and Family Social Work*, 7 (1): 47-56.

Cree, V.E. (2003) 'Worries and problems of young carers. issues for mental health', *Child and Family Social Work*, 8 (4): 301-309.

Cree, V.E., Kay, H., Tisdall, K. and Wallace, J. (2004a) 'Social support and children affected by parental HIV, *European Journal of Social Work* 7 (2): 195-210.

Cree, V.E., Kay, H., Tisdall, K. and Wallace, J. (2004b) 'Stigma and parental HIV', *Qualitative Social Work*, 3 (1): 7-25.

Cree, V.E., Kay, H., Tisdall, K. and Wallace, J. (2006) 'Listening to Children and Young People Affected by Parental HIV: Findings from a Scottish Study', *AIDS Care*, 18 (1): 73-76.

Cree, V.E. (2008) '*It's Good to Go for a Test', Report of the Evaluation of Waverley Care's HIV Testing Campaign in Glasgow*, Edinburgh: Waverley Care.

Crusaid/Waverley Care (2007) *Poverty and HIV*, Edinburgh: Waverley Care.

Drotar, D. (Ed.) (2000) *Promoting Adherence to Medical Treatment in Chronic Childhood Illness. Concepts, Methods, and Interventions*, London: Psychology Press.

Eiser, C. (1990) 'Psychological Effects of Chronic Disease', *Journal of Child Psychology and Psychiatry*, 38 (7): 823-829.

Ely, A. (2008) *Looking after HIV: Considering the Needs of HIV Positive Looked After Children*, London: National Children's Bureau.

Evans, R. and Becker, S. (2007) *Hidden Young Carers: The Experiences, Needs and Resilience of Children Caring for Parents and Relatives with HIV/AIDS in*

Tanzania and the UK: Stakeholder Report Executive Summary, Nottingham, UK: School of Sociology and Social Policy, University of Nottingham.

Evans, R. and Becker, S. (2009) *Children Caring for Parents with HIV/AIDS: Global Issues and Policy Responses,* Bristol: The Policy Press.

Foster, C.J., Biggs, R.L., Melvin, D., Walters, M.D.S., Tudor-Williams, G. and Lyall, E.G.H. (2006) 'Neurodevelopmental outcomes in children with HIV infection under 3 years of age', *Developmental Medicine & Child Neurology*, 48: 677-682.

Gibb, D., Duong, T., Tookey, P.A., Sharland, M., Tudor-Williams, G., Novelli, V., Butler, K., Riordan, A., Farrelly, L., Masters, J., Peckham, C.S. and Dunn, D.T. (2003) 'Decline in mortality, AIDS, and hospital admissions in perinatally HIV-1 infected children in the United Kingdom and Ireland', *British Medical Journal* (327): 1019-1024.

Gray, D.E. (2009) *Doing Research in the Real World*, 2nd edition, London: Sage.

Green, G. and Sobo, E.J. (2000) *The Endangered Self. Managing the Social Risks of HIV*, London: Routledge.

Hankin, C.D., Newell, M.-L. and Tookey, P. (2007) 'Long-term follow-up of uninfected children born to HIV-infected women and exposed to antiretroviral therapy: survey of parents' and professionals' views', *AIDS Care*, 19 (4): 482-486.

Health Protection Agency (HPA) (2009) 'New HIV diagnoses in the United Kingdom: data to the end of December 2008', *Health Protection Report* [serial online] 2009; 3 (12): HIV/STIs. Available at: www.hpa.org.uk/hpr/archives/2009/hpr1209.pdf/

Health Protection Agency (HPA) (2008) *HIV in the UK: 2008 Report*. December 2008. Available at: www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1227515299695/

Health Protection Scotland (HPS) (2008) *Focus HIV in Scotland 2007: review*, HPS weekly report. 2008; 42: 0804: Available at www.hps.scot.nhs.uk/bbvsti/

Health Protection Scotland (HPS) (2009) HIV infection and AIDS: Quarterly report to 31 March 2009 (ANSWER), Available at: www.hps.scot.nhs.uk/ewr/

Health Scotland (2008) *Respect and Responsibility: Delivering Improvements in Sexual Health Outcomes 2008-2011*, Available at: www.healthscotland.com/uploads/documents/8411-R&Routcomes200820011_final.pdf

Health Scotland (2009) *Health Care Needs Assessment of Treatment and Care Services for People Living with HIV – Scrutiny review of draft report (Jan 09),* Available at: www.healthscotland.com/uploads/documents/9752-Scrutiny%20final%20220509.pdf/

Hindle, D. (1998) 'Growing up with a parent who has a chronic mental illness: one child's perspective', *Child & Family Social Work,* 3: 259-266.

Honigsbaum, N. (1991) *HIV, AIDS and Children. A Cause for Concern,* London: National Children's Bureau.

Imrie, J., Coombes, Y. (1995) *No Time to Waste: the Scale and Dimension of the Problem of Children Affected by HIV/AIDS in the United Kingdom,* London: Barnardos.

Inglis, S. and Morton, S. (1996) *Children affected by HIV in Dundee, Edinburgh and Glasgow*, Edinburgh: Children in Scotland.

Johnman, C. (2009) *Treatment and Care Needs Assessment: People Living with HIV*, *Scottish Public Health Network (ScotPHN) Report: Draft For Stakeholder Review (09/03/09-08/04/09)*, Edinburgh: ScotPHN.

Judd, A., Doerholt, K., Tookey, P.A., Sharland, M., Riridan, A., Menson, E., Novelli, V., Lyall, E.G.H., Masters, J., Tudor-Williams, G., Duong, T. and Gibb, D.M. (2007) 'Morbidity, Morality, and Response to treatment by Children in the United Kingdom and Ireland with Perinatally Acquired HIV infection during 1996-2006: Planning for Teenage and Adult Care', *Clinical Infectious Diseases* 45 (1 October): 918-924.

Kay, H., Cree, V.E., Tisdall, K. and Wallace, J. (2003) 'At the Edge: Negotiating Boundaries in Research with Children and Young People', [54 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* [On-line Journal], *4*(2). Available at: www.qualitative-research.net/fqs-texte/2-03/2-03kayetal-e.htm/

King E, De Silva M, Stein A, Patel V. (2009) 'Interventions for improving the psychosocial well-being of children affected by HIV and AIDS', *Cochrane Database of Systematic Reviews* 2009, Issue 2. Art. No.: CD006733. Available as DOI: 10.1002/14651858.CD006733.pub2/

Lee, R.M. (1993) *Doing Research on Sensitive* Topics, London: Sage.

Lewis, E. (2001) *Afraid to Say. The Needs and Views of Young People Living with HIV/AIDS*. London: National Children's Bureau.

Logan, D., Zelikovsky,N., Labay, L. and Spergel, J. (2003) 'The Illness Management Survey: Identifying Adolescents' Perceptions of Barriers to Adherence', *Journal of Pediatric Psychology*, 28 (6): 383-392.

Malcolm, A., Aggleton, P., Bronfman, M., Galvao, J., Mane, P., and Verrall, J. (1998) 'HIV-related stigmatization and discrimination: its forms and contexts', *Critical Public Health* 8 (4): 347-370.

Mason, S., Berger, B., Ferrans, C.E., Sulzman, V. and Fendrich, M. (2009) 'Developing a Measure of Stigma by Association with African American Adolescents Whose Mothers Have HIV', *Research on Social Work Practice*, Online First, published on April 23, 2009, Available as DOI:10.1177/1049731508330223.

McLaughlin, H. (2007) *Understanding Social Work Research*, London: Sage.

McClory, J. (1996) 'What Shall I Tell the Children?' in Morton, S. and Johnson, D. (eds) (1996) *Children and HIV. Supporting Children and their Families,* Edinburgh: The Stationery Office.

Melvin, D. (1997) 'Don't Forget the Children': Families Living with HIV Infection', in Sherr, L. (Ed.) *AIDS as a Gender Issue*, London: Taylor & Francis.

Melvin, D. and Biggs, R. (2007) *Monitoring Developmental Outcomes in Paediatric HIV Infection*, London: CHIVA Children's HIV Association of UK and Ireland, Available at: http:www.chiva.org.uk/protocols/Developmental.html

Melvin, D. and Sherr, L. (1993) 'The Child in the Family – Responding to AIDS and HIV', *AIDS Care* 5 (1) 35-42.

Melvin, D., Krechevsky, D., Divac, A., Tacconelli, E., Miah, J., Waugh, S. *et al* (2007) 'Parental reports of emotional and behavioural difficulties on the SDQ for school-age children with vertically acquired HIV infection living in London', *Psychology, Health & Medicine* 12 (1): 40-47.

Miah, J. (Ed.) (2004) *Talking with Children, Young People and Families about Chronic Illness and Living with HIV*, London: National Children's Bureau.

Miller, R. and Murray, D. (1999) 'The Impact of HIV Illness on Parents and Children, with Particular Reference to African Families', *Journal of Family Therapy*, 21: 284-302.

Mok, J. and Cooper, S. (1997) 'The Needs of Children whose Mothers have HIV Infection', *Archives of Disease in Childhood,* 77: 483-487.

Morris, K. (Ed.) (2008) *Social Work and Multi-Agency Working. Making a Difference*, Bristol: BASW/Policy Press.

Morton, S. and Johnson, D. (eds) (1996) *Children and HIV. Supporting Children and their Families,* Edinburgh: The Stationery Office.

Papola, P., Alvarez, M. and Cohen, H.J. (1994) 'Developmental and Service Needs of School-age Children with Human Immunodeficiency Virus Infection: a Descriptive Study', *Pediatrics*, 94: 914-918.

Prime, K.P., Jungmann, E.A. and Edwards, S.G. (2004) 'Decline in morality in children with HIV in the UK and Ireland. HIV positive adolescents urgently need dedicated serices', *British Medical Journal*, 328: 524 (February).

Rutter, M. and Taylor, E. (2002) *Child and Adolescent Psychiatry*, 4th edition, Oxford: Blackwell Science.

Schafer, W. (2005) 'The uneven globality of children', *Journal of Social History,* Summer 2005: 1027-1039, Available at: http://muse.jhu.edu/

Scottish Executive (2005) *Respect and Responsibility: Strategy and Action for Improving Sexual Health,* Edinburgh: Scottish Executive, Available at: www.scotland.gov.uk/Resource/Doc/35596/0012575.pdf

Scottish Government (2007) *Better Health, Better Care: Action Plan*, Edinburgh: Scottish Government, Available at: www.scotland.gov.uk/Resource/Doc/206458/0054871.pdf/

Scottish Government (2009a) *HIV Proposed Action Plan in Scotland, Phase One: May 2009 to March 2011*, Available at: www.hps.scot.nhs.uk/bbvsti/spotlightdetail.aspx?id=187/

Scottish Government (2009b) *HIV Action Plan in Scotland, September 2009 to March 2014, Final Draft 10 August 2009*, Edinburgh: Scottish Government.

Scottish Parliament (2008) *Getting it Right for Every Child,* Edinburgh: Scottish Government, Available at: www.scotland.gov.uk/Topics/People/Young-People/childrensservices/girfec/

Sethi, G., Lacey, C.J., Fenton, K.A., Williams, I.G., Fox, E., Sabin, C.A., Shaw, A. and Kapembwa, M. (2004) 'South Asians with HIV in London: is it time to rethink sexual health service delivery to meet the needs of heterosexual ethnic minorities?' *Sexually Transmitted Infections,* 80: 75-76.

Shanbhag, M.C., Rutstein, R.M., Zaoutis, T., Zhao, H., Chao, D. and Radcliffe, J. (2005) 'Neurocognitive functioning in pediatric human immunodeficiency virus infection: effects of combined therapy', *Archives of Pediatric Adolescent Medicine* 159 (7) 651-656

Sidhva, D. (2004) *Living with HIV/AIDS: Turning Points, Transitions and Transformations in the Lives of Women from Bombay and Edinburgh,* Edinburgh: The University of Edinburgh, Unpublished PhD Dissertation.

Sinyemu, E. and Baillie, M. (2005) *HIV Becomes your Name*, Edinburgh: Waverley Care.

Sontag, S. (1988) *Illness as Metaphor; AIDS and its Metaphors*, London: Penguin.

Thorne, C., Newell, M. L., Botet, F.A., Bohlin, A. B., Ferrazin, A., Giaquinto, C., de José Gomez, I., Mok, J.Y., Mur, A. and Peltier, A. (2002) 'Older Children and Adolescents Surviving With Vertically Acquired HIV Infection', *Journal of Acquired Immune Deficiency Syndromes*, 29: 396–401.

Tisdall, E.K.M., Kay, H., Cree, V.E. and Wallace, J. (2004) 'Thinking positively. Listening to Children and young people whose parent or carer is HIV positive', *British Journal of Social Work* 34 (8): 1097-1115.

Tisdall, K.M., Davis, J.B., Gallager, M. (2008) *Researching with Children and Young People: Research Design, Methods And Analysis*, London: Sage.

Triseliotis, J. (1973) *In Search of Origins*, London: Routledge and Kegan Paul.

Triseliotis, J., Shireman, J. and Hundleby, M. (1997) *Adoption: Theory, Policy and Practice*, London: Cassell.

UNICEF (2009) *HIV Prevention with Young People: The Key to Tackling the Epidemic,* Available at: www.unicef.org.uk/publications/pub_detail.asp?pub_id=199/

Wallace, J., Cree, V.E., Kay, H., Tisdall, K. (2006) 'Risk and HIV: Scottish Schools' Approaches to HIV Education, *Scottish Affairs* 55: 107-124.

Wigersma, L., Singh, S. and van den Boom, F.M. (1998) 'Meeting the Needs of those Infected and Affected by HIV/AIDS, *AIDS Care* 10 Suppl 1: S5-8

7. Appendices

7.1 Questionnaire on Affected Children

HIV and Children and Young People in Scotland

Name of Organisation:

Please complete the following form for each child and young person (under 18) known to your service:

Codes	
parent/carer HIV infected	H
parent/carer HIV infected who has died	D
brother/sister HIV infected	SH
brother/sister HIV infected who has died	SD
other household member HIV infected	OH
other household member HIV infected who has died	OD

Sample
Eight year old Joanne McFie's mother has died of AIDS, and her step-father is HIV infected:

				Nature of household (see above codes)					
	initials	**age**	**gender**	**H**	**D**	**SH**	**SD**	**OH**	**OD**
1	JM	8	F		X			X	
2									

				Nature of household (see above codes)					
	initials	**age**	**gender**	**H**	**D**	**SH**	**SD**	**OH**	**OD**
1				☐	☐	☐	☐	☐	☐
2				☐	☐	☐	☐	☐	☐
3				☐	☐	☐	☐	☐	☐
4				☐	☐	☐	☐	☐	☐
5				☐	☐	☐	☐	☐	☐
6				☐	☐	☐	☐	☐	☐
7				☐	☐	☐	☐	☐	☐
8				☐	☐	☐	☐	☐	☐

9				☐	☐	☐	☐	☐	☐	☐

7.2 Interview Schedules

7.2.1 Practitioners

At beginning

Explain about the research project; why the study is important; what will be done with information given.

The interview

The interview should address six main areas.

1. What services does your agency provide? How long has your organisation been in existence? Who are your service users? Has this changed at all, if so, how? What do you see as the strengths and limitations of the services that your agency provides? Do you see any barriers to people accessing your agency's services?

2. Which other agencies do you work closely with? Are these statutory or voluntary or both? Are these general or specialist or both? What do you see as the strengths and limitations of the services that other agencies provide? Can you identify any barriers to using those services?

3. Does your agency provide services for children? What are they? Are these targeted at affected or infected children or both? What do you see as the strengths and limitations of the children's services that your agency provides? Are there any barriers to children accessing your agency's services?

4. What do the children and young people who use your services tell you about the services that they use?

5. What else could/should be done that isn't being done now? Are there any gaps in provision that you can identify? Do you think that children and young people's services should be exclusive to children or delivered as part of family services?

6. What do the children and young people who use your services tell you about their needs and about their aspirations for service delivery in the future?

7. Is there anything finally you would like to tell me?

7.2.2 Parents & Carers

At beginning

Explain about the research project; how we heard about them; why the study is important; confidentiality limits and about what will be done with information given.

The interview

The interview should address six main areas.

1. Who is in your family? Who isn't in your family anymore? How does everyone get on with each other?
2. Where do you stay? Are people round about friendly? Do people help each other out with child care or anything else? Have you ever had to move house? Why?

3. What else is going on in your life? Are you working at all? Or studying? What about voluntary work?

4. Who in the family has HIV? Who knows about this? How does HIV affect you? And how does it affect your child/children? Do they have to do housework or help you in any other way? Do they come to the hospital or doctor's surgery with you?

5. What support do you have in your life? Who do you talk to about HIV? What services do you use? How do you feel about them? (mainstream/general and specialist (ie HIV) services) Are there any barriers to using services? What services do your children use? How do you feel about them?

6. What else could be done to help you that isn't being done now? – any ideas about what you might use if it were available? What should we be suggesting that government and charities should set up in the future?

7. Is there anything finally you would like to tell me?

Wind down

Share information/leaflets about possible avenues of support.

7.2.3 Infected Children and Young People

At beginning

Explain about the research project; how we heard about the young person; why it is important; confidentiality limits and about what will be done with information given.

The interview

The interview should address six main areas. The discussion should be free flowing and follow the leads from the child.

1. Who is in your family? *(in words or pictures, or using props)-* close and extended family; parents, grandparents, siblings, aunts/uncles; who is inside and who is outside the family? Who isn't in your family anymore? How do you get on with the folk in your family?

2. Where do you stay? Are people round about friendly? Do people help each other out with child care or anything else? Can you go outside to play? What things do you enjoy doing? Have you ever been bullied in the neighbourhood? Have you ever had to move house or school? Why was this?

3. Where do you go to school? Do you like school or not? What is it that you like about school? Do you have a favourite teacher? Who is this and why? What do you do after school? Are there any clubs and organisations that you go? What do

you like about them? Do you take part in any sports at all? Do you help out in any way at school or a club or anything else?

4. What do you know about HIV? Who told you about it? Who else in your family has HIV? How does HIV affect you? – are you ill at all? – what happens when you're ill? do you have to go to hospital sometimes? What happens? Do you have a regular doctor or nurse that you see? What about your medication?

5. What support do you have in your life? Who do you talk to if you have a worry? (family member/ doctor/nurse/ teacher/ social worker/ friend?) (try to check out any distinction being made between mainstream/general and specialist (ie HIV) services).

6. What else could be done to help you that isn't being done now? – any ideas about what you might use if it were available? What should we be suggesting that government and charities should set up in the future?

7. Is there anything finally you would like to tell me?

Wind down
Share information/leaflets about possible avenues of support.

7.2.4 Affected Children and Young People

At beginning
Explain about the research project; how we heard about the young person; why it is important; confidentiality limits and about what will be done with information given.

The interview
The interview should address six main areas. The discussion should be free flowing and follow the leads from the child.

1. Who is in your family? *(in words or pictures, or using props)-* close and extended family; parents, grandparents, siblings, aunts/uncles; who is inside and who is outside the family? Who isn't in your family anymore? How do you get on with the folk in your family?

2. Where do you stay? Are people round about friendly? Do people help each other out with child care or anything else? Can you go outside to play? What things do you enjoy doing? Have you ever been bullied in the neighbourhood? Have you ever had to move house or school? Why was this?

3. Where do you go to school? Do you like school or not? What is it that you like about school? Do you have a favourite teacher? Who is this and why? What do you do after school? Are there any clubs and organisations that you go? What do you like about them? Do you take part in any sports at all? Do you help out in any way at school or a club or anything else?

4. What do you know about your mum/dad's HIV? Who told you about it? Who else knows? Does anyone else in your family have HIV? How does your mum or dad's

HIV affect you? – are they ill at all? what happens when a parent is ill? What are you expected to do at home? Is this different or the same if parent is unwell? Are there any gender differences here between you and your sibling/s (change language!) Does this seem to be similar to other children you know or not?

5. What support do you have in your life? Who do you talk to if you have a worry? (family member/ teacher/ doctor/nurse/ social worker/ friend?) (try to check out any distinction being made between mainstream/general and specialist (ie HIV) services).

6. What else could be done to help you that isn't being done now? – any ideas about what you might use if it were available? What should we be suggesting that government and charities should set up in the future?

7. Is there anything finally you would like to tell me?

Wind down

Share information/leaflets about possible avenues of support.

---

[1] It has recently been estimated that there are 5.5 million young people aged 15–24 years with HIV worldwide, about two-thirds of whom are female (UNICEF, 2009).