Children, HIV, Asylum & Immigration

An overview of the current situation for children living with HIV and insecure immigration status

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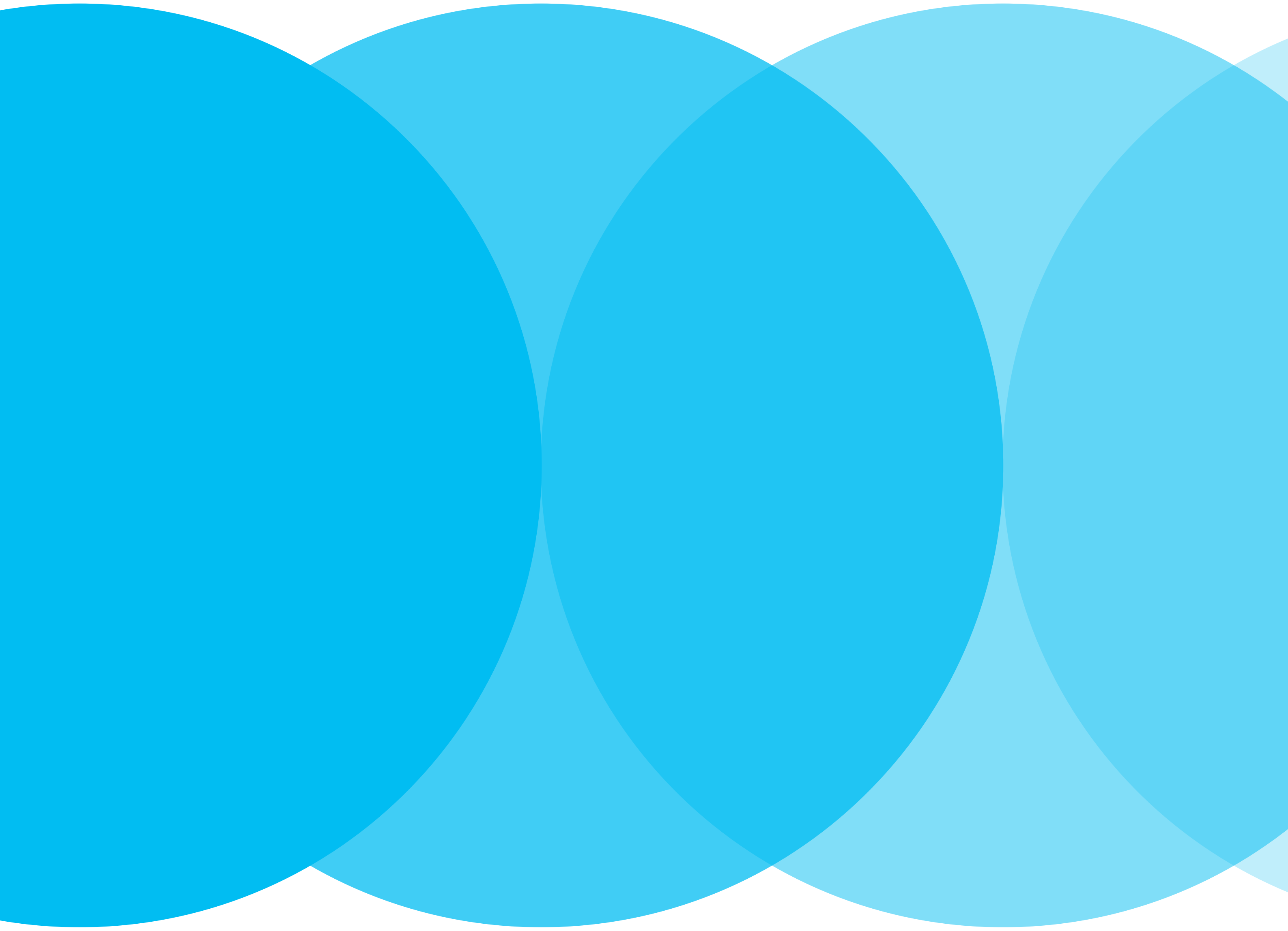

Content

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Foreword

Asylum and immigration has over recent years been high on the political agenda and generated much press coverage, frequently negative. A number of reports have presented the impact that the system has had and is having on adults living with HIV and separately on children in general, issues often ignored in the media.

This report combines an examination of current policy and legislation with case studies and practitioners responses, exploring areas of the immigration system and the experiences of children and their families within these. It allows us an insight into the specific issues faced by children infected with, or affected by HIV inside and outside of the asylum system, a group who until now have been silent and their experiences not reported.

The recommendations within this report suggest possible changes that would offer practitioners clarity in their work, ensure they can provide the best service available to these children and make a positive impact on their lives and their families.

Neil Gerrard

NEIL GERRARD MP
Chair of the All-Party Parliamentary Group on AIDS

Introduction

This report presents the experiences of children and families who are either infected with, or affected by, HIV and who have insecure immigration status. The aim is to see if HIV makes a difference to the lives of these children and the issues they face being in the UK as asylum seekers, visa overstayers or undocumented people. There are many issues for children in the UK living with insecure immigration status, but this report strives to understand how children and their families experience the combined impacts of living with HIV while also living with insecure immigration.

The Children and Young People HIV Network collected information and data through questionnaires, case studies and through a number of interviews. To this end, the information presented is dictated by practitioners' responses. All unreferenced quotes are from the returned questionnaires.

Section 1 presents the current legal and political situation and includes immigration and asylum, health and children's policy and legislation, as well as relevant frameworks and strategies.

Section 2 explores how practitioners see the situation for families living with HIV impacting upon child development and the child's interaction with services.

Section 3 reports on the general findings relating to children and families living with HIV and their experiences in the immigration system.

Section 4 looks specifically at dispersal and detention of children and families living with HIV.

Section 5 explores the issue of access to free NHS treatment for both HIV infected pregnant women and HIV infected children with insecure immigration status.

Section 6 uses a case study of a children and family HIV service to demonstrate the impact that asylum and immigration has had on practitioners and the nature of the services being provided.

Section 7 concludes the report and offers recommendations.

There are approximately 1,200 HIV infected children being seen in HIV paediatric services in the UK, half were not born in the UK[i]. Not being born in the UK does not immediately infer insecure immigration status. Our sample of health questionnaires represented 611 HIV infected children. On average services reported 19 per cent of their children as having insecure immigration status. Therefore, we estimate approximately 200–250 HIV infected children with insecure immigration status are living in the UK.

For practitioners attempting to address the health and support needs of children and families, there is clearly a struggle with the complexities of asylum and immigration legislation. Some services may have concluded that a family has no financial entitlements, when actually they do, or that a family has financial entitlements under current legislation, when they do not. This highlights how keeping abreast of complex and changing asylum and immigration legislation is not always possible.

Unaccompanied asylum seeking children (UASC) rarely featured in the information gathered. The presumption is that those whose age is not disputed are in public care and therefore theoretically have better support, have access to free NHS services and at present are neither dispersed nor detained. Therefore, a recommendation is that further research is undertaken in relation to the experiences of UASC infected with HIV.

Terminology

For the purpose of this report the following terminology will be used:

Affected refers to a person who has one or more family members infected with HIV

ARVs (Anti-retrovirals). This is the general name given to the combinations of HIV-suppressing drugs that are prescribed to patients

Child/ren refers to those under 18 years of age

Infected refers to a person who is infected with HIV

Insecure immigration status refers to those whose case is in the process of being considered within the immigration system, who have failed in an attempt to remain in the UK or who have entered or currently reside here illegally. It includes asylum seekers, refugees, visa overstayers and undocumented people. With the exception of UASC, this refers to the immigration status of the parent/guardian, as children do not make separate claims within the system and are included on an adult claim.

Living with HIV refers to both infected and affected people/families

NASS National Asylum Support Service

Parent/carer is used to represent anyone with parental responsibility for a child, so includes carers, foster parents and stepparents

UASC Unaccompanied asylum seeking children

VCS Voluntary and community sector

Information and Data Collection

Health, statutory and voluntary sector services were approached to provide information for this report. Predominantly they were asked qualitative questions and to relay their experiences through questionnaires, interviews and case studies. Many organisations and individuals requested they be kept anonymous. To this end, all quotes and case studies make no reference to names, places and regions, and do not refer to individuals or services.

Questionnaires were distributed to give practitioners the opportunity to share their experiences from the last year (August 2005 to July 2006).

Health Questionnaire

To the health questionnaire we received 15 responses, with the number of children treated by each centre varying from 1–200, with an average of 41. In total, 611 HIV infected children were represented by the questionnaires. This represents just over a half of the entire number of HIV infected children being treated by paediatric HIV services across England, Wales and Northern Ireland. We then asked what percentage of cases had insecure immigration status. Responses varied with the mean as 19 per cent; therefore this report represents the experiences of approximately 116 HIV infected children.

Each centre or service was asked to send one reply per team. These teams varied from ‘2 Nurses, 3.5 Doctors, Psychologist, Dietician, Pharmacists and Coordinator’ to ‘1 [Doctor] – me, plus support when required from adult genitourinary medicine (GUM) doctor and nurse specialist’; 40 per cent of responses were from outside of London. Therefore, this is a fair representation of current spread of service provision for HIV infected children across the country.

Support Service Questionnaire

Thirteen support services returned questionnaires. All of these were from specialist HIV services. Initially, we wanted to establish how many families living with HIV had been seen at the HIV service over the last 12 months. This ranged between five and 150, with the total number of 555 families. Again we asked what percentage of cases had insecure immigration status. This varied between 4 per cent and 100 per cent, with the mean as 45 per cent; therefore this report represents the experiences of approximately 250 families.

Interviews were conducted with a number of individuals from a variety of organisations. These provided a more in-depth insight into the current situation for children and families. The case studies were gathered through interviews and by distributing case study forms. In total, 25 case studies were gathered, many of which are present in this report.

Section One

The Implications of Policy and Legislation for Children Living with HIV and Insecure Immigration Status

Children with insecure immigration status who are infected or affected by HIV come under a wide range of policy and legislation in the UK. These policies can sometimes be in conflict with, and may not always be driven by, the need to ensure that these children achieve the best outcomes both for their health and general well-being.

The first conflict to acknowledge is that children's rights issues are UK-wide, and immigration and asylum is a reserved issue, which means it is the responsibility of the Westminster government. Child welfare issues are devolved, which means that the legislation governing children's social care, and the delivery of strategies such as Every Child Matters, are different in each of the four nations (England, Wales, Scotland and Northern Ireland). This presents some tensions in that child welfare and immigration policy are not joined up. Health adds further complexity; although NHS services are available across the UK, the planning and resource structure is different in each of the four nations.

This section explores children's rights, child welfare, health policy, and immigration and asylum policy within the context of how they impact on children living with HIV and insecure immigration status.

1.1 Children's Rights

The UN Convention on the Rights of the Child (UNCRC) was ratified by the UK in 1991. This Convention sets out the basic rights of children under 18 years without exception or discrimination of any kind, stipulating that the best interests of the child must be the primary consideration in all matters affecting children (Article 3); that children's survival and development must be ensured (Article 6); and that children have the right to participate in decisions that affect them (Article 12).

As well as these general rights, the UNCRC sets out two articles that are of particular interest when looking at the health needs in respect to this group of children:

> 'Article 24: States parties recognise the rights of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States parties shall strive to ensure that no child is deprived of his or her right of access to such healthcare services'

> ‘Article 22: State parties shall take appropriate measures to ensure that a child who is seeking refugee status or who is considered a refugee in accordance with applicable international or domestic law and procedures shall, where unaccompanied or accompanied by his or her parents or by any other person, receive appropriate protection and humanitarian assistance in the enjoyment of applicable rights set forth in the present convention and in other international human rights or humanitarian instruments to which the said states are parties.’

However the UK has a reservation to Article 22 of the UNCRC that has the effect of making immigration law take precedence over any child welfare legislation that prioritises the best interests of the child. The reservation reads: ‘The UK reserves the right to apply such legislation (in so far as it relates to the entry into, stay in and departure from the UK of those who do not have the right under the law of the United Kingdom to enter and remain in the UK, and to the acquisition and possession of citizenship) as it may deem necessary from time to time. The UNCRC was not designed to provide new immigration and nationality rights and the UK government believes our reservation to the Convention is necessary in the interest of effective immigration control.’

The wording ‘from time to time’ may be open to debate. Since 1991, there have been six major pieces of immigration, asylum and nationality legislation, and more is expected in the 2006–7 session of Parliament. In short, the UK’s reservation to the UNCRC means immigration law takes precedence over the best interests of the child ‘where the two conflict’.

The Joint Committee on Human Rights[ii] and the UN Committee on the Rights of the Child (concluding observations 1995 and 2002) have both recommended that the reservation be withdrawn on the basis that it contradicts the object and purpose of the UNCRC yet, to date, it still remains.

Everyone in the UK has the protection of the European Convention on Human Rights (ECHR) as enshrined in UK law in the Human Rights Act 1998. This is not child-specific, but relevant Articles include: Article 2 (the right to life); Article 3 (the right to not be subject to torture and inhuman and degrading treatment); Article 5 (deprivation of liberty); and Article 8 (right to a family and private life).

1.2 Child Welfare

Child welfare is a devolved issue, which means that arrangements are different in each nation of the UK. In England and Wales, the relevant pieces of legislation are the Children Acts 1989 and 2004; and the main policy document is Every Child Matters published in 2003.

Every Child Matters sets out five outcomes that all children should be supported to achieve:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic well-being

Under the ‘be healthy’ outcome, children and young people should be physically healthy, mentally and emotionally healthy, sexually healthy, have healthy lifestyles and choose not to take illegal drugs. However the targets and indicators used as measurements under the outcome do not currently cover HIV prevalence.

The Children Act 1989 sets out that the best interests of the child should be the primary consideration in any court decision on the upbringing of the child, and that wherever possible a child should be brought up and cared for within their own families.

The Children Act 2004 provides a new framework for children’s services in England and Wales. This includes a new duty on relevant bodies to make arrangements to ensure that their functions are discharged having regard to the need to safeguard and promote the welfare of children (Section 11). What is important here is that the new duty does not apply to the National Asylum Support Service (NASS), immigration removal centres or Chief Immigration Officers at a port of entry. The rationale from government is that ‘a duty to have regard to the need to safeguard and promote the welfare of children could severely compromise our ability to maintain an effective asylum system and strong immigration control.’[iii] In contrast, Police, probation boards and Youth Offending Teams are covered by Section 11.

The Children Act 2004 also establishes a Children’s Commissioner for England (and separate Commissioners for Northern Ireland, Scotland and Wales), who has responsibility for promoting awareness of the views and interests of children in England and undertake inquiries, but not to take up individual cases. The Children’s Commissioner for England has responsibility for reserved issues, such as speaking out on immigration and asylum.

Unaccompanied asylum seeking children (UASC), by definition, fit the criteria for being looked after by a Local Authority under Section 20 (1) Children Act 1989. These children who are looked after by a Local Authority are entitled to the same services as other looked after children: assessments that identifies their needs, care plans that address all aspects of the care and well-being and that these assessments be regularly reviewed and updated as needs change. The Children (Leaving Care) Act 2000 also applies to help 16- and 17-year-olds who have been looked after by a Local Authority move to independent living with appropriate support.

The child welfare system is slightly different in Scotland and Northern Ireland. In Scotland the main piece of legislation on child welfare is the Children (Scotland) Act 1995, which deals with local authorities’ responsibilities and the Children’s Hearing System. In Northern Ireland, the relevant legislation is the Children (Northern Ireland) Order 1995.

1.3 Immigration and Asylum Policy

Children seeking asylum in the UK are either unaccompanied (UASC) or travelling with their families. An accompanied child will usually, but not always, be part of their family's asylum claim, whereas an UASC will apply for asylum individually. A person becomes an asylum seeker once their claim has been lodged with the Immigration and Nationality Directorate at the Home Office, and until that claim is decided.

Immigration and asylum legislation sets out the legal framework for the asylum process, discretionary leave to remain, appeals, asylum support services, withdrawal of support, immigration detention, returns procedures and so on. The most recent Government strategy on asylum is the five-year plan published in February 2005: Controlling our borders: Making migration work for Britain. This sets out proposals on who should be allowed to stay in the UK and why, including a points-based migration system. It also includes the establishment of the New Asylum Model (NAM) to provide a faster and more streamlined asylum process and to make removing failed asylum seekers easier. Cases will be divided into 'segments' according to the characteristics of the case; there will also be fast track processing and a case management system. One of the 'segments' is for minors, and will only relate to children who claim asylum in their own right. The precise details were not worked out at the time of writing this report, but this may have an effect on how claims are processed, particularly for those where there is an age dispute.

The Home Office makes decisions on claims based on the 1951 UN Convention on Refugees, which the UK ratified in 1954, and incorporated into law under the Immigration and Asylum Appeals Act 1993. The Convention places a responsibility on countries to provide protection for those who have fled their country because of persecution. It also defines the term 'refugee', and refugees' rights and obligations to the host country. A refugee should not be returned to a country where he or she fears persecution.

A person whose claim is successful is granted refugee status. This means that they can live and work in the UK, and access all services in the same way as British citizens. Since September 2005, this refugee status is for a limited period of five years after which the person's case will be reviewed. Children are normally granted discretionary leave until their eighteenth birthday.

A person whose claim is unsuccessful has appeal rights to the Asylum and Immigration Tribunal, but when all appeal rights have been exhausted the person is deemed to be a 'failed asylum-seeker' who must return to their own country as soon as it is safe to do so.

During the asylum process, asylum seekers are entitled to some support. UASC will be treated as looked after children and either placed in care or supported by Social Services, unless there is a dispute about whether they are under 18, in which case they may be detained. Accompanied children may be detained with their families in some circumstances (during induction and while their claim is being processed), but are usually housed with their families across the UK in line with the dispersal measures introduced by the Immigration and Asylum Act 1999 to alleviate pressure on the South East of England. The Immigration and Asylum Act 1999 also established NASS to provide housing (through emergency accommodation, induction centres and dispersal accommodation in the private and statutory sector) and financial support to asylum seekers.

In some cases NASS support is not available – for those who have failed to claim asylum in good time, and for failed asylum seekers. Section 55 of the Nationality, Immigration and Asylum Act 2002 removed NASS support from asylum seekers who had failed to make their claim for asylum as soon as reasonably practicable – in practice within 3 days of arriving in the UK. Guidance on Section 55 was revised in 2005, and is now only used to deny support to those who have made a claim for asylum after a long period in the UK under a visa. Under the legislation there were also exceptions to the application of Section 55 for families with dependent children under the age of 18 (Section 55 (b) and (c)).

The Asylum and Immigration (Treatment of Claimants etc.) Act 2004 amended provisions for withdrawing support from failed asylum seekers. Its intention is that families who are refused asylum and do not comply with arrangements to remove them from the UK no longer have a right to NASS support under Section 9 of the Act. Only at the point of refusing to comply with the arrangements made for the family to leave the UK will Section 9 be enacted. When section 9 is enacted, all support is withdrawn from the family, but in line with the duty of care under the Children Act 1989, children under the age of 18 can be provided for by being taken into the care of the local authority. Their parents cannot receive any support.

This is being piloted across the UK and is yet to be fully implemented or decided upon. To date, Local Authorities have refused to take any child into care during these pilots. The Government committed to undertake an evaluation of Section 9 in December 2005, but as yet no report has been issued. In response to a parliamentary question this year, the Government has stated that the evaluation will be available at the end of 2006.

To summarise, there are a number of issues facing children in the asylum process:

- Age disputes. This is where the child claims to be under 18 but the authorities dispute this and require medical assessments to determine age. In 2005 there were 2,425 applications where age was disputed.[iv] The applicant in age-disputed cases is treated as an adult until the case is resolved.

- Leave to remain until eighteenth birthday. This creates uncertainty about the child's future in the UK, particularly in relation to health care and education. The new five-year period to remain in the UK as a refugee before the case is reviewed also creates continued uncertainty for children in families.

- The New Asylum Model, as of yet not set out in detail, and the changes this will imply to case management.

- Dispersal to accommodation across the UK to areas where the asylum seekers do not have any links, adequate support and/or healthcare services in place.

• Children in families and age disputed UASC being placed in detention centres and the issues this presents. In 2005, 1,860 children under 18 years were recorded as leaving immigration detention.[v]

• The Asylum and Immigration Act 2004 Section 9. Children removed from families and the implications this has for those children. Additionally, families going underground to avoid deportation or their children being removed, thus being unable to access health care and other necessary services.

1.4 Rulings

Two recent rulings have had a significant impact on the success of asylum claims by HIV infected people and families.

The case of 'N'

The case of 'N' was decided by the House of Lords in May 2005 and has been seen as definitive case law in the British system regarding the applicability of Article 3 of the European Convention on Human Rights (ECHR) to HIV related cases.

'N' is a Ugandan woman, aged 30 years. On arrival in the UK in March 1998 she applied for political asylum. Shortly thereafter, diagnosed as HIV-positive with AIDS defining illness, doctors said that without drugs and facilities her prognosis was 'appalling' and she would suffer ill health, discomfort, pain and death 'within a year or two'.

Her application for political asylum was refused on March 2001. In July 2002, the adjudicator (immigration judge) said that under Article 3 of the ECHR her case for protection was 'overwhelming'. In February 2003, the then Immigration Appeal Tribunal allowed an appeal by the Home Office, which found that the appellant's evidence did not bring her within the 'extreme' class of case to which it must belong if a claim based on Article 3 is to succeed. 'Extreme' is defined as 'not only exceptional, but extreme; extreme, that is, judged in the context of cases all or many of which (like this one) demand one's sympathy on pressing grounds'.[vi] In short, due the size of the HIV/AIDS epidemic, N's situation could not be deemed as extreme. N was deported.

The Case of 'O' and 'W'

'O' was a young single Nigerian woman who entered the UK with a false travel document in October 2003 while pregnant. Within six weeks, she gave birth to a boy, 'W', at which point both mother and son were diagnosed HIV positive. The mother was, and remains, well and not on HIV treatment. The son's HIV has manifested itself in brain ancephalopathy and this has led to various forms of developmental damage.
O applied for political asylum in June 2005 on the basis that she has a well-founded fear of persecution if returned to Nigeria. Also that any suffering that she or her son might be exposed to due to not being able to access necessary medical treatment as

a result of removal would be sufficiently severe as to amount to a breach of Article 3 (ECHR). The Home Office refused the application on both grounds.

At appeal, the part of this case upheld was the Tribunal's belief that this case was difference from that of N because the focus of concern was W. Were he to be returned, his mother would have to watch him deteriorate and die as his ancephalopathy would re-establish itself quickly without appropriate treatment. The Tribunal judged that this made the case different, as to let that happen would be inhuman and degrading and would cross the high threshold necessary to be a breach of Article 3 (ECHR). The family were granted asylum.

This case was argued and decided by the Asylum and Immigration Tribunal in November 2005. This is not a precedent that needs to be followed by other courts but offers some hope in cases involving children living with HIV.

1.5 Health

NHS services are available across the UK, but the planning and resource structure is different in each of the four nations. In England, Primary Care Trusts (PCTs) are responsible for the planning of services; in Wales the National Assembly issues regulations and guidance, but the implementation is the responsibility of local health boards; in Scotland NHS health boards are responsible for planning; and in Northern Ireland there are Health and Social Services Boards.

In England, in relation to HIV/AIDS the most relevant policy documents are the National Service Framework (NSF) for Children, Young People and Maternity Services[vii]; and the National Strategy for Sexual Health and HIV[viii] and the associated implementation action plan.[ix]

Standard 8 of the NSF relates to disabled children and young people including those with complex health needs such as HIV. The objective of this standard is to ensure that these children receive 'coordinated, high quality child and family-centred services which are based on assessed needs, which promote social inclusion and where possible, which enable them and their families to live ordinary lives.' The National Strategy for Sexual Health and HIV includes goals for reducing the spread of HIV; sets standards for the treatment, support and care of people living with HIV and makes proposals for furthering the evidence base on HIV prevention.

All of the above impact on the healthcare needs of children and young people with insecure immigration status, and in particular HIV treatment. The Government has published specific documents about the health care of asylum seekers. In 2003 a research study was submitted to the Home Office on Asylum Seekers in Dispersal – healthcare issues. This report highlighted that:

> 'There is a lack of specialist healthcare services for asylum seekers in some regions, including HIV services and counselling support for victims of torture. In addition, the expense of travelling to health centres can make it difficult for asylum seekers to access healthcare services, basic and specialist, a problem also affecting other low-income groups in the UK.'

In December 2005, NASS published a policy bulletin on dispersing asylum seekers with healthcare needs,[x] following a review of the process by Hilary Scott.[xi] The review recommended that a policy bulletin be developed to include NASS' approach to primary, secondary and tertiary care, and specialist services such as for HIV positive asylum seekers. The policy bulletin sets out the principles underlying it, which are:

> All asylum seekers and their dependents supported by NASS are entitled to free NHS treatment whilst awaiting the outcome of their application
> NASS supported asylum seekers can also get help with prescription costs, travel costs to and from hospital for NHS treatment, NHS dental care, free sight tests, etc.
> Where an asylum seeker has been unsuccessful and all rights of appeal are exhausted, the individual is still entitled to continue any course of treatment which began while his or her asylum claim was being considered, without charge for the duration of their stay in the UK NASS aims to ensure that all asylum seekers it supports who have health care needs are able to access appropriate medical care and any special facilities they may need and, where appropriate, that continuity of treatment is arranged on dispersal.

The policy bulletin contains a whole section on dispersal of asylum seekers with HIV/AIDS. The following paragraphs from the guidance are particularly relevant to children:

> '9.5 Extra care should be taken when finding accommodation for families with children infected with HIV. Caseworkers will need to satisfy themselves that any accommodation is located where there are appropriate facilities for treating children with HIV/AIDS. The NASS Medical Adviser should be asked to provide advice about specific locations.
>
> 9.6 Those working with asylum seekers within or on behalf of NASS should ensure that disclosure of an HIV diagnosis will not affect their asylum application. This is a major concern for many and leads to late disclosure of significant medical information causing difficulties to NASS and to both treating and receiving clinical teams.[xii]'

On 1 April 2004, new charging arrangements came into force for overseas visitors seeking NHS treatment.[xiii] These charging arrangements do not apply to asylum seekers or refugees, but do apply to failed asylum seekers, that is, those who have exhausted all rights of appeal, and to undocumented migrants and overstayers. Under the new charging arrangements, primary care services (registration with a GP), treatment in Accident and Emergency Departments, and diagnosis and treatment of communicable diseases necessary to protect public health remain free to all. There is also help available for prescription costs for those on low incomes. Treatment of sexually transmitted diseases such as HIV/AIDS is limited to a diagnostic test for evidence of HIV infection and counselling associated with that test or its result. Hospital treatment following referral from a sexual health clinic is not exempt from charging.

1.6 Conclusion

What we see is a system of legislation that holds some inherent contradictions. The focus of children's legislation holds that the child's welfare is the paramount consideration when making any decisions concerning the child's well-being. The focus of immigration legislation holds that the need to exercise immigration controls and restrictions is paramount. The complexity around the application of some of the policies such as charging for NHS services and access to support services creates considerable inconsistency. The responsibility for implementing some of these policies frequently lies with professionals outside of the immigration service, that is, health and social care professionals, who have as the focus of their professional practice the need to support the health and well-being of families to their best capacity. What these conflicts reveal is that either immigration controls take precedence and compromise a child's health and well-being, or that practitioners place the child's well-being first, potentially placing them at odds with policy, legislation and the law.

Many of these contradictions and conflicts within practice will be illustrated in the rest of this report.

Section Two

Child Development and Interaction with Services

This section presents the current situation for HIV infected children with insecure immigration status who are accessing, or attempting to access, NHS paediatric HIV services and support services. It also includes how the parents/carers access to healthcare services impacts upon HIV affected children.

Questionnaires and interviews alike asked practitioners to assess whether the immigration situation for the family was seen to have additional impacts on the development of the HIV infected/affected child and how that child responded to services and to their peers. They were asked to compare the situation of children and families with and without insecure immigration status in the context of child development and interaction with services.

It has been well documented that children of asylum seeking families can suffer from the experience of migration and that this can impact upon both their physical, psychological and emotional health and well-being. This can be due to their experiences in their country of origin, how they entered the UK and their experiences once here.[xiv]

It has also been documented that children both infected and affected by HIV can face poor psychological and emotional health and well-being.[xv] There is much secrecy, fear and isolation and a large proportion of families will choose not to tell a child about their own or a family member's HIV diagnosis. Many children access health care or are aware that a family member has significant health needs, without knowing that this is because of HIV.

It is important to highlight elements of the health care that HIV infected children need to understand how immigration situations can impact upon them. HIV medication is highly toxic and demands a high level of adherence. Missing even one dose a week could lead to the virus mutating and becoming resistant to the medication being taken. Paediatric dosing requires close monitoring of a child's growth, as the medication must increase in line with the child. Again, if this is not maintained, the child's virus will very quickly develop resistance to the drugs. Drug resistance means that the viral load suppressed by the medication, 'bounds back' and rises dramatically. This in turn puts pressure on the child's immune system and leaves them open to opportunistic infections and, if left untreated, AIDS defining illnesses.

2.1 Interaction with Service

A child's relationship and interaction with a service that supports them has an important impact on that child's health and well-being. Health professionals noted that the circumstances of the family could have a negative impact on their interaction with health in a very practical way, as:

> *'[It is] harder to see [the child] regularly in clinic so health monitoring not so good.'*

Support services, which see both infected and affected children in a number of different settings, noted differences between those with insecure immigration status:

> *'Children [with insecure immigration status] seem very reluctant to talk to us, or interact and are very clingy to parent. Seem withdrawn, visibly stressed out, angry. Will not leave mum even for a short while.… Becomes very distressed when mum is not in eye line.'*

> *'We have observed and concluded that children in this category are under immense distress. Their behaviour can sometimes be irrational and sometimes react by doing things that are not in keeping with their usual way of life according to the parents.'*

Thirty-five per cent of respondents to the health questionnaire said they had noticed a difference in how the child and parents interacted with health care professionals.

> *'People who have been in UK for a while (legal or not) make better use of health services. They come forward when there is a problem because they understand that the service is there to help them. People not used to living in the UK are not so proactive in their dealing with our services and can present with problems at a later stage. The nurse spends more time contacting these people to ensure nothing is amiss.'*

Practitioners from both health and support services agreed that insecure immigration status has an impact on how a child interacts with them.

2.2 Peer Interaction

Interacting with your peer group is an essential part of childhood and child development. Play, in all its forms, is where children discover the world and others in it. For children living with HIV, peer interaction can be problematic. Many have reported that they struggle with their peers, especially as teenagers, as they cannot talk about the realities of their situation and the real worries they have.[xvi] Those completing the questionnaires were asked if they saw any significant difference in the peer interaction of those children with insecure immigration (remembering that all children using these services are living with HIV).

> *[The children with insecure immigration status] take longer to relax and to engage with other kids.'*

> *'I am aware that children living in families with insecure immigration status often have very little money, poor housing and it is difficult for children to come to play at their homes, or to take part in activities that cost money like attending birthday parties, school trips, etc.'*
>
> *'Their family circumstances tend to be difficult to discuss so they cannot be as open with their peers as they may wish to be.'*

One health professional pointed out that the system worked against this group's peer interaction and therefore impacted upon their development:

> *'The family are so isolated and the child cannot access a free nursery place because of the family's immigration status. So there is no interaction with their peer group which is leading to developmental delay.'*

Case study 1

The family arrived in the UK in 2004 on a visitor's visa after the death of the father. The mother became very ill and was then diagnosed as being infected with HIV. The children were then tested, and one is also infected with HIV. The family were originally financially supported by friends and were sleeping on people's floors. The mother applied for asylum and the family began to receive support through NASS.

The mother has considerable health concerns with a liver condition and diabetes. Her HIV further complicates these. The HIV infected child has had in-patient stays in hospital over the last year, missing a lot of school, and therefore finds it difficult to make friends and interact fully with its peers. The child is withdrawn, which can be attribute to both its health and the uncertainty of the family's situation. The child does not like to take its medication because it makes the child 'feel bad'.

The older child has a substantial caring role with both the mother and the HIV positive sibling. This child can also be withdrawn, but does access more services, as their health does not impose on this. The mother can not, and will not, talk with her children about her own health, their health and the asylum process they are in. There is no support network to take the strain and relieve the caring responsibilities of the older child. Their housing is extremely damp with mould growing in most of the rooms, but they are afraid to complain because they fear they will be dispersed out of the area. The mother feels this is not worth the risk, and so she compromises her own and her child's health for this element of stability.

The mother does the best she can in the circumstances. She is resilient, but she does become very distressed when she talks about what will happen if they are forced to return. Her complex health needs mean she could not survive long without access to treatment, and the positive child does not have a particularly good prognosis either. She fears her children will be orphaned and that then her older child will then have to watch the younger die.

2.3 Getting on at School

School and a child's interactions within it are extremely important not only as this is where they gain their education, but school also provides the opportunity for peer interaction and building relationships with other significant adults.

Impacts were especially noted around the dual stigma of being a refugee and being from a BME community.

> *'Issues of children getting on at school have been raised by mothers in which they have highlighted concerns around children being bullied and being left out. One kid was asked at school if he was an asylum seeker and also if he would want to buy a British passport. Some parents have been asked by the kids what asylum meant?'*

Other issues reported were that of children being withdrawn and struggling within the system.

> *'[We support a] young boy who refuses to speak English at school, even though he is capable of it. He's very bright but withdrawn.'*

> *'Some children report it very hard to make friends because of difference in cultural norms or language.'*

There were positive attributes noted with one respondent stating, "They seem more committed to their studies".

Dispersal, both the threat and its realisation, was also seen to impact on a child's interaction and experiences at school.

> *'What we see in families that are NASS supported is that they are subjected to many moves and this further undermines the stability there is [with the school].'*

This final point will be explored further in Section 4 of this report

2.4 Adherence to Medication

Ensuring proper adherence to a child's medicines is essential in effectively treating HIV, maintaining the child's health and preventing drug resistance. Interestingly, insecure immigration status was reported as leading to better adherence for some children and families.

> *'[Children with insecure immigration status] tend to be better at adherence, parents feel lucky to be here, ensure children take medication.'*

But this was dependant on how well the family are coping with living with HV and insecure immigration status and how external factors such as insecure housing impact the ability to adhere to a drug regime.

> *'A minority have expressed despair at having medications they feel they cannot continue if they are forced to return.'*
>
> *'They may miss a dose [of medication] due to moving or may have to hide medication in different households.'*

Secure housing for families with children on medication is extremely important to support good adherence. Insecure housing may not offer a safe or appropriate place to store medication or facilities to clean equipment needed to administer medication. The risk of failure of medication due to insecure housing can mean that health professionals postpone putting a child on HIV treatment until they are in secure accommodation.

2.5 Affected Children

It is common for HIV affected children to take on caring responsibilities. As HIV is a highly stigmatised illness, many HIV infected parents will rely more heavily on their children, as they fear the implications of asking for help elsewhere. This caring role can relate to mental health needs as well as physical health needs, with older children taking household responsibilities and caring for younger siblings when their parent/carer is experiencing periods of ill health. It is not unusual for children to not know the name of their parent's illness, although many find out through finding letters, medication or overhearing conversations.[xviii]

Case Study 2

This family had suffered multiple bereavements in Africa: both through the political situation and through AIDS-related deaths. They arrived in England and were processed at the Home Office in Croydon. At the interview, with the whole family present, the home office representative
casually talked about the mother's HIV status.

The younger child described finding this out in that situation as 'feeling like I'd been shot and then was falling back into myself.' At that time the children's only experience of HIV had been in the context of Africa and people dying.

They worried about what would happen to their mother if they were sent back, they new she would die. Also, they noticed how when their mother was worried about their immigration status, it impacted upon her health and she was weaker and unable to care for them.

The children could only talk to their peers about issues surrounding their immigration, and could not say why they were so concerned about what the future held for them, their mother's health and how they feared being orphaned.

Living with insecure immigration status has been documented as a time of extreme stress[xix] and has a negative impact on the mental health and well-being of families.

This will necessarily impact on the health of an HIV infected person, and therefore impacton the HIV affected child. Further caring responsibilities, concerns for the future and the loss of childhood through responsibility and worry play a role here. These children take on a huge amount of responsibility, and live with the reality of being sent back to their country of origin with an HIV infected parent/carer. Many children who have grown up in countries with high HIV prevalence have suffered multiple bereavements. Their experience of HIV/AIDS is of certain death. Most believe that the only hope for their parent/carer is to remain in the UK.

Case Study 3

The mother was in the UK under the sponsorship of her grandmother and was allowed to work but had no recourse to public funds. Her child (now 17 years old) had come to the UK on a visitor's visa and had not returned. The family lived in privately rented accommodation. The mother was hospitalised due to being AIDS defining. At the time the woman was experiencing cognitive difficulties. In hospital the child was told that the mother was HIV positive. The child was afraid she had contracted the virus from her mother as when caring for her at home, she had had to change her mother's sanitary wear and, as they did not have a washing machine, wash her mother's soiled underwear by hand.

After a lengthy stay in hospital that included a period in a mental health unit, the mother was discharged. Whilst the mother was in hospital, the child needed an enormous amount of support. Now the only income the family had was statutory sick pay (£50 per week), which covered the cost of their rent. Not long after the mother was hospitalised, their property was condemned and the family were given notice to quit. The council would not help to rehouse the child, as she did not have recourse to public funding. Social services adult and children's teams refused to help for the same reasons. It was suggested by Social Services that the child return to the country of origin, but to do so would mean abandoning the sick mother.

A voluntary sector service supported the child with visits to the hospital and home visits, advocacy in case conferences at the hospital, and also at visits to Social Services and Housing. They arranged for the child to see a solicitor who specialised in immigration law, and provided money for gas, electricity and food. The child was left practically destitute in addition to coming to terms with the shock of the mother's sudden ill health and HIV diagnosis.

2.6 Conclusion

This section illustrates some of the issues that impact upon child development, childhood and interaction with services, and shows how when living with both HIV and insecure immigration status, the impact and pressures are heightened. Concern's about a child's own or their parents health and future, increased isolation from peers, how this added stress effects their interaction with school, health and support services and the additional caring responsibilities many of these children face, all place them under extreme stress.

Section Three

Children, Families and the Immigration System

This section looks at the general findings relating to children and families living with HIV who are in the UK immigration system. It is important to note from the start that a child being HIV infected is now no guarantee of a successful ruling to remain in the UK.

NASS was set up in April 2000 to exercise powers under the Immigration and Nationality Act (1999). NASS is part of the Immigration and Nationality Directorate which is part of the Home Office. The role of NASS is to provide support to asylum seekers, who would otherwise be destitute, while applications are being considered. This support can be in the form of accommodation and subsistence, accommodation only or subsistence only.

In 2005, NASS reviewed its working practice in regard to dispersing asylum seekers with health care needs and new guidelines were presented in NASS Policy Bulletin 85.[xx] A number of questions were asked in the questionnaires to both health and support services to gauge the experiences of children and families living with HIV in the immigration system, and whether there have been notable changes in practice in the working relationship between NASS, health professionals and support services since this policy change.

3.1 Working with NASS

Interaction and cooperation between NASS and health care and support service providers is extremely important when meeting the needs of families living with HIV. This relationship can be critical in ensuring that the welfare of HIV infected and affected children are considered.

Health care professionals were asked whether they had a named contact within NASS. Twenty-seven per cent (n=4) said that they did. When asked to share their experiences of working with NASS, over half of both health and support service respondents said that NASS was difficult to make contact with, and all responded that NASS was ‘bad’ at informing them if a patient was going to be dispersed. HIV infected children need specialist care which means that making arrangements for a move and ensuring that they have access to specialist health care services in their new location are paramount to the health and well-being of the child. This is acknowledged by NASS in paragraph 9.5 of NASS Policy Bulletin 85.

One respondent commented on recent improvements in contacting NASS:

> *‘[Making contact has] improved considerably recently, [NASS] will answer all queries but will not expand on information unless specifically asked direct questions.’*

Another said that ‘there has been great improvement in our relations with NASS over the last year’. But for the rest, the communication was extremely poor:

> *‘They frequently fail to get back to us, fail to make decisions within their own target times, and we have had one refusal of a Section 4 letter (which we challenged) where the case worker told the positive person that settled tax payers should have first call on the country’s resources!’*
>
> *‘I have found NASS very difficult to make contact with, it is hard to get to speak to the right person, no one ever calls back, and even when you speak to someone they don’t always want to help. I have never had voluntary follow-up from NASS. I have had to chase every case.”*

When asked how NASS fared at taking into account the additional needs of children and families living with HIV, out of the options ‘good’, ‘ok’ and ‘bad’, 60 per cent replied ‘bad’.

> *‘In terms of taking into account additional needs, I have had two families moved at short notice by NASS, despite every effort to stop this. The families in question were vulnerable and it had taken a lot of hard work and time to get them supported in this area. NASS moved them completely away from all their support.’*
>
> *‘I have a young child with HIV and when we informed [NASS] she was in hospital and enquired about help with the fares to and from the hospital they withdrew the funding for the child for the duration of the stay as they said her subsistence was being provided elsewhere.’*

The one simple difference between respondents having a good or a bad experience or relationship with NASS, is having a named person and their direct contact details.

> *‘It is only when I speak to [name removed] that I am heard. Then and only then do I get the right information and an effective diagnosis about the needs of a family.’*

For those without this contact, the frustration is clear. Issues mentioned included dispersal (note: this is since the NASS Policy Bulletin 85).

> *‘Children disappear without us knowing. They are still moved even though kids are on [Antiretroviral Therapy].’*
>
> *‘NASS has been ruthless, in that there are certain instances where they have stopped benefits without prior warning and no due consideration for families in distress.’*

Working relations between NASS and the health and support services vary and on the whole need to improve. One simple practice change would be that each NASS case worker responsible for families with HIV infected children should contact the child's consultant and provide them with their name and contact details as soon as they are given the case. This way, dialogue can happen if and when issues arise and the child's well-being can be central to decision making.

Case Study 4

The mother was in the UK on a student visa with her 7-year-old child. There are two other children left in Zimbabwe. She was legally working for an agency as a care worker to complete her training. Following her diagnosis in August 2005, she was too unwell to work and the agency refused to provide sick pay, leaving her with no income to live on and support her daughter. The mother was advised to apply for asylum under medical grounds with Social Services stepping in to support her as a duty under Section 21 of the National Assistance Act 1948, amended by the Health and Social Care Act 2001. Her immigration case was initially picked up by one caseworker but later handed on to another. While the requested medical report was sent to the Advisory Service, several attempts to contact the caseworkers have been futile. The mother has yet to receive formal acknowledgement of her immigration application from Home Office. This makes her very anxious and worried about her stay in the country, as she is never sure of when 'the Immigration Officers will knock on the door'.

Since being taken on under NASS, she and her daughter have been moved twice in a period of 12 months. Both times the child has had to change schools, which in itself has been very unsettling. Additionally their current accommodation is also temporary, which adds further uncertainty. The mother receives NASS weekly support of £60 per week, which she struggles to stretch to meet all the expenses. They accessed hardship fund to meet some utility bills and school uniforms for each change of school. For the mother, being diagnosed HIV positive has meant that she is unable to work and struggles at times to look after herself and her child. The child does not know the mother is HIV-positive and therefore does not understand why she is not able to do the things she used to do before and this causes the child obvious worry.

3.2 Legal Representation

For asylum seeking families and individuals it has become more difficult to access legal aid since restrictions on funding for asylum cases were introduced in 2004.[xxi] Responses reported that this has lead to it being increasing difficulties in acquiring legal representation, and that the quality of representation available varies significantly.

> *'A major issue that many of our clients is around accessing legal support, as this is becoming increasingly hard to find. HIV itself seems to be taking less significance in relation to*
> *immigration claims, which is making options more limited for clients.'*
>
> *'The lack of legal representation and wide variations in the quality of representation.'*

Families need lawyers who are aware of significant rulings such as the cases of ‘N’ and ‘O and W’ (see Section 1). Lawyers need to include the issues for the child/children in the case, the impact upon them and what they will have to face if returned.

Case Study 5

The mother was pregnant and delivered without having an antenatal HIV test. A month later, the baby became critically ill with PCP (Pneumocystis carinii Pneumonia) and was transferred to a regional paediatric intensive care unit. At this point an HIV test was carried out, which was positive. The parents were obviously shocked and devastated and took HIV tests themselves, both of which were positive. The parents both had student visas and had no intention of remaining in the UK permanently, but in light of the child’s HIV diagnosis, they decided to claim asylum and were advised to retain a lawyer.

They had to approach almost 40 law firms before they found one that would take their case. Included in their asylum claim was a supporting letter from the Hospital stating that if the child were returned to its country of origin then, due to previously related health problems, it would not survive a year.

The child initially was doing extremely well but then became ill and developed drug resistance. A new drugs regimen was introduced but the child’s health remained a concern. The family then received a letter from the immigration services informing them that their asylum application had failed and the family lodged an appeal. They received a court hearing for the next month. The child’s consultant sent a second letter explaining that in the country of origin there are not the specialist facilities to monitor the child’s health and drug. The child would be at high risk of death within a year of repatriation. The family and the consultant spent the day waiting at court to be told that, due to a technicality, the hearing would be moved to another day. They have not received a new date as yet.

The situation is impacting on all family members’ health. The family are described as living on a knife-edge. The mother is distraught as the child is acutely ill at the moment and she knows that returning to their country of origin will mean certain death for her child.

3.3 Advocacy and the Home Office

Changing policies and ‘tightening’ of the immigration system means that the role of service providers has altered. Over half of the responses to the questionnaires had been involved in some form of lobbying such as letter writing and phoning at the request of solicitors and as a result of concern:

> *‘[I have been] phoning NASS to inform them of patient’s health status, with urgent requests that it is not safe to disperse.’*

> *'I have been involved in 3 cases recently for children in need to be dealt with fairly and in the least disruptive manner to their well-being and education.'*
>
> *'[We have] written letters for solicitors, for the Home Office and for families, at least 10-20 per year.'*

More specifically, 21 per cent had been involved in court action on behalf of a child (all more than once), which included letter writing, medical reports for court, being an expert witness and attending hearings to offer support to the family.

Finally, when asked about how much of the team's time was taken up by these interactions with the immigration service and the courts, the responses are best summarised by one respondent:

> *'[It] varies from 0 to 50%. The problem is that it is always an urgent situation, as families are given no notice before they are meant to deal with huge changes.'*

Practitioners are experts in their field, whether this is health or social care. The present immigration system is placing a strain upon them. Their support for families now must extend to lobbying, numerous phone calls and letter writing, which will necessarily impact upon their capacity to undertake the other aspects of their work, such as meeting the health needs of chronically ill children.

3.4 Conclusion

To conclude, the working relationship between NASS and those supporting families living with HIV is, at present, poor. The stark lack of communication from NASS frustrates practitioners and places pressure on their time and resources. If the family's NASS caseworker simply provided direct contact details to the HIV infected child's consultant this would partly relieve this.

What is clear is that there has been a noticeable change in the work of both paediatric HIV health professionals and those working in HIV support services. They now need an understanding of the asylum and immigration system, and spend their time supporting the patient/service user and their family to meet basic needs such as accommodation and sustenance, and more complex needs such as legal representation. This is explored further in Section 6.

Section Four

The Dispersal and Detention of Children and Families Living with HIV

This section explores two specific issues, dispersal and detention. Both can have a potentially huge impact on the lives of children living with HIV and insecure immigration status. It presents the findings on the impact of the NASS policy change for dispersing asylum seekers with healthcare needs, followed by the detention of HIV infected and affected children.

4.1 Dispersal

Dispersal, introduced in Section 97 of the Immigration and Asylum Act 1999, has meant that those housed through NASS support can be moved into alternative accommodation at any point and to any location. The most recent guidelines for dispersal are set in NASS Policy Bulletin 31. This states that 'in general' due regard should be given to the provision of health care in the area where a person is being dispersed to.[xxii]

In 2005, NASS reviewed its working practice in regard to dispersing asylum seekers with health care needs and new guidelines were presented in NASS Policy Bulletin 85.[xxiii] As mentioned previously, this makes specific reference to HIV infected children.

> *'9.5 Extra care should be taken when finding accommodation for families with children infected with HIV. Caseworkers will need to satisfy themselves that any accommodation is located where there are appropriate facilities for treating children with HIV/AIDS. The NASS medical advisor should be asked to provide advice about specific locations.'*

Children and Young People HIV Network distributed questionnaires to health and support services in August 2006, eight months after this policy change. All questions asked respondents to refer specifically to the six months prior to this policy change, and the time after it. A distinction was made between children moved to areas and from them.

4.1.1 Dispersal of HIV Infected Children

> *'Children who are moved from area to area experience much disruption to their education and sense of belonging to a community. It compromises their friendships and any sense of security. The needs of asylum seeking children who have experienced loss and trauma are overlooked.'*

As established in the introduction to this report, the number of HIV infected children with insecure immigration status is relatively small. Of the approximately 120 HIV infected children with insecure immigration status represented in the health questionnaires, in the six months prior to the NASS policy change, seven had been reported as being moved through dispersal (an additional child and family had been moved back to London as they had complex health needs and needed to access a hub centre for treatment). In the six months after the change, a further seven were reported as being dispersed into an area, although this number would have been nine, had it not been for the intervention and lobbying of health workers to stop two of these moves.

Of families living with HIV represented in the support service questions, twelve were moved during the six months prior to the NASS policy change, and nine in the six months after.

In addition to these moves out of an area, frequent moves within areas were noted, and the disrupting effect these have on families:

> *'There have been lots of moves because of housing providers losing contracts so although NASS guidelines are clear we make sure that they are adhered to (telling people to refuse to move if all else fails). The NASS system can still shuttle people about. One person with a young child has been moved several times in a week.'*

4.1.2 Children Moved into an Area

Those involved in receiving new patients or service users through dispersal were asked whether the handover of a child's care/healthcare had improved since NASS policy change. All replied it was 'about the same', (options were 'I have had more notice', 'About the same' and 'I have had less notice').

Asked about how dispersal impacts upon the children they treat or support, the areas of most concern for all practitioners were the mental health and well-being of the child, and the impact on the parent/child relationship, with 75 per cent of practitioners saying that they had seen dispersal have either a 'negative' or 'very negative' impact on these two areas.

Of those organisations who had experienced families being moved into their area, over 80 per cent felt that this had had an impact on their work and the work of their organisation (this related to capacity issues and changing support needs of service users).

> *'Over the last 3 years dispersal has had significant impact on our work with now 90 per cent of our workload from African countries (45 adults, 20+ children) newly referred in the last few years. We have had to increase capacity but funding from statutory sector rarely reflects this. This then causes insecurity for staff':*

The complex needs of a family living with HIV or insecure immigration status are further complicated when the two are combined:

> *'Time is at a premium for us and capacity is a big issue, support needs have changed away from simple support, benefits advice and advocacy, to full on assistance with finding solicitors and support through asylum claims, emotional support needs are great in these families. Also [HIV infected] children are not treated locally, so travelling and financial support for this is required, not to mention the stress of travelling 80 miles for a hospital appointment.'*

4.1.3 Children Moved from an Area

The same question on improved notice periods was asked of those who had had a child and/or family move from their area. Again, all commented that they had had 'about the same' amount of notice given in regard to dispersing an HIV infected child as they had before the practice changes set out in Bulletin 85, (options were 'I have had more notice', 'About the same' and 'I have had less notice'). One respondent did tick 'about the same', but added 'i.e. none', another said 'No notice' and a third said:

> *'I think there has been an improvement in so much as there is a policy, housing providers and NASS will still attempt to flout it, it also relies on a person having to disclose their HIV status which I still have issues with but it is clearly better than nothing at all.'*

Improvements set out in NASS Policy Bulletin 85 on the dispersal process mainly focus on having additional time to make preparations. When asked if, since the NASS policy changes respondents had more, less or about the same amount of time to identify an appropriate clinic/clinician and arrange transfer of care and treatment, all except one of the fifteen respondents ticked 'about the same.'

Support services reported the same, that there was no apparent difference in the time given to identify appropriate service and arrange transfer of care. Two examples of recent cases were offered by different respondents to highlight the lack of change:

> *'We have had two women who had also just been diagnosed HIV positive and needed to stay locally so they could access psychosocial support but the next we heard about them was that they were in Scotland.'*
>
> *'The time given to these people has been very short in [our] most recent case just one week, how can this benefit anyone?'*

Finally, on the issue of dispersal, respondents were asked whether they thought children infected with HIV, once they are accessing treatment, should be dispersed at all? 79 per cent said 'No' and 21 per cent said 'Yes'. All who answered 'Yes' agreed that it was acceptable if, and only if; dispersal was carried out properly and at the right time.

> ‘Once a child is stable on treatment, if managed properly and planned with family, it is possible that for some families it could be a positive experience i.e. better housing, schools and access to primary and specialist health care services. If this were the case I would support dispersal.’

For those who answered ‘No’, the reasons given were the need to access specialist care, continuity of treatment, the child’s well-being and patient confidentiality:

> *‘Families are reluctant to disclose to anyone new. The one family that has been moved returns to us for clinics and treatments. This is not a satisfactory way of working but when patients turn up in your department and refuse to go to their local hospital what can we do? …. You will find that anyone with diabetes, cystic fibrosis, Crohn’s disease, etc, is very reluctant to change doctor/nurse and will be very cautious about moving. Yet these people with HIV are not accorded that choice.’*

> *‘In order that adherence can be achieved children must be in a stable more long-term home environment where they feel safe and able to quickly settle and get into a routine and only have to worry about taking medications and not worry about what where they could end up.’*

> *‘Some families who were moved by NASS are travelling long distance (Derby to Luton) in order to continue their follow up [treatment] where it started rather than to be referred to a new team. Again people find it hard to build a trusting relationship with a new health team.’*

4.1.4 Additional effects of dispersal

Between 2002-2005, over 3500 HIV infected women gave birth, approximately 80-90% of these were diagnosed before they delivered, and approximately 100 babies were infected with HIV.

The mothers of HIV infected babies fall into two groups, those that went undiagnosed (approximately two thirds) and those who were diagnosed before or during pregnancy (the other third). Approximately three quarters of the women having HIV infected babies were originally from an African country.

For the diagnosed women having HIV infected babies, the question that needs to be asked is ‘why did this happen?’ With the correct medical care mother-to-baby transmission should on the whole be preventable. Preliminary results from a recent audit of cases where there had been mother-to-baby transmission in England suggest that a majority of these women had serious problems concerning their immigration status or housing, or had major mental health or social problems.

> *‘I have spent a lot of time with the families that have been moved into the area, setting up support, only last month (July) a lady who was 34 weeks pregnant was moved to my area, away from her family, her support not to mention her medical team, the stress caused her to go into labour and she delivered a very small and poorly baby.’*

There will always be undiagnosed pregnant women, as you cannot make a woman take an HIV test. Hospitals who have HIV specialist teams and significant clinical experience of treating women from migrant communities are more likely to recognise the women who are a higher risk of being HIV positive, and as such can provide the kind of interventions which may be necessary to support women in accepting their need for an HIV test. As it stands a system which disperses vulnerable pregnant women from migrant communities with high HIV prevalence to areas without expertise in this area, potentially creates a greater risk that babies will be born HIV positive.

Case Study 6

A family from sub-Saharan Africa, where both mother and father were unknowingly HIV infected, were dispersed to a town with no specific care facilities for HIV infected families. The mother declined an HIV test in pregnancy, and no one reviewed that decision with her. She subsequently delivered a baby who was HIV infected and presented very ill at the local hospital with an AIDS defining illness at 8 weeks of age. The baby's condition deteriorated significantly and despite obtaining advice from one of the specialist HIV centres in London, the local team felt out of their depth caring for this child.

Special arrangements were made with the help of NASS to have the family re-located back to London so that the child could have here care in a specialist centre. This of course took months to organise, but the family were very happy to be relocated.

The family described that when they received their HIV diagnoses they felt extremely unsupported, as there was no multidisciplinary support available. They also felt "like they were in a zoo" as an HIV infected baby was such a rare phenomenon in the hospital and everyone came to examine the child.

Continuity of health care and specialist services are essential in preventing the transmission of HIV between mother and baby (for more details on this see Section 5: Pregnant women). If immigration and dispersal are negatively impacting on mother-to-baby transmission of HIV, and therefore placing unborn children at unnecessary risk of acquiring a chronic and potentially life threatening illness, this needs to be addressed as it is undermining the state's duty of care to children as outlined in the Children Act 1989 and Articles 2 (right to life) and 3 (freedom from inhuman and degrading treatment).

4.1.5 Conclusion

These findings show that in practice, the NASS policy change set out in Bulletin 85 on dispersing HIV infected children and adults does not seem to have changed practice. HIV infected children are still being dispersed, as are families living with HIV, and there has been no difference in the notice given or preparations made. This research only sampled those supporting children, and we recommend a larger sample be looked through adult services to see if they mirror the experiences presented here.

HIV infected children with insecure immigration are a relatively small group in the UK: as stated in the Introduction, an estimated 200–250 children. Yet these children have complex health needs and require highly specialised treatment and care. It is questionable whether it makes economic or ethical sense to move them around the country.

4.2 Detention

> *'This is obviously the last place any child should be, never mind a child who is extremely immuno-suppressed, requiring complex medications.'*

Detaining a child on the grounds of their own or their parents' immigration status is contra to UK children's legislation, the ECM agenda, human rights and the UN rights of a child. It presents many complex issues for any child: their access to play, the psychological impact of being imprisoned, their access to general health care and education, and the implications of this on their childhood. Detention staff are not trained in handling children and there is a lack of information given to children and their parents about what is happening to them (some families are even unaware of where in the UK they have been taken). Being removed from support networks (friends and teachers), and having parents under such pressure that they are unable to cope, are terrifying for children.[xxiv] The detention of children living with HIV creates further complications.

4.2.1 HIV Infected Child in Detention

Although, to date, the detention of an HIV infected children is extremely rare, it has happened and therefore there is a potential for this occurring again. As has been stated in this report, a child infected with HIV has a complex chronic illness that requires close specialist medical attention to maintain good health and well-being.

Case Study 7

The mother and the HIV infected child were both on ARV treatment under the care of a family clinic. The family were taken from their home, with no notice, to a detention centre and they were not allowed to take their HIV medications with them. The family solicitor alerted the child's consultant to the situation.The consultant spent most of the day contacting the centre where the family were taken, trying to speak to a person in authority who had responsibility for the health needs of the family to explain about the child's treatment and how important it is that not a single dose is missed. No medical person was ever available. All the staff that were spoken to from the detention centre did not have any understanding of the management of HIV or the significance of the risk of missing even one dose of medication, which could lead to the HIV rebounding and the development of drug resistance.This family were lucky. With the persistence of their consultant and their lawyer they were released after 24 hours and only missed one dose of their medication.

Case study 7 presents the dangerous risk of treatment failure through detaining HIV infected children. It also highlights how sensitive confidential health information is shared beyond the immediate professionals caring for the child. The lack of HIV awareness in the detention centre raises the question of whether not only would they be able to provide the necessary health care for the child, but also whether they are equipped to protect this sensitive information and ensure the family are protected from discrimination.

In February 2006, the Inspector of Prisons undertook interviews with children in Yarl's Wood detention centre.[xxv] The average time spent in detention for a child was 23 days, with the longest at that time being 112 days. An HIV infected child without medication could become chronically ill over this period of time and possibly need to be hospitalised. Even with medication, withoutthe specialist health care and monitoring required, the child's health would be put in serious jeopardy. This is sub-optimal care of children who, under Department of Health directives as failed asylum seekers, are entitled to the continuation of an already established health service. Paediatric HIV is a specialist service and it is unrealistic to expect this level of specialism from detention centre health staff.

4.2.2 The HIV Affected Child in Detention

It is likely that an HIV affected child would experience greater adversity in detention that an unaffected child. If their parent is denied the essential specialist treatment and care that HIV requires, their health is likely to deteriorate quickly, particularly under stressful conditions. The affected child will experience watching their parent/carers health deteriorate and will necessarily take on further caring responsibilities.

The implications for the HIV affected child are the psychological effects of watching your parent's/carer's health deteriorate, fear of bereavement if the appropriate health care is not accessible and caring responsibilities. These are additional to what all children in detention face.

4.2.3 Conclusion

Although to date we have few examples of HIV infected children in detention, it has occurred and therefore it is fair to presume will happen again. Detention offers little possibility for an HIV infected child to access the specialist health and support they need, and as children are spending substantial time in detention, there is a large possibility that this will have an impact on the child's health and well-being. This is not to mention how this stands against UK policy and legislation established to protect children and international human rights legislation.Detention of a family living with HIV places added burdens on an HIV affected child, who will have to take on additional caring responsibilities. The practicalities of families needing to store and take regular medication, access specialist health care, and the discrimination they will face if the information about their families HIV status all add further pressures and problems on the already problematic situation of detaining families in this environment.

Section Five

Access to Health Services: HIV Infected Pregnant Women and HIV Infected Children

An important distinction in the category of ‘insecure immigration status’ is between those who are at present in the process of claiming asylum or appealing a claim, and those who have failed their claim, who have overstayed a visa or who are undocumented. This section presents how this distinction is exemplified through practitioner’s reports regarding access to free NHS care and treatment for HIV infected pregnant women and HIV infected children.

5.1 HIV Infected Pregnant Women

An asylum-seeking woman is currently entitled to free NHS care. Therefore she will be in the antenatal system, hopefully having been routinely tested for HIV, and then given the specialist care and treatment to prevent mother-to-baby transmission of the virus. Antenatal care is seen as immediate and necessary treatment and as such must be provided. However, general antenatal care is chargeable so a woman not eligible would be billed at some point during her pregnancy, although this should not prevent the care being provided. An HIV test is free to everyone. The care and treatment necessary if a test is positive will be charged.

It is important at this point to clarify what treatment an HIV infected pregnant woman needs to prevent giving her baby the virus. In brief, the prevention of vertical (mother-to-baby) transmission of HIV in the UK is nothing short of a public health triumph. Prior to having the interventions in place, an HIV positive pregnant woman had between a one in three or four chance of transferring the virus to her baby. Now, mother-to-baby transmission of HIV in the UK is now as low as one in one hundred, using a simple set of interventions that include: avoiding breastfeeding; antiretroviral treatment to mother in pregnancy and to baby after delivery; and appropriately planned delivery, (whether elective caesarean section or vaginal delivery which is possible for women with completely suppressed HIV viral load on treatment).

These interventions virtually guarantee the child will be HIV negative; therefore successfully stopping transmission, saving the NHS future costs for the care of this child, and upholding UNCRC Article 6 (the child’s right to survival and development).

Early presentation and finishing the set course of treatment are both extremely important factors in preventing transmission between mother and baby. The problem with the current system of charging is two-fold. Firstly, it can deter early presentation, which increases risk to all women and babies, primarily and significantly to undiagnosed HIV positive women. Secondly, it places healthcare workers in a situation where theoretically they cannot treat people who cannot first show a means of payment for HIV treatment.

Case Study 8

An expectant mother had her initial antenatal appointment at 14 weeks and was offered routine antenatal screening tests (including HIV). She agreed to have all of the tests and was given an appointment to come back for her routine antenatal follow up and test results. When she returned 2 weeks later as arranged, she was immediately approached by the Overseas Payment Officer who wanted to interview her about her eligibility for free NHS care. At this point she panicked and fled the hospital, prior to having had her appointment, and prior to getting any of her results, including the HIV result.

Some weeks later, as is routine policy in this hospital, the HIV clinic received a copy of the HIV positive result of this woman. No one recognised the patient's name and she was tracked down to her attendance at the antenatal clinic. Fortunately, after much effort and time she was found in the community, visited and convinced to come to the clinic. She was then given her positive HIV result. At this point she was some months into her pregnancy, but was successfully treated and her baby was born HIV negative.

Fortunately, the HIV Unit and Hospital Laboratory had a robust policy for reviewing all HIV positive results in the Hospital and so her HIV test result was picked up. They were then able to actively pursue her, re-assure her and persuade her to re-access services, despite her continued fear of the Overseas Patient Officer and uncertainty about her immigration status.

Without these actions the woman would have remained ignorant of her HIV positive status throughout the remainder of her pregnancy and during breastfeeding. She would either not have re-presented for antenatal care at all, or just very late. She would then certainly have had a high-risk pregnancy, and possibly an HIV positive baby.

As it turned out, she was actually eligible for free NHS care anyway.

Information about the current situation for these women was gathered through the questionnaires. Firstly, we wanted to establish how many women have either been treated or have attempted to access health care that were not entitled to free maternity care in the last 12 months. In total, 75 women have been seen across the15 health services that completed questionnaires, although numbers varied from zero to 30.

Respondents were then asked who, in their opinion, out of these women, had access to funds to meet any requested payment. The unanimous consensus was 'none.'

The reality of the situation is that on the whole these women do receive some form of health care, but more through health practitioners manipulating the system and Trusts agreeing not to chase unpaid bills.

> *'Funding concerns are not raised with pregnant women. All women (so far) have received free treatment, regardless of entitlement.'*
>
> *'As it stands, the system is not sustainable. It is inconsistent, relies on good will and*

> *compromises health professionals, the majority of whom are for all intents and purposes, at times working against the law.’* Improving the health and well-being of HIV positive pregnant women has been a significant medical achievement in recent years with a dramatic reduction in mother-to-baby transmission. Deterring women from early presentation for specialist antenatal care because of the threat of charging means that this medical achievement may become severely compromised. The prevention of mother-to-baby transmission of HIV needs to be given priority over immigration issues.

5.2 HIV Infected Children

Although HIV infected children being refused treatment on the grounds of their families immigration status is on no account normal, the fact that it has happened means that it has the potential to re-occur, especially as practitioners are reporting a ‘tightening’ of the implementation and enforcing of charging systems.

Case Study 9

An HIV infected child was diagnosed at a Trust when the child’s health was stable. The child’s consultant at the time made a referral for the child to access some of its care from a ‘hub centre’. After a short amount of time, the child’s health began to deteriorate and the mother brought the child back to the hospital. However, during the period between visits, the hospital had investigated the family and told the mother that her child was not entitled to free NHS treatment on the grounds of their immigration status and she would have to pay in advance if her child was to go on Antiretroviral Therapy.The mother immediately took the child to the hub centre to which the referral had been made. This involved travelling a great distance but the child was immediately treated.

Without this referral directing the mother to another service, the child may not have had access to the necessary healthcare to stabilise its health, and the implications of this for the child would have been huge.

There are very few HIV infected children who under the current system are not entitled to free healthcare, but they do exist and on the whole are treated without question. But as immigration legislation changes and NHS Trusts face growing overspends, those health practitioners who treat without question could potentially be reprimanded by their NHS Trust for knowingly giving free healthcare services to families who should be charged.

> *‘[The Trust] has not been enforcing the charging policy in the HIV clinic. The overseas officer in the hospital has so far kept their distance. But there is no formal arrangement and it is likely to change as a new policy of tracing people’s paper trail back to their original postcodes is coming into place, which will mean much more close scrutiny of patients, whereas at present those without status etc., can just get mixed up with everyone else and won’t really draw any attention to themselves.’*

Although the above quote was relating to adult HIV services, it highlights a growing problem. The larger child's clinics may be able to 'loose' or 'hide' the occasional child whose family are not entitled to free treatment and have no means of paying, but for those small treatment centres, this may not be possible. Therefore it is possible that more children, whose families have no means to pay, will be refused treatment on the grounds of immigration status.

5.3 Conclusion

Responses inferred that immigration issues are now beginning to hold greater precedence in the assessment of health care provision. It is not uncommon for patients who are faced with charges at one clinic to 'find their way' to another where they can receive treatment without being asked questions on their immigration status. This practice is unsustainable and compromises the health of all HIV positive people, both children and adults.

Preventing HIV transmission, which is a public health issue when related to blood screening, sexual transmission and through IV drug use, must also include mother-to-baby transmission and therefore be freely accessible to all as free emergency treatment. There needs to be open debate on the ethical issue of chronically ill children who are living in the UK, not being able to access drugs that will stabilise their condition and maintain their health as their family cannot afford to pay. The implications of the threat of enforced payment on taking up services should not be underestimated. Treating children and adults before they become seriously ill will not only save the NHS money, but also prevent unnecessary suffering.

Section Six

The Impact on HIV Family Services: A Case Study of Health Through Action

When looking at the current situation for children living with HIV with insecure immigration status, it is important to examine the impact that the changing situation has had on VCS service capacity and development. These services provide essential support for families outside of health provision; they often support families with financial, social and legal issues.

This section will present the impact that the changing issues faced by children and families living with HIV have had on VCS services by looking specifically at one children and HIV specialist service.

Health Through Action is a Barnardo's Project based in the heart of Manchester. The service was originally set up in 1995 to provide a planning, support and bereavement service with an emphasis on supporting parents to share information about their HIV illness with their children. Peer support and one-to-one support was provided for affected children. With the majority of families accessing the service now asylum-seekers or refugees from sub-Saharan Africa, the service has had to change its model of delivery.

Families accessing the service have experienced significant trauma in their country of origin, and then they experience issues determined by their immigration status such as poverty, isolation and insecurity. They need advocacy support, practical and emotional support and support to reduce their isolation. With many families being moved repeatedly into new geographical areas, this can require these links being made over and over again.

6.1 The Changing Face of Service Users

6.1.1. Regional Data

By 2005, 4,195 individuals were presenting to treatment centres throughout the north west of England, a 17 per cent increase on the 2004 figure. Although a small number of families do move by choice, the impact of dispersal is a significant factor in the changing demands on services such as Health Through Action. Since dispersal began, the number of applicants (including dependents) that have been moved to Manchester is 1,090,[xxvi] making Manchester the fourth largest dispersal area in England. Health Through Action covers Greater Manchester and Lancashire, which includes other key dispersal areas such as Salford, Stockport and Bolton.

6.1.2 Staff

The impact on the service is reflected in the staffing. In 2000, Health Through Action's staff team comprised of one full-time social worker supported by administration time and 5 hours management time. Six years on, the organisation has expanded to 12 staff members, including social workers, early years and family support workers as well as a volunteer coordinator and administrator. This expansion has occurred to meet the growing need and expanding client base.

6.1.3 Children and their Families

Table 1 (below) illustrates the increase in numbers of families who have insecure immigration status accessing Health Through Action. Cases have grown steadily more complex with issues such as women who are victims of sexual assault and have experienced multiple losses though civil war or violence; children born out of rape; and unaccompanied minors who have contracted HIV through rape. Some children in referred families have witnessed violence including the killing of their family members.

Table 1: Children and families accessing Health Through Action who are refugees, seeking asylum or who have no access to public funds

	2000	**2001**	**2002**	**2003**	**2004**	**2005**	**2006**
Families	1	5	14	21	34	53	89
Infected children	0	2	4	9	18	23	26
Affected children	1	9	27	41	63	97	149

6.2 Managing Refugee and Asylum Issues

Health Through Action has found immigration, nationality and refugee law to be so complex and so changing, that it disempowers both applicants for asylum and the agencies that seek to provide support. The Home Office guidance that upholds rights and entitlements for asylum seekers (that is, standards of accommodation, not being moved from locality to locality, etc.) is, in practice, not adhered to and there is no effective machinery to challenge or contest when things go wrong.

Case study 10

The mother watched the militia kill her father and brother and then was taken and systematically raped over a number of years. Her family managed to find her and secure her passage out of Africa and she arrived in the UK. It was then that she discovered she was pregnant and had been infected with HIV. She gave birth and the baby is HIV negative.

She applied for leave to remain. At her initial interview with NASS lawyers, she was confused and unsure of where she was. Her initial statements did not stand up in court and she was told that the court did not believe her story and her application failed. At the appeal, the court accepted that the trauma and extreme violence she had faced had affected her ability to give clear statements about what she went through, and they granted her limited leave to remain.

The trauma the mother has been through has severely impacted upon her mental health and being told by a court of law that she was a liar has scarred her deeply. She does not believe that the court will not change its mind and send her back.

The mother has said that she has nightmares and relives the horror of her experiences. She wonders who was the father of her child. She fears making a bond with her baby as she is worried that she may die from her HIV and that the child will then feel the loss she herself has to live with. She cries a lot in front of her child, and sometimes she cannot stop for a long time. Night holds many fears for her, and so she and the baby have strange sleep patterns, as she often sleeps in the day. She does not socialise and does not like leaving the house.

6.2.1 Article 3 Applicants

Family applications under human rights legislation for humanitarian protection (typically on medical grounds, for example, a child being HIV infected) are leaving families with no access to public funds and ineligible for support under NASS. The parents are not entitled to undertake paid employment. The responsibility should then fall to the local authorities, although Health Through Action has often had to advocate long and hard with individual local authorities to get support for these families.

6.2.2 Failed Claims and Vouchers

When a family has unsuccessfully reached the end of the appeals process there may be many reasons why they remain in this country (for example, no government agreement to return failed asylum seekers to their home country). Often the family will receive support from NASS or the Local Authority, and this is typically issued in the form of food vouchers. The service has had many examples of these vouchers being refused by supermarkets when a parent has tried to purchase baby milk. They also cannot be used for some of the basics, like feeding bottles (essential for the prevention of mother-to-baby transmission) and household necessities.

6.2.3 Accommodation

Recent changes in housing contractors, which were supposed to cause ‘minimum disruption’, have seen families moved away from their treatment centres without planning and with only a few days notice, despite the guidelines in NASS Policy Bulletin 85. Children have lost their school places or established nursery places, missed deadlines to gain nursery and school places, and new housing has not provided some of the necessary basics, for example, a bath.

In Health Through Action’s experiences, many housing providers do not equip their accommodation in line with NASS standards. Accommodation is often damp and with broken appliances such as boilers. Families are often placed in ‘hard to let’ properties in disadvantaged areas where the host community itself feels deprived and less accepting of newcomers into the area. Racial harassment is common to many of the families.

Each time a family moves, there is a temporary suspension of their benefits while a new post office is arranged. Very often, this leaves the family with no support and a typical NASS help line response has been that a payment will be made to them within 3–5 working days and that they should remain indoors for its delivery. When asked what the family should do in the meantime, the advice has been that they should find a voluntary agency to give support. No mention is made of the housing providers’ responsibilities in these situations or indeed of any relevance of Social Services support via Section 17 of the Children Act 1989. This explains why so many families come to Health Through Action for emergency money and for food, nappies, toilet rolls, etc.

From time to time, most of the families in contact with Health Through Action have their money suspended for no reason. They will receive a letter saying that this has happened due to their changed circumstances even though there has been no change.

Case Study 11

The mother came to the UK on a work visa after the father died. Soon after their arrival the health of her youngest child deteriorated. During a period of hospitalisation, the child was diagnosed HIV positive and then the mother tested and received a positive diagnosis. From this point she could not work, as she had to care for her sick child. She made a Human Rights Application to remain in the UK and was told that while this was processed, she would not receive support through NASS, but that Social Services would support her under Section 17 of the Children Act 1989.

The family are living in private accommodation. They could not pay the rent so as an interim measure, the mother moved her family all into one room, and rented out the other rooms to another family. Social Services initially gave the family a little package of money that covered school meals, school uniforms and some food, but there was no clear system of finance setup and no arrangement agreed. The Social Services Team Manager and the Service Manager were both written to but no reply was received. Eventually after writing to the Senior Service Manager a reply arrived (this took three months), which simply stated they were looking into this case. During this time the gas was disconnected from the house, due to non-payment of bills. It was wintertime and the HIV positive child was suffering from Chicken Pox. The voluntary organisation provided the family with food packages and home visits.The mother is now receiving £51 per week. She was told in June 2006 that she would receive an additional £46 but to date, this money has not arrived. One year on, Social Services agreed to pay the rent, on the condition that a rent book was produced. But the Landlord will not provide a rent book, so renting out rooms to other families is still paying the rent.

The family has on the whole lived off handouts. The children are often hungry and the fact that the HIV infected child needs a nutritious diet to help sustain its health is not possible. On one visit a voluntary sector social worker looked into the family food cupboards to find nothing but some cereals and lentils. The fridge was empty.

6.2.4 Access to Health

Families experience disruption in health care received as a result of dispersal or the renegotiation of the housing contracts. Although housing providers are required to assist with GP registration, this is usually no more than tokenism. A typical case example is one mother of a 3-year-old who has been moved between four different local authorities in the last year. She has been unable to register with a GP and this has resulted in her child not having access to a health visitor even though he has developmental problems.

6.2.5 School

Many of the children in contact with Health Through Action have to move schools repeatedly, so new uniforms are needed for each move and only some Local Authorities will provide these. There are many unanswered questions over issues around asylum seekers' entitlement to free school meals, help with transport and parental choice over schools and school uniform grants, etc. There is no consistency between Local Authorities and decision-making processes are not thought through.

Some schools and governing bodies have no idea about their responsibilities to asylum seeking children. They ask parents to produce documentation, such as passports for a child, and deny a place when these cannot be produced, even though this is because the documentation is lodged with the Home Office. There have been several examples of schools refusing to enrol a child once their HIV status has been revealed and very often this information has been divulged to a school without parental consent.

6.3 Conclusion

The impact on this service has been huge, as is demonstrated in this section. For Health Through Action one of the key issues is that Local Authorities seem confused about how the Children Act (both 1989 and 2004) applies to children in the asylum process. Confusion is heightened by the discrepancies between children and asylum law (see Section 1), or when Section 17 of the Children Act is not seen as applicable. There are other complex areas where these children may well be entitled to assessment under the Children Act, such as families with disabled children. Clarification of responsibility for Local Authorities and better communication with NASS would benefit children and their families, and allow staff at Health Through Action the time to focus on the emotional and psychological needs of these children and their families.

Section Seven

Conclusion and Recommendations

7.1 Conclusion

This report has shown that HIV complicates further the situation for children and their families who live in the UK with insecure immigration status. The combination of HIV and insecure immigration intensifies issues already faced by these children, such as peer interaction, drug adherence and viral immunity. Certain areas of the asylum system work against these children, placing barriers to their access of health care and support services.

The findings in this report conclude that NASS interaction with health and support services is mainly poor. Opening up dialogue here would take much of the strain off of the practitioners supporting these families, and improve the family's lives greatly.

Taking a pragmatic look at the cost of treating HIV infected pregnant women, compared to the cost of intensive care treatment of HIV infected babies being born, is essential. Free and accessible treatment needs to be made available in the short term to avoid greater costs in the long term. Equally, the ethical and moral issues of refusing chronically ill children free life saving treatment when there is clearly no way their family can meet the costs cannot be ignored. Being returned to a country of origin where the reality of accessing HIV medication is costly or unavailable to most people, places extraordinary pressure on families. Paediatric HIV medication is even scarcer, with few facilities and little training in this complex area. The thought of returning to their country of origin to die, or witness their child die, overshadows the lives of many of these families.

Significant from this research is the incredible resilience that families have shown in the face of immense adversity, sustaining their efforts to keep their families together and offering their children opportunities for a positive childhood. This is in contexts where many have experienced immense traumas in their countries of origin, and when arriving at an expected place of safety, they have frequently found themselves living in poverty, receiving an HIV diagnosis, having periods of ill health, hospitalisation and threatened with detention.

7.2 Recommendations

7.2.1. All asylum seeking families applying under Article 3 (EHRA) should obtain the same level of state support as those applying through NASS. The amount of, and who is responsible for, this should be clearly set out in guidelines and this should be accessible to all through the Home Office website.

7.2.2. Local Authorities still have a duty of care to children from failed asylum seeking families. This needs to be clarified and guidelines produced to set out who has responsibility for what and what the minimum level of income is on which a family is expected to live. Again this should be accessible to all through the Home Office website.

7.2.3. A public health assessment is needed to review the impact of the new charging policy for NHS treatment and care for overseas visitors. There needs to be particular attention given to whether this is having an impact on the take up of antenatal care, and if so, at what stages in pregnancy these women are presenting. This should include close attention as to whether this is resulting in an increase in the incidence of mother-to-baby transmission of HIV.

7.2.4. All pregnant women regardless of immigration status should have access to free antenatal care. HIV positive women need to present early in their pregnancy to receive all the specialist interventions required to protect against mother-to-baby transmission of HIV. The implications of the threat of enforced payment on women taking up services should not be underestimated.

7.2.5. Children with complex health needs, whether this is HIV or any other chronic illness, must have their basic needs acknowledged, including access to appropriate specialist health care. Realistically, in the case of HIV, this has to mean that these families, of whom there are no more than a couple of hundred, are exempt from involuntary dispersal as continuous contact with the same expert specialist paediatrician will support a healthier child and therefore costs the NHS less money in the long term.

7.2.6. Children with compromised immune systems must live in healthy housing, enjoy a balanced and healthy diet, and be able to travel to hospital and health clinics. The long-term cost benefits to the NHS outweigh the shorter-term costs to the benefits system. We recommend that both NASS and Social Services provide the families that they are supporting, who have an HIV infected children, with disabled children's allowance in recognition of the increased expense of meeting their specialist health needs.

7.2.7. Children living with HIV should not be detained in Immigration Removal Centres. Moving families who need to adhere to complex drugs regimes can impair health further and it makes little economic sense and is unnecessarily inhumane.

7.2.8. Our research has shown that the NASS Policy change set out in '*NASS Policy Bulletin 85: Dispersing asylum seekers with health care needs',* has made little to no difference to the practice of dispersing children and families living with HIV. We strongly recommend that NASS commission an external review of the experiences of people living with HIV and ensure their policies are being translated into practice.

7.2.9. Finally we recommend that all NASS case workers with an HIV infected child should be directed to liase with the child's consultant and provide them with their contact details when they first receive the case. This simple task will go a long way to alleviating the suffering of families, upholding the guidance set out in Policy Bulletin 85 and relieving the pressure on health professionals.

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Section Nine

Annex

Questionnaire: Paediatric HIV Unit

GENERAL

1: Is your centre (please tick):

A hub centre
A shared care centre
In London
On the London rim
Outside of London

2. How many whole time equivalent members are there in your team:

Nurses
Doctors
Psychologists
Dieticians
Physiotherapists
Pharmacists
Coordinators
Social Workers
Others (please specify):

3. How many HIV positive children have you treated since July 2005?

4. Do you routinely ask families about immigration status? (please delete)
YES / NO

5. How do you record this?

Do families ever try to hide information about their immigration status?
(please tick)

Never
Rarely
Sometimes
Often

Please expand on any of your answers

6. What percentage of children in the clinic have insecure immigration status (this also includes unaccompanied asylum seekers)?

7. Have you observed any differences between the children you treat with insecure immigration status and those with secure status in the following areas:

i. Child development (Please circle) Yes / No
If yes, please explain how.

ii. Interaction with health care professionals (Please circle) Yes / No
If yes, please explain how.

iii. Adherences to medicine (Please circle) Yes / No
If yes, please explain how.

Did your families have difficulty getting legal help with immigration issues?

Did you refer families to NGOs? If so which ones:

**8. In your experience, how helpful has NASS been in the following areas:
Do you have a named contact at NASS? If so who is it?**

Easy to make contact with (Please circle)
Good OK Bad

Informing you if a patient is going to be dispersed (moved from the area)
Good OK Bad

Taking into account the additional needs of children and families living with HIV
Good OK Bad

Please expand on any of your answers

9. What changes, if any, would you like to see made to the immigration system that your patients have to go through?

10. Of the HIV positive children you have treated in the last year, how many of them and/or their families:

Have received leave to remain
Have been sent back to their country of origin
Have disappeared from your service
Other (please specify)

11. Have you lobbied immigration services on behalf of any children in your care or their families? (Please circle)
Yes / No

If you answered yes, please specify the details of your involvement and the number of cases you have been involved in

12. Have you been involved in court action on behalf of any children in your care or their families? (Please circle)
Yes / No

If you answered yes, please specify your role and the number of cases you have been involved in.

13. On average, what proportion of your working week is spent dealing with immigration and asylum related issues, rather than medical issues?

DISPERSAL

Dispersal has been a significant issue for families living with HIV. At the beginning of this year (2006), NASS changed their Policy and Practice to acknowledge the need for preparation time before moving those accessing medical care. Therefore, within this section, you are asked to comment on the impact of this change of practice

Children moved TO your area

14. How many HIV infected children were moved into your area through NASS dispersal:

a) Between July – Dec 2005?
b) Between Jan – June 2006?

(If the answer is none, please go to question 17)

Are you aware of any children who were separated from their family / parents in this process?

15. In what ways, if any, has the handover of a child's care improved since NASS policy change? (Please tick one answer)

I have had more notice
About the same
I have had less notice

i. If you think it has improved, can you explain how?

ii. If you think it has not improved, can you explain how?

16. In your view, has dispersal had a negative, positive or no impact on the following aspects of the lives of the children who have moved into your area through this process?: (please circle)

Adherence to medication:
Very Negative Negative No Impact Positive Very Positive Don't Know

General health:
Very Negative Negative No Impact Positive Very Positive Don't Know

Mental health and well-being:
Very Negative Negative No Impact Positive Very Positive Don't Know

Parent/child relationships:
Very Negative Negative No Impact Positive Very Positive Don't Know

Child development:
Very Negative Negative No Impact Positive Very Positive Don't Know

Children moved FROM your area

17. How many of the HIV positive children and/or families in your care have been moved out of your area through NASS dispersal:

a) Between July – Dec 2005?
b) Between Jan – June 2006?

(If the answer is none, please go to question 21)

Are you aware of any children who were separated from their family / parents in this process?

18. Have you had more, less or about the same amount of notice given to you and your patient(s) since the NASS policy changes? (Please tick one answer)

I have had more notice
About the same
I have had less notice

i. If you think it has improved, can you explain how?

ii. If you think it has not improved, can you explain how?

19. Have you had more, less or about the same amount of time to identify an appropriate clinic/clinician and arrange transfer of care and treatment since the NASS policy changes? (Please tick one answer)

I have had more time
About the same
I have had less time

i. If you think it has improved, can you explain how?

ii. If you think it has not improved, can you explain how?

20. Do you think that children infected with HIV, once they are accessing treatment, should be dispersed at all? (Please circle)
Yes / No

Please explain your answer:

DETENTION

21. How many HIV positive children who you have cared for in the last 12 months were:

a) Already in a detention centre
b) Taken to a detention centre

(If the answer is none to both a and b, please go to question 27).

Are you aware of any children who were separated from their family / parents in this process?

22. Where children have been moved to detention centres, in how many cases have you had the opportunity to hand over care? (Please tick one answer)

In every case
Some cases
No opportunity

Please expand on any answers

23. Given that many children are unaware of their own infection, in how many cases have you had the opportunity to talk to detention centre staff about this issue? (Please tick one answer)

In every case
Some cases
No opportunity

Please expand on any answers

24. What proportion of children or families detained have you remained in contact with?

(If the answer is none, please go to question 27)

25. In your experience has living in a detention centre had a negative, positive or noimpact on the following aspects of the lives of the children you were caring for? (please circle)

Adherence to medication:
Very negatively Negatively Not at all Positively Very positively

General health:
Very negatively Negatively Not at all Positively Very positively

Mental health and well-being:
Very negatively Negatively Not at all Positively Very positively

Parent/child relationships:
Very negatively Negatively Not at all Positively Very positively

Child development:
Very negatively Negatively Not at all Positively Very positively

26. Is there anything else you would like to add about HIV infected children in detention centres?

27. Finally, are there any other issues that you would like to raise in relation to the treatment of children and families living with HIV? (Please circle)

No / Yes (please give details)

PREGNANT WOMEN

This questionnaire aims to gauge how entitlements to free NHS care are impacting on pregnant women living with HIV and vertical transmission rates.

We want to establish whether the cost of NHS treatment has stopped some women that are not entitled to free care accessing the interventions that can, in the majority of cases, stop vertical transmission.

1. How many pregnant women with HIV have you treated or have attempted to access your care in the last 12 months who were not entitled to free maternity care on the NHS?

2. Of these, how many in your opinion, had access to the funds to meet any request for payment?

3. Of these, how many disappeared before the completion of their care?

If you have any particular cases that you feel illustrate well a particular point, please contact us as we are gathering practice examples, case studies and in depth interviews.

Email hiv@ncb.org.uk or telephone 020 7843 1911.