

## **UPDATE: HIV positive children and families in the asylum system**

The Children's Society asked for information to inform a parliamentary inquiry to examine whether the current asylum support system provided by the Home Office for those seeking protection in the UK meets the needs of children and families.

The Children's HIV Association surveyed its membership – over 150 practitioners from health and social care based across the UK – to provide a snap shot of the current situation for children who are in the asylum and immigration process and who are also HIV positive or currently have an indeterminate diagnosis<sup>1</sup>.

### **HIV positive children in a health care setting**

There are 1190 HIV positive children and young people currently accessing NHS services across the UK (CHIPS 2012).

A total of 12 organisations/centres responded to the on-line questionnaire, 11 from health and 1 from social care.

The 11 health responses represented a total of 42% (n=496) of the HIV positive children and young people living in the UK.

Of these, 12% (n=58) had in the last year been involved in the asylum system to some extent.

Of the group involved in the asylum system, 31% (n=18) were reported as having no recourse to public funds.

3 of the 11 centres reported that, to their knowledge, over the last year none of the children accessing their service had been in the asylum system. This reflects the spread of people seeking asylum in the UK, with concentrated centres in different parts of the country.

### **HIV positive families in support settings**

The 1 social support service that responded stated that they currently have 300 regular service users. Over the last year, 400 service users and their families who have come through have been involved in the asylum system. Of these 400, 19% (n=75) have had no recourse to public funds.

### **The survey**

A number of qualitative questions were asked relating to how these practitioners viewed the experiences of the children, young people and families they are supporting. The following reflect the responses from the 8 medical centres that do see children in the asylum system and the 1 social support service.

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<sup>1</sup> This relates to those children who are born to an HIV positive mother but due to their age, their HIV diagnosis is still unknown.

## **Question one: Have you found that the current levels of support provided to your asylum-seeking patients are adequate?**

Of the 12 responses, 3 stated yes whilst 9 stated no. Our data collection does not allow us see whether those responding 'no' were also the 3 centres who do not treat children in the asylum system, but it is fair to presume this is so.

Respondents were asked to expand on their 'yes' or 'no' answer, with five key themes arising.

### **1.1 Health services capacity to support children and families in the asylum system**

As was also noted in previous research<sup>2</sup>, health care providers will try to support their patients within the asylum system where there is no local support available, yet there are huge capacity issues with this:

*I am a single-handed part time Infectious Diseases consultant with no dedicated Nurse or Social Worker*

*[There is] no voluntary sector support and social services support is poor*

Even where there are local services available, respondents reported that families struggle to navigate their way around the system:

*There are very few services that provide families with advice or legal information. The services that do exist are often based in London or are over subscribed and cannot offer a great deal of support for navigating the asylum/immigration system.*

*Parents and children do not necessarily understand systems and processes in place and are reprimanded because of this.*

*Asylum teams in the local area are over burdened and do not view these children's cases as a priority.*

### **1.2 Psychological impact**

As is well documented, there can be a profound impact on children growing up with HIV. Respondents reported an additional psychological impact on these children and families through being in this asylum process.

*Many families are living with a strong sense of the unknown as they go through appeal processes. This brings a heavy psychological burden. HIV positive families are particularly concerned as they often worry about accessing treatment following deportation. They fear services and often worry that agencies will "appear in the night" unexpectedly.*

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<sup>2</sup> Conway, M. Asylum, Immigration, Children and HIV. (NCB 2006)

### **1.3 Dispersal of pregnant women**

The dispersal of pregnant women becomes of huge concern when the woman is HIV positive. The movement of clinical care, especially later on in the pregnancy, could have an impact on the effectiveness of the prevention of mother-to-baby transmission of HIV.

*Of particular concern is when pregnant women are dispersed with no warning, particularly late in pregnancy.*

The economic impact to the NHS, over a lifetime, of an infant acquiring HIV is estimated at £350,000-£500,000 per child. Even if a family is soon to be deported, a sick baby could still need general paediatric or intensive care treatment, with admissions costing around £2000 a day.

Mother-to-child HIV transmission is, in the main, preventable. Putting a child at risk of HIV transmission through unnecessarily moving an HIV positive pregnant woman and therefore moving her care makes no financial or health sense.

### **1.4 Basic needs**

When looking at basic needs, such as housing, food and clothes, it is key to remember that these children are living with compromised immune systems. Again, aside from the moral argument, keeping an HIV positive child well through the provision of basic needs makes financial sense. If a child becomes ill due to living in poor conditions or through lack of adequate clothing or food, the inpatient or emergency care needed will amount to thousands of pounds.

*Extremely poor housing, low incomes & sudden, un-planned moves to completely different towns/cities & thus schools, colleges etc.*

*70% of benefits - vouchers which mean people cannot buy what they want/need or is cheapest. Bills being paid direct mean families are cold and do not learn how to budget. Destitution speaks for itself.*

This effect becomes more profound where the family has no recourse to public funds.

*Where there is no access to public funds there is often challenges in ensuring basic financial support by social services, patients are often not provided for and food and basic essentials are not always factored in to the little financial provisions that are made.*

### **1.5 HIV related needs**

Having a chronic health condition means regular hospital appointments and managing complex medication regimes. Respondents reported how being in the asylum system could impact on simple aspects of a child's care:

*When children need appointments parents are often not able to afford transport costs to clinic and this is not considered by local social services to be something which they should fund.*

And more complex situations where there is family breakdown:

*2 of the young people I have been working with were thrown out of their family accommodation, the older male has been placed in a B&B with financial support and he is only 17yrs old!!*

Also raised were issues relating to how the asylum system does not recognise the complexity of paediatric HIV care.

*... a growing number of HIV infected children now under threat of deportation despite being on treatment. If their countries of origin having poor or some availability of ARVs the process/immigration process is more likely to favour deportation ...*

## **Question two: Is the accommodation provided to your patients adequate in maintaining their health?**

As stated above, the quality of accommodation is key in the management of any immunocompromising condition such as HIV. There were various responses to this question, with 4 respondents saying 'Yes, *on the whole*' or they were '*not sure*' and the rest reporting 'no'.

The issues raised by those reporting 'no' fall into 3 main areas.

### **2.1 Confidentiality**

This refers to people living with HIV wanting to keep this information confidential due to the extreme discrimination many people with HIV have experienced.

Shared housing presents a real issue in this area, with private letters coming to the house and the storing of medication (some of which needs refrigeration) being the two key issues specific to HIV.

*Often families are put in bedsits with no access to private fridges for medications so a parent or child's HIV status can easily be found out when residents all share one fridge.*

*No [the accommodation is not adequate] when in shared housing due to confidentiality issues affected by taking/storing medication, appointment letters, clinic letters, home visits.*

### **2.2 Standard of accommodation**

A recurring theme about accommodation is over crowding and that there is mould present, the latter being a particular issue for children with a compromised immune system.

*[We see] many families living in multiple occupation, or below standard (e.g. children living in bedrooms with mould).*

*Families I have worked with have been placed in cold, draughty bedsits with mould growing up the walls and been told they have no alternative.*

*..... often damp, inadequate heating systems etc and in general poor repair and over-crowded. Some accommodation is shared and therefore there's a lack of privacy.*

### **2.3 Insecurity**

The final issue highlighted was that of families being moved many times, and the impact this has on engaging with healthcare professionals, education and the psychological impact on the family.

*....it seems to involve multiple moves which is not good for psychological state and schooling.*

**Question three: Do you think the current asylum support system enables children in asylum-seeking families to have a standard of living adequate for a child's physical, mental, and social development? Please explain your reasoning.**

Respondents felt quite strongly that the asylum system does not provide families with the standard of living they need to manage HIV.

The answers fell into three broad categories.

### **3.1 Adverse impact on mental health**

Respondents commented on the instability families experience within the asylum system and the detrimental impact this can have on parents as well as children's mental health.

*I think the instability can be very unsettling, particularly as the parents tend to be very stressed about immigration. Being dispersed/moved is not good in terms of schooling and building healthcare links for the children.*

*The strain and anxiety of a lack of support from asylum teams or other asylum professionals causes parents to become very upset and struggle to manage day to day tasks. Parents have become clinically depressed, the standard of living has impacted previously adherent patients to lose adherence as stress, anxiety and chaotic lives in B&B or hostels means that routines are lost and poor adherence is often the result.*

The last point is crucial as the respondent is referring to adherence to medication. HIV medication must be taken daily at the same time(s) otherwise the virus can mutate and the medication will no longer work. This in turn will lead to the child becoming ill. As there are limited combinations of paediatric HIV medication available this will reduce the medical options for the child in the future.

### **3.2 Practical issues**

Respondents reported problems for their patients in relation to practical matters, such as keeping to medical appointments and accessing services. Respondents also report a lack of food for their patients.

*Patients can struggle to get registered with GPs and dentists so children can't have important immunisations or access to primary care services. A number of families cannot afford food or cannot provide adequate dinners to children because the money does not stretch this far.*

*We often have to apply for extra funding for food from charities, food donations, food parcels and staff handouts to ensure families can have enough to eat.*

*...housing issues, issues with money to travel to clinic often by multiple buses/trains.*

*Insecure living conditions and receiving only very basic provisions for extended periods of time have a detrimental impact on all levels of a child's/young persons physical, emotional & spiritual health. There is extensive & long-standing research that identifies poverty as a key factor in children's inability to reach their full potential.*

### **3.3 Accommodation Issues**

Again the issue of accommodation and its associated problems was raised in response to this question.

*I think that the housing conditions often impact on children's emotional, social, behavioural and educational development. Multiple moves in temporary accommodation (I have seen up to 7) give the family a permanent sense of instability, affecting the formation of relationships and attainment at school (children being moved during exams).*

*Poor accommodation and high levels of poverty.*

#### **Question four: How does the current asylum support system affect families where the child has HIV?**

It appears from our survey that there is no extra support within the asylum system for families where the child or children have HIV and this is not taken into account when looking at housing and moving families. This seems surprising as these are chronically ill children who need extra care to maintain their health, and extra support to manage growing up with a highly stigmatised chronic condition.

The answers fell in two areas.

##### **4.1 Knowledge of HIV**

Respondents reported that HIV is not taken into account and that there appears to be little understanding of this condition and the impact it can have on a family within the asylum system.

*There is no additional support provided. There is often no or very little understanding about the impact of HIV on a child/young person's physical & emotional health and wellbeing.*

*Don't think there's extra support available than what non-affected families receive.*

##### **4.2 Deportations**

This lack of understanding has led to a number of HIV positive children being returned, despite health care experts setting out cases to say why the child's HIV is an exceptional circumstance and that there will be a detrimental impact on the child's health.

*The system does not take a child's HIV status in to account. If parents are economic migrants this is viewed as a reason for children to be deported if they previously lived with a relative for a significant amount of time. There is no allowances or increased support where a child has HIV.*

*In the past have had 2 children deported as emergency with HIV despite going to court to try to prevent it.*

**Question five: Any other comments:**

Finally, respondents were given the opportunity to add any additional comments about this area that they felt were not covered in the set questions.

Three members responded with further comments and concerns.

**5.1 Stigma**

One person highlighted the discrimination feared by the families and how they felt the immigration system – due to its lack of knowledge and understanding about HIV – would discriminate against them.

*Many families do not disclose their HIV due to stigma in the immigration process. They fear their families will be split up. I have concerns about the conditions of children affected by HIV being detained in detention centres before deportation.*

**5.2 Immigration Control**

One respondent commented on the restrictions within the survey.

*I think the survey should address families subject to immigration control rather than just within the asylum system. Many countries have no access to children's medication therefore all children - subject to immigration control - should get leave to remain.*

**5.3 Case Study**

*We currently have a young child of 10years with HIV and severe cognitive development delay who is trying to be deported alone back to live with his aging grandmother despite his biological mother having leave to remain. Initially the mother was made to prove he was her child by obtaining a DNA test which we had to get charity funding to support. This was then proved and she then continued to have to fight his denied access for leave to remain.*

*She has leave to remain so she works to provide everything for her child but as he is not considered a British citizen the child could not be registered with a GP and could not have access to funds to support him. His mother was not able to seek help from asylum agencies as she was told she wasn't an asylum seeker. She has received no support from any external agency to help her achieve asylum for her son. The physical, emotional, psychological impact that the asylum process has on people and families is terrible and families are made to negotiate a system they are unfamiliar with often totally unsupported.*

## **Conclusion**

This 'snap shot' of the current situation for children living with HIV in the asylum system shows some very clear areas of need.

HIV medication can be complex, needs to be stored safely and taken regularly. Adherence is paramount and without accommodation which has the facilities for patients to do this, a child is less likely to be able to take their medication regularly. This will then have a detrimental impact on their health, leading to a higher potential for hospitalisation and higher costs to the NHS.

The asylum system severely lacks knowledge and understanding about HIV, even though information has been produced through organisations such as the National AIDS Trust. It would seem that those within the system do not take account of the health needs of children and accommodate them appropriately so these health needs can be met.

Dispersing HIV positive pregnant women has the possibility of increasing the potential of their child becoming HIV positive.

Moving families is not conducive to building and maintaining the necessary relationships with the health care providers that ensure chronically ill children get the medical attention they need. Financial restraints can further impact on this, leading to children missing health care appointments.

Children in the asylum system face difficulties in accessing basic health care such as GP's and immunisations. This in itself will have a larger impact on all children they come into contact with. It becomes more challenging when the child has a compromised immune system due to HIV and needs this access to maintain their health.

The most crucial issue that arose was that of accommodation and food. All children need stability and basics such as adequate accommodation, clothing and food. A child with a compromised immune system needs these basics to maintain their health. Keeping these children in poverty, without enough food, and in poor over-crowded, mouldy accommodation will further compromise their health, and must be seen as unacceptable in the UK today.

*All information was gathered and analysed by Abi Carter and Magda Conway for the Children's HIV Association during November/December 2012. Thank you to all CHIVA members who sent in responses.*