

## Exploring the support needs of HIV positive mothers with uninfected children

An account of speaking with ten local women  
about life, motherhood and HIV



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An account of speaking with ten local women about life, motherhood and HIV

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In partnership with



"Faith in people with HIV" is a registered charity offering spiritual and pastoral support and affirmation to people affected by HIV in Leicester, Leicestershire and Rutland.

Working with people of all faiths and with those who have no formal religious affiliation, the term "spiritual" is understood to mean the wider aspects of emotional and physical wellbeing.

The project is managed by the Bishop of Leicester's Chaplain for people affected by HIV. Its services are available to anyone living with HIV or affected by it (e.g. partner, family or carer) irrespective of background, culture, beliefs, ethnicity, sexuality, age or disability. The service is confidential and respects the rights of people affected by HIV.

"Faith in people with HIV" helps to raise awareness of HIV in faith communities and other groups and, working in close partnership with other voluntary and statutory agencies, seeks to promote good sexual health, foster understanding and break down barriers of stigma and discrimination.

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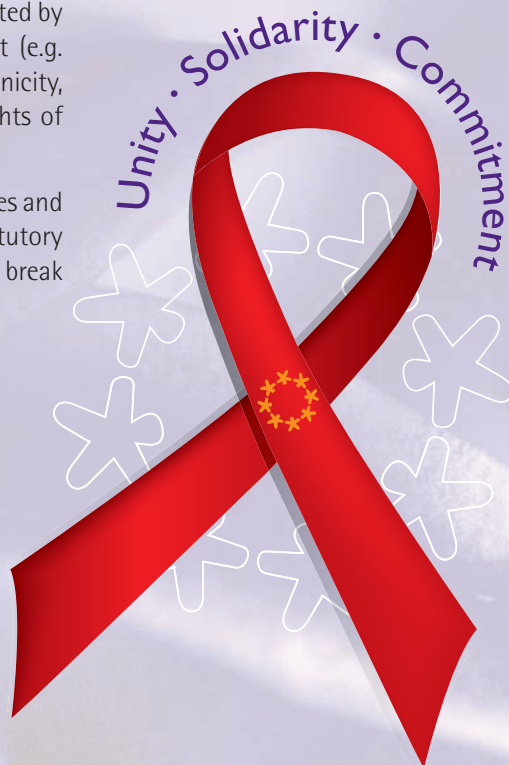
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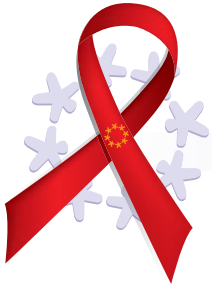
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# Executive Summary

...In the UK approx  
58,300 people are  
living with HIV...

Exploring the support needs of HIV positive mothers with uninfected children: An account from speaking with ten local women about HIV and motherhood

## Background

Globally 40.3 million people are living with HIV (UNAIDS Epidemic Update 2005). In the UK, approximately 58,300 people are living with HIV (London Health Protection Agency Centre for Infections 2005).

Locally, it appears infection rates in Leicester, Leicestershire and Rutland (LLR) are also increasing. (Choosing Health In Leicester 2005 :13).

In August 2004 the Leicester Health Protection Agency recorded the following data:

- 605 cases of HIV were diagnosed through statutory health across the 6 Primary Care Trusts in LLR.
- 301 were females.
- 44 were white females and 257 were women who classed themselves as having a Black or Minority Ethnic (BME) background. (Leicester Health Protection Agency 2004)

This research was required because local anecdotal information suggested uptake of medical, social and welfare support services by HIV positive women (most often, although not exclusively from BME origins) in LLR appeared to correlate with significant HIV related events (i.e. at the time of HIV diagnosis or during pregnancy), but it was thought that access of support services may not continue in the longer-term. Given the limited knowledge around the type of formal and informal support networks that positive mothers and uninfected children may have been accessing or requiring, this study aimed to identify the:

- services they were currently accessing
- services they would welcome
- barriers that they experienced in accessing support services
- issues to consider to inform future service provision

AIDS = Acquired Immuno Deficiency Syndrome  
HIV = Human Immunodeficiency Virus

...Two women were widowed by their husbands dying of AIDS related illness...

## Method and Sampling

Cluster and purposeful sampling<sup>2</sup> procedures (see Denscombe 2003 :14, 15, 16) were used. Ten semi-structured interviews were carried out; nine in Leicester City and one in the County. (We did not have any participants from Rutland).

## Key findings

### Participant Profile

AGES	RELIGION	ETHNICITY	IMMIGRATION STATUS
24	Pagan	Mixed Race British	British Citizen
25	Christian	Black African	Asylum Seeker
28	Christian	Black British	British Citizen
29	Christian	White British	British Citizen
29	Christian	Black African	Asylum Seeker
30	Christian	Black African	Refugee
33	Christian	Black African	Asylum Seeker
36	Christian	White British	British Citizen
42	Christian	Black African	Refugee
46	Hindu	British Indian	British Citizen

### Women's lifestyle

- Three women were born in Leicester; one migrated to Leicester in 1968, one in 1993, one in 2001, two in 2002, one in 2003 and one in 2004.
- Two women were the owners and the occupiers of their houses. Two lived in rented accommodation. Six lived in council housing or housing provided through National Asylum Support Service (NASS).
- Five women lived in one postal area of Leicester. Eight women felt a sense of belonging in the area in which they lived. Two mentioned they would feel more content if there was a safe place for their children to play.
- Four owned a car.
- Four had part time jobs, two were full-time students and one was a part-time student.
- Two women were widowed by their husbands dying of AIDS related illness. Three women were living with their partners of whom two of the partners were HIV positive. One was going through a divorce. Another was separated and two were looking for long-term relationships.

2. Purposeful sampling selects information rich cases for the purpose of the study and Cluster sampling is when the researcher would approach existing groups and services to find possible participants.



...Seven mothers thought HIV affected their life in many ways including; appetite, sleep, libido, relationships and the future...

- Various sources of income funded household running costs including, paid work, benefits, loans and child maintenance paid by the fathers (where applicable).
- Seven mothers were single parents. Six said that they would like to attend college to fulfil their potential but were unable to do so until their children commenced school. Therefore they recognised that their choice was limited.
- All ten mothers walked 15 minutes or more daily. Two smoked regularly and drank occasionally.
- Eight women ate healthy food. One woman (who is a refugee and a single mother of four children, three of which are living with her) experienced hunger due to impoverishment and lack of food for her family to share.
- Four used a local library.

### Language

- Whilst all ten women spoke English, three African women felt that the accent of the indigenous population in the UK was not easily understood by them.
- Six different mother tongues (first languages) were spoken between the women. These were; English, Shona, Ndebelé, Swahili, Chichewa (Nyanja) and Gujarati.

### HIV

- Five were on anti-retroviral therapy (ART).
- Six mothers believed that despite their HIV status they were generally in good health. Four women said that they regularly felt unwell.
- Seven mothers thought HIV affected their life in many ways including; appetite, sleep, libido, relationships and the future. These seven women said they experienced difficulties of living with HIV and being a single parent as being tiring and/or hard work.
- Regarding HIV tests: Four women were diagnosed in 2004, three in 2003, two 1998 and one in 1992. Four mothers were tested for HIV during anti-natal screening. Two women said their infection was a result of being raped in Africa.

### Support

- Three mothers used a local Surestart scheme.
- All ten women appeared to have very little knowledge of what Leicester City Council and Social Services provided or offered.
- Nine women used Leicester Royal Infirmary (LRI). Eight said that Genitourinary Medicine (GUM) clinic was too busy and took too long for them to be seen, although most of these women said that staff at GUM clinic were caring and friendly. All the mothers and their children were registered with a general practitioner (GP). Mixed comments were made

...general public continue to stigmatise HIV positive people and this is often harder to live with than the HIV infection itself...

about GP's. Some said that their GP did not understand their condition and others were confident that they did.

- Four women who were diagnosed during pregnancy felt they were fully supported and encouraging and positive comments were made about the level of support provided by a specialist paediatric nurse.
- Two mothers diagnosed at blood donor centres said no support was offered. Four women who were diagnosed at Leicester GUM clinic saw a health advisor who provided minimal pre-and post test support/counselling.
- Six women said their families were offered no formal help or support.
- Four used Leicestershire AIDS Support Services (LASS) and one also used 'Faith in people with HIV' for enquiries concerning their HIV. Two women used GUM for enquiries.
- Two women suggested professional guidance on diet was lacking.
- All ten mothers were the main carers for their children. Whenever the mothers became ill, the children's fathers would help with childcare (in the cases where the fathers still kept in regular contact with the mother for the child (ren). One mother was confident that her eldest daughter who is in her late teens would look after her other younger siblings.
- Nine mothers received domestic help from family. One mother who was on her own in the UK received support from new friends.
- Four mothers received help from their children in and around the household, including help from older children looking after their younger siblings.

### Disclosure

- Six mothers had disclosed their HIV status to a partner/member(s) of their family. Most of the women who have not yet disclosed their HIV status said that they believed their families would be supportive.
- Nine mothers had not disclosed to their child (ren). The ages of the children varied. Four mothers had one or more pre-school aged children, four had children who were school-aged and one had adolescent children.
- The mother who had disclosed her HIV status to her children said that they were in their adolescence when she told them and since then they have been very supportive.

### HIV and the future

- All the women said that further campaigning is required to promote positive messages of living with HIV.
- Most of the comments on perceptions and how to change society suggested that the general public continue to stigmatise HIV positive people and this is often harder to live with than the HIV infection itself.
- Seven women said that after disclosing their HIV status to their children they would like to be able to access a mother and children group for social and emotional support. They said that mothers and or their children can



meet others in a similar situation to theirs. Additionally two women said it would be useful for somebody on the same premises to look after their children at this social group so that mothers could meet other mothers and their children can meet other children.

- One mother (who was seeking asylum in the UK and who was a single mother) said assistance with childcare should be offered for when mothers have to attend important appointment's e.g. at GUM or the Solicitors.
- Three mothers would like a "one-stop shop" or resource centre where all contraceptives, informal support and free immigration advice can be offered.

...the best practice in disclosure to children should be identified...

## Recommendations

In light of the key findings the following is suggested to improve the quality of life of HIV positive mothers with uninfected children:-

### Children and Young people affected by HIV

Further research needs to be carried out to explore the impact of children and young people having responsibility to provide domestic help and care for HIV positive parent(s), in line with other young people affected by chronic illness within a family. Additionally HIV services should ensure a link with existing mainstream youth services available so that children and young people affected by HIV are supported.

### Co-ordinated Services

Specialist HIV services should work closely together to provide a more co-ordinated package and to liaise with mainstream services so that they are aware of issues around HIV (including stigma and discrimination). Liaison could take place between specialist HIV and mainstream services in the Leicester area which will help provide more accessible facilities to people living with / affected by HIV.

### Support with Disclosure

Existing HIV services should consider avenues such as self help/training courses/ workshops to enable HIV positive women to consider ways in which to disclose their HIV status to family members including children and friends etc, so that disclosure can become an easier process. With regards to children, the best practice in disclosure to children should be identified so that HIV positive mothers could be supported to disclose to their children at the right time using the most appropriate approach for them. Support regarding disclosure should also include access to other support services that are available such as family therapy if required. Information about support that is available regarding disclosure should be promoted widely so that HIV positive mothers are aware of this.



...After disclosing their HIV to their children, mothers said it may be useful to access support and help from specialist services together as a family...

## Information

HIV services and information about a range of issues regarding HIV needs to be promoted widely across all routes of HIV testing, so that people infected or affected by HIV (including HIV positive mothers with uninfected children) can know where to get help and support. This information could cover for example:

- How to access pre and post test counselling
- Healthy eating and access to a dietician, if required
- Advice on future sexual health for people infected or affected by HIV

## Stigma

It is recommended that some of the mothers who took part in this research should be given an opportunity to share their experiences (should they wish) in the form of an activity through poetry/drama or art on or around World AIDS Day 2006 which would represent their views on the stigma of living with HIV.

## Conclusion

This study provided a snapshot of the experiences of ten HIV positive mothers living with HIV, and therefore it can not be generalised to a wider population of HIV positive women. The mothers in this study were participating in daily activities that included employment and education. Additionally the mothers were supported informally by family and friends. The mothers identified difficulties that included access to information and support services/areas in which their lives can be improved such as: More social/friendship-type of support after they disclose their HIV status to their children and consistency in information/advice that was being offered regarding sexual health (e.g. oral sex) as well as the need for consistency in counselling (pre and post HIV test).

After disclosing their HIV to their children, mothers have said that it may be useful to access support and help from specialist services together as a family.

It is anticipated that this study will inform future partnership working in HIV services and mainstream services in Leicester and surrounding areas. The report will be disseminated widely for information sharing and expand knowledge base about this particular service user group (HIV positive mothers with uninfected children).



## Reflection from the mothers about the research findings

After showing the findings to the women who participated in this work various comments were made:

*"I didn't realise there were so many other single mothers living with HIV. I will be more at ease in participating in any other research... anything that helps."*

*"It's nice to know that I am not the only one who experiences difficulties in understanding the English accent [a comment was made by another mother about understanding the accent in Leicester]. Plus if this research didn't happen I wouldn't have had such a lovely day to Lincoln Cathedral" [This mother become a service user at 'Faith in people with HIV' after participating in the research. Faith... held a trip to Lincoln Cathedral in August – which this mother came along to]."*

*"I'm not surprised about the numbers of women who had to wait so long for appointments at GUM. The recommendations seem spot on."*

*"I can't believe that in this day and age people in Leicester experience hunger – it's very sad that this happens." [A comment made by a participant saying she experiences hunger]."*

*"It's nice to see my experience counts in your report. I would love to see some changes around improving the pre and post-test counselling especially in the blood donor centres across the country."*

*"It's good to show me what the other women said, as it helps me to learn from other people's life. Through sharing experience we will one day not stand alone in the fight against HIV/AIDS."*

*"I would really like to meet the other women. I will do my bit for World Aids Day. Well done for completing this." [Comment made about one of the recommendations in the report]."*

*"It was interesting to read about the other woman's experience over disclosing to her children. That's really brave of her, its making me think about how I will do it with my kids. Maybe I can contact you [Faith] when I decide to disclose to my kids. The recommendation about helping us learn the skills around disclosure is a good one, it sounds like exactly what might just help us feel like we can have help if we need."*

*"It's positive to hear we are all strong, intelligent women keeping busy with work and education and bringing up the little ones."*

*"Who knows, your next research should be a follow up study in 5 years time to see what we are up to and whether the other 9 of us have disclosed to our grown up kids!"*



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## Useful telephone numbers

### Leicester City, County and Rutland

Faith in people with HIV:	0116 273 33 77
Leicestershire AIDS Support Service (LASS)	0116 255 999 5
TRADE	0116 254 1 747
Specialist Dietician	0116 258 67 35
Department of G.U Medicine (Leicester)	0116 258 52 08
Department of G.U Medicine (Loughborough)	01509 56 88 88
Midwife Specialist	0116 258 599 0
Drug Advice Centre	0116 222 5 999
Turning Point (Substance Misuse) Loughborough	01509 611 111
Rape Crisis	0116 255 88 52
New Futures	0116 255 96 96
Refugee Action	0116 261 6 200
Social Services (Leicester)	0116 258 51 41
Social Services (Leicestershire)	0116 258 69 86

### National

National AIDS Helpline	0800 567 123
Positively Women (London)	020 7713 0222
Terrance Higgins Trust	0845 12 21 200



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- Juliet Houghton (RGN; RSCN; MSC), Children's HIV Specialist Nurse - University Hospitals of Leicester - National Health Service (NHS) Trust
- The Rev. Canon Michael Wilson (MA, MBA). Leicester Cathedral
- Rev. Trevor Thurston-Smith, Director of 'Faith in people with HIV' and the Bishop of Leicester's Chaplain for people affected by HIV

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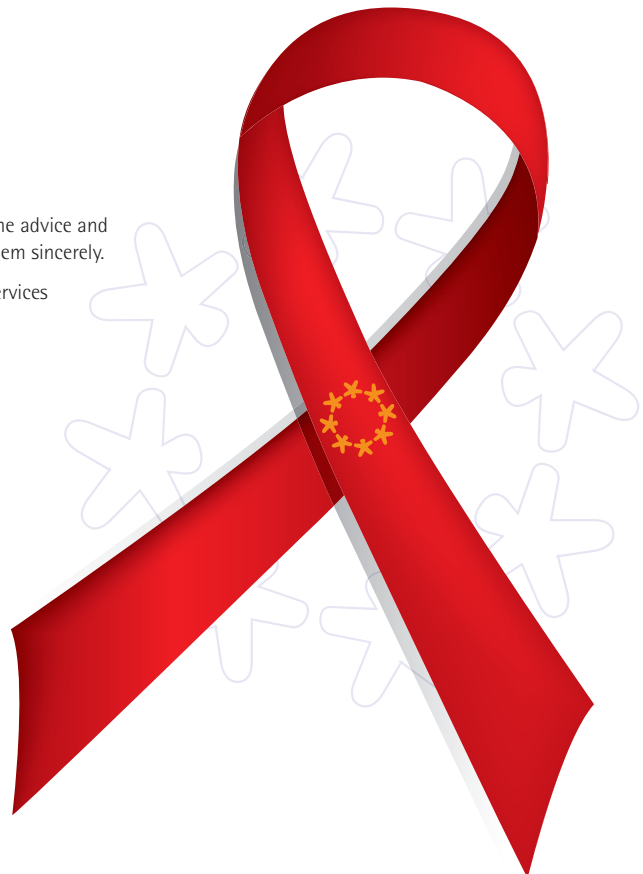
- Leicestershire AIDS Support Services (LASS)
- University Hospitals of Leicester NHS Trust
- Leicester Social Services Adult Team
- Leicester City Council
- Positively Women (London)
- African HIV Policy Network (London)

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