



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

Children and HIV in Scotland'

Citation for published version:

Cree, V & Sidhva, D 2009, 'Children and HIV in Scotland'. in Seminar to launch research report.

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Other version

Published In:

Seminar to launch research report

Publisher Rights Statement:

© 2009: 'Children and HIV in Scotland' with Dina Sidhva, seminar to launch research report, The University of Edinburgh.

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Children and HIV in Scotland

Professor Viv Cree &

Dr Dina Sidhva

The University of Edinburgh



Background

- A cross-sector needs assessment
- Aim to provide up-to-date information about infected and affected children
- To inform policy and practice
- Initiated and funded by the Elton John AIDS Foundation
- Supported by a Steering Group of local HIV agencies



The study

- 3 parts:
 - Scoping study
 - Epidemiological surveys of infected and affected children
 - Interviews with practitioners, parents and carers, children and young people
- Terminology: infected and affected
- Timescale: February to July 2009



Epidemiological survey 1

- Children infected with HIV – data from:
 - Health Protection Scotland
 - Institute of Child Health (London)
 - Paediatric clinics
- Numbers: 35, 43 or 47 infected children



Age and ethnicity

- No children born in Scotland with HIV since 2001
- 2 distinct groups of infected children and young people:
 - Younger children, born outside Scotland (mainly black African)
 - Older young people, born in Scotland



Epidemiological survey 2

- Children affected with HIV – data from:
- Questionnaire survey of HIV service providers in Scotland
- Following up and extending 1996 survey on affected children
- Estimates around 833 affected children



Age, ethnicity & region

- Overall decrease since 1996 survey
- Large increase however in Greater Glasgow and Clyde Health Board
- Rise in under 5s in Greater Glasgow and Clyde and Lothian, and these are largely black African children
- Decrease in Tayside
- Small pockets throughout Scotland
- Note for future – there has been a significant rise in adults receiving treatment for HIV – hence a rise of affected numbers is predicted



Qualitative study: interviews

- 20 practitioners
- 16 parents and carers
- 5 children and young people infected with HIV
- 7 children and young people affected by HIV



Findings 1: Practitioners

- There are very few services (except for health services) that focus directly on children who are infected or affected
- There is a lot of inter-agency work but collaboration can be difficult
- Children want same things as other children
- Need for transitional services for teens
- Children need to be able to access safe, non-stigmatising services
- More public awareness is needed



Findings 2: Parents and carers

- 'HIV is an illness of uncertainty and hardship and that's bound to affect our children in every which way.'
- There is a lack of services in the West of Scotland: 'We don't want anything for ourselves; we just want something for our children.'
- Stigma remains: 'It's still very much there, you have to keep it secret, it's a constant, it's as strong as it ever was.'
- Parents and carers want time for children to have fun AND to get support around HIV



Findings 3: Infected children

- 'I want to be like the others in my class, same well like them, same well like other childrens.'
- 'People just try to make the world so complicated, but everything is normal if you want it to be. [...] HIV is just normal, you don't have to make a fuss about it - like on TV when they talk about HIV, they just try to make out as if it's the end of the world, but it isn't.'
- But... medication Also stigma & secrecy



Findings 4: Affected children

- '[My life] was quite different to other children. I mean, everybody's got their problems. I just feel that because mine was such a big secret, I couldn't tell anyone about it.'
- 'It's weird talking to someone, because I've never really talked to anyone about my mum's HIV, or my feelings about it. It's like if you've never driven a bike and someone suddenly gives you a bike to ride. It's a bit weird.'



Moving forward

- Children are invisible in HIV and children's services
- They have specific needs in relation to age and ethnicity and those with HIV have clinical needs
- There are regional differences across Scotland
- Parents and children need support for disclosure & there needs to be a public education campaign to challenge stigma
- Need for more consistent data collection
- Need for continuing coordination across different sectors



Thanks

- Thank you to all the practitioners, parents and carers, children and young people who took part in the study
- Also to our funders (EJAF) and to the University of Edinburgh for supporting the study
- Thank you all for your attention – we look forward to discussing further the issues with you in the next part of the seminar