

10 Years on: Talking about HIV - The Swedish Model by Dr Lars Navér, Consultant in Paediatric Infectious Diseases, Karolinska University Hospital, Stockholm, Sweden

At CHIVA 2011, Lars and his colleagues laid out a fresh approach to talking to children about their HIV diagnosis in the clinic setting. Subsequently labelled 'The Swedish Model', it entailed talking openly from the first appointment about HIV, without negotiation with the parent /carer. The 'British model' was a process of building up knowledge about HIV from an early age with a negotiated time-scale for 'naming' the virus, by the end of primary school.

The multi-disciplinary clinic sees about 80 mostly school age children, 30% are internationally adopted (IA) and 7% are unaccompanied migrants. Since 2009, a time when there is even less reason to treat HIV differently, the clinic decided that by doing so they might be contributing to stigma, and that they needed to be able to talk to their patients about HIV - 'really talk'.

How?

- by giving correct information at the language and level of the child, with non-stigmatising vocabulary (i.e secret) - using simple tools, like cards with cartoons for the virus and medication, and a game that starts the discussion.
- Being honest and encouraging discussion, and to stimulate parents to talk about HIV at home
- Establish that it's up to them who they can inform, but that the clinic can help
- Allow rest of the family to visit the clinic i.e. HIV-ve siblings
- National education and support camps, for each age group and one for families (subject to major funding cuts)

Lars also presented developmental challenges, family issues, internationally adopted children, and why the adults don't want to tell.

10 years on - what have we achieved?

We have talked about HIV

All patients know they have HIV

No families have been lost

The families with IA children talk at home about HIV

But the most of the immigrant families will talk in the clinic but at home there is mostly silence.

Still to do

Work together with families (including aligning appointments where children and yp are the same age)

Get more immigrant families to attend the family camps.

Co-operation with NGOs (voluntary sector)

What do our young patients tell us?

'We want to feel that we do not need to lie' 'that it feels good to talk without having to think about negative things' 'we want to feel free'

Victoria Morris

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