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Webinar 3: Mental health, wellbeing and HIV related stigma

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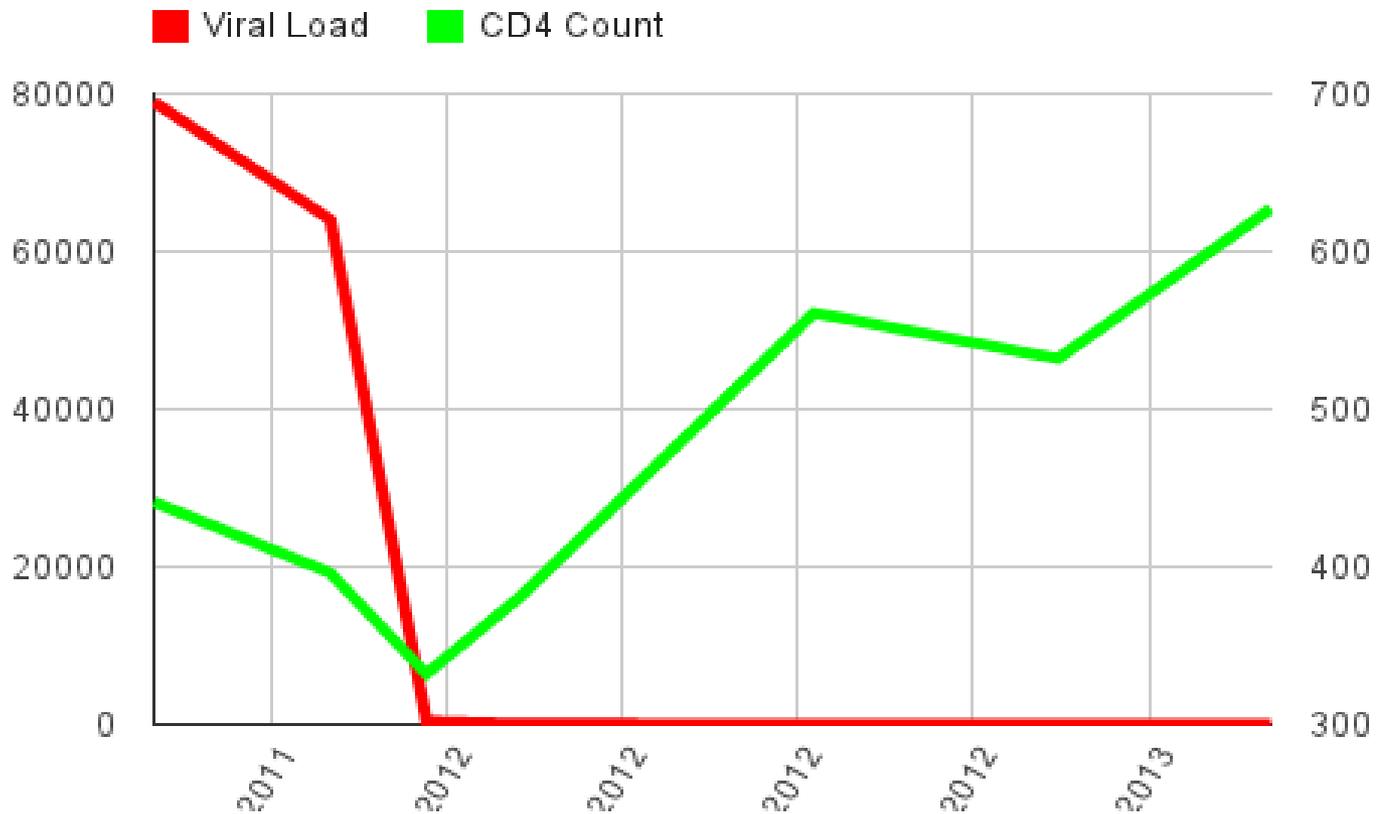
Children's HIV Association UK.

Achieving mental health and well being for young people

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- Understanding issues around mental health and wellbeing of all young people
- How HIV related stigma can impact mental health and wellbeing of young people living with HIV in particular.

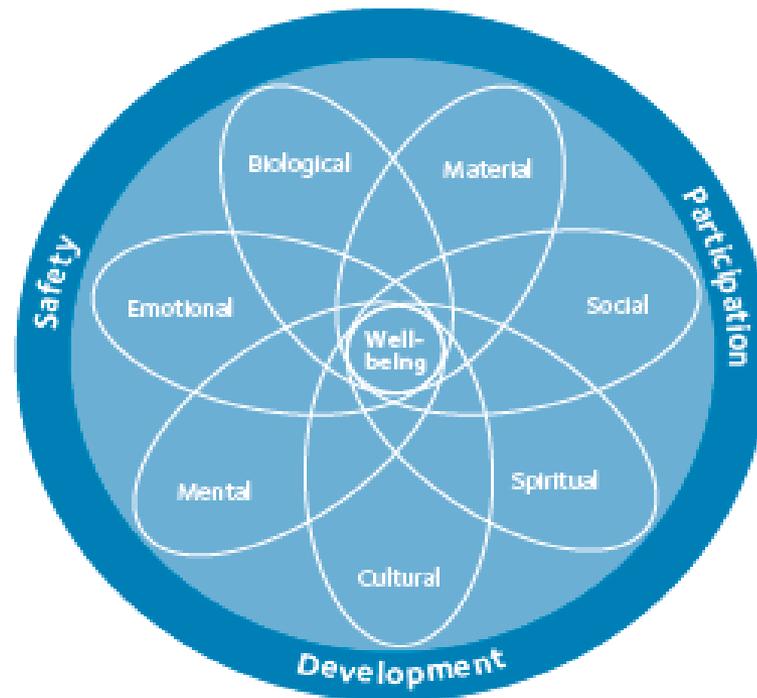
Health / Wellbeing



(WHO 1978) defined health as:

'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' Wellbeing has evolved as an overarching concept which is generally held to describe the quality of people's lives.

- Psychosocial wellbeing represents the relationship between the psychological and social aspects of our lives



Key experiences from direct work with YP with HIV

Young people largely talk about the negative or more difficult impacts of HIV on their lives and a compounding **fear of rejection from their peers**

Coping strategies frequently involve working hard to maintain HIV as a secret – reinforced by the family experience – creating a context where **fear and anxiety and a self stigma** around HIV are common

These complex social and psychological impacts construct young peoples capacity to manage their health & willingness and capacity to engage with clinical care and manage medication adherence in the long term

What can we learn from others?

Historical changes in approaches to disability

A Medical Model:

The medical model historically focuses on the dysfunction or impairment of the individual and seeks to 'cure' the impairment rather than address the disabling factors in the environment

to



A Social Model:

The social model of Disability asserts that the impairment in itself is not an obstacle for a person with disabilities, but is a socially-created problem that demands a political and social response

Addressing Psycho social wellbeing:

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- **Greater social support and acceptance of illness is associated with lower levels of perceived HIV stigma, anxiety and depression**
- Opportunities for young people with HIV to have their voices heard
- More involvement in shaping the care they receive
- Young people with HIV need support to talk openly and confidently about their HIV in a range of contexts- supporting the development of resilience
- Support to YP understanding the potential benefits of being able to tell others about their HIV and support in planning how to do this
- Providing opportunities for positive sharing of stories- not relying on the 'single story'
- Ensuring peer engagement opportunities

Why understanding stigma matters?

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Stigma links to **discrimination** this can harm psychological well being of young person and can lead to unequal outcomes (health, social, economic)

Many studies illustrate negative impact of stigma on mental health and overall adjustment of YPHIV

Negative effects may reduce capacity for self care and increase other risk behaviours



How stigma impacts

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- Stigma occurs when **differences are 'labelled'** and linked to undesirable or negative characteristics
- Leads to separation of **'us' and 'them'**
- Can lead to people being considered of **unequal worth** leading to further discrimination & exclusion, powerlessness,
- Affecting **personal sense of self worth.**

□ Internal self stigma:

Person living with HIV believes society driven negative attitudes around HIV and accepts them

Once negative attitudes incorporated into own beliefs can experience expectation of rejection; shame; guilt; worthlessness

□ Layered experiences of stigma:

People can find themselves experiencing stigma at different levels because of membership to different groups

HIV stigma associates it with particular groups eg Gay people and to behaviours already stigmatized eg. Drug use

Not all stigma is experience based

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- **Enacted stigma** – actual experiences of stigma and discrimination
- **Perceived stigma** - a fear or anticipation of stigma



Not all stigma is intended or intentional

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- Not telling a child about their HIV due to desire to protect them
- Not telling others eg schools and advising YP not to tell other people
- Family experiences of shame and guilt impacts on how HIV is coped with in family

Child internalizes the idea that HIV is something that has to be hidden / is shameful

Strategies to address impacts of stigma

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- Promote individual coping skills
- Provide group based social support where possible
- Discuss YP's experience of HIV and pay attention to difficulties in sharing HIV info with friends, family, adjusting to diagnosis and self esteem
- Discuss how different groups in society have been stigmatized at different times, address the sense that HIV is 'different' focus on similarities with other experiences.
- Focus on decreasing negative feelings in self and about others in relation to HIV
- Support YP to plan sharing of HIV to others- to build support networks & combat fears of rejection

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Recognising and addressing stigma and mental health issues in practice

Look at different examples of how this can manifest itself in care givers and young people

Explore other possible impacts on children and young people

How to address these

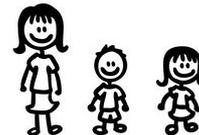
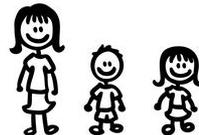
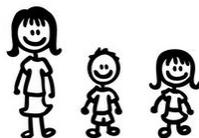
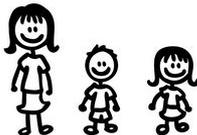
Case one: Anna (mum)

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The Family: Anna, daughter 12 and son 5

- ★ Anna diagnosed when her daughter was sick as baby
- ★ Anna and daughter never taken ART regularly
- ★ When pregnant with son, family lost to follow up
- ★ Defined by two different clinical teams as an 'impossible' family
- ★ Daughter's CD4 below 50

**Withdrawn
Anxiety
Low level
depression?**



How to address this?

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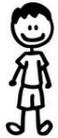
- ★ Find out why she has made those decisions
- ★ Build a relationship with Anna
- ★ Talk to her: about her diagnosis, what was that like? Who has she shared this with? Where does she get support?
- ★ Linked her with other mothers

Case two: Danya

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- ★ Mum acquired HIV through rape
- ★ Passed to Danya during pregnancy/birth
- ★ Mum dies of AIDS related complications
- ★ Father (negative) re-marries, does not tell new wife about Danya's HIV. They have other children
- ★ Danya has HIV named at 12 years old and told this is how his mother died

**Depression
Anger
Poor
adherence**



How to address this?

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Bereavement

- The loss of his mother
- How his mother acquired HIV

Memory book,
photos,
conversations

Counseling

'Othered' at home

- Difference
- Medicine and appointments hidden
- HIV never mentioned in the home

Disclosing to step-mother

Family conversations about HIV

Storing medicine

Case two: Galina

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- ★ Born with HIV
- ★ Lives with mum, dad and brother (all have HIV)
- ★ Told her HIV status at 10, was able to join a support group straight away
- ★ Mum links with another mum with an HIV+ daughter
- ★ Dad working away
- ★ Mum becomes ill, in and out of hospital

**Galina very
tearful at
school and
school calling
home
concerned**



How to address this

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- ★ Speak with Mum – school needs to know she is in hospital
- ★ Mum's permission to tell school her HIV?
- ★ Galina needs support around mum being in hospital
- ★ Physical support for family – are children being left on their own?

Case four: Tatiana

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- ★ Born with HIV
- ★ Lives with mum, dad (both positive) and siblings (negative)
- ★ Tatiana told her HIV diagnosis at 12, told not to tell anyone else
- ★ Good adherence

**Every day
eats a little
bit of washing
powder**



How to address this?

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- ★ Why - 'Pica' Eating Disorder? Feeling unclean? Both? Clinical psychological help
- ★ Outside of this, conversations – holistic assessment – talk about stigma and self-stigma

Conclusion

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- ★ The experience of stigma – intended, unintended, self-stigma - can lead to poor mental health and well-being in children and their families
- ★ It may be unclear whether the mental health issue is
- ★ Addressing this may be complicated and take a long time
- ★ Being honest, listening, not judging and explaining stigma can all help

Thank you

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Funding for this project was made possible by a CIPHER grant from the International AIDS Society. The views expressed in written materials or publications do not necessarily reflect the official policies of the International AIDS Society