

HIV AND AFFECTED CHILDREN

Positive Parenting and Children



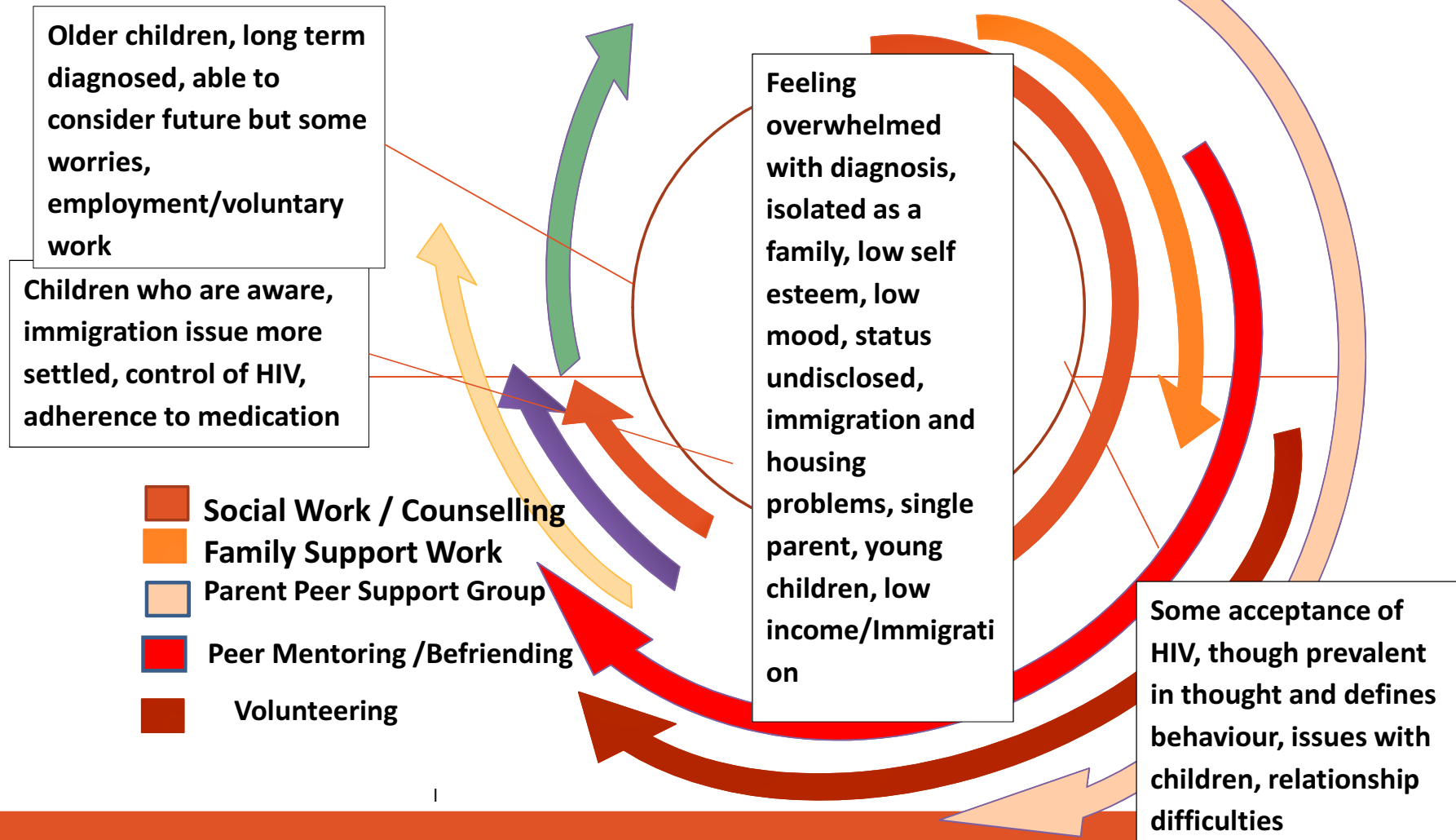
History and Background

- Positive Parenting and Children known as *PPC*, was formed in the mid-1980's as a self-help group for the partners of people living with HIV/AIDS.
- As the work of the organisation developed, the needs of children living with or affected by their family's HIV status became more apparent, and much of PPC's work is now focused on children.
- In March 2008, Karibu, Welcare's HIV project, became part of PPC adding to our skills and experience.





Positive Parenting and Children - Service Model



SHARING, NAMING, TELLING AND TALKING



Sharing Something Important

Barriers to sharing

- Fear
- Stigma & Discrimination
- Rejection
- Burden on Children

Stages:- shock, disbelief, denial, despair and sadness, regret and guilt, recrimination and resentment, anxiety depression (repressed anger), withdrawal, isolation

(Kübler-Ross, E. (2005))

Predicted benefits of sharing

- Increased Closeness
- Greater understanding
- New Outlook
- Emotional Support



Sharing Something Important

We have found that there are three main pathways that establish the personal choices made by parents living with HIV:

- 1. To tell no one,***
- 2. To tell some and not others***
- 3. Or to tell everyone.***

Sharing a diagnoses is a process and not a one time-event for the parents and the children. Our specialist work with Fathers has shown that Fathers experience many of the same fears as mothers.



Sharing Something Important

There is no easy way , no best time, no ideal circumstance.

A child may react with some painful and difficult feelings.

The parents are the ones who know the children best, it makes sense for them to tell, as opposed to children hearing it from someone else



Confidentiality vs Secrecy

Research and experience with families living with HIV, shows that often children are aware something is wrong and feel confusion and anxiety.

Parents are less likely to share their diagnosis with younger children; and mothers are more likely to tell female children.

Mothers who have not shared their diagnosis sometimes assume that their children are doing well, as they believe the children are unaware of any problem.

The burden of keeping the information a secret may cause stress to children. Moreover, some children worry a lot since finding out and often do not want to talk about their concerns.



The child who knows / The child who is unaware

The child **who knows** about HIV in the family is likely to have some fears about their parents or siblings health, many of the children's concerns mirror the parents

- trust decision making, stigma which also exists for affected children often worrying what their peers would say if they knew their parents or siblings HIV status.

The revelation of a parent's HIV can come as a relief to children, making sense out of disjointed observations like medication , frequent doctor appointments, regular blood tests, whispering on the phone, a parent's lack of energy, interest and motivation.



Lessons Learnt ..

- The UK Family Project was a collaborative initiative that aimed to reduce the impact of secrecy and stigma on families living with HIV, facilitate more comprehensive and earlier testing for undiagnosed children, improve family communication on HIV, sex and relationships and ensure that families receive support using the best possible practice models and methods.
- In 2009 a residential was held (maybe the first of its kind), where all children over 8 needed to know about HIV in the family, PPC continued to build on the projects work.
- 2011 *“Time to Talk”* research project with affected young people
- 2011 second residential of the UK Family Project.



Issues

- Parent sending an older sibling to clinic/ GP appointments without full knowledge
- Child reading parents mail, often in cases where the parent cannot read English
- Researching medicines online
- Developmental problems lack of nurturing and attachment to younger children
- Self stigma
- Transference
- Highly critical- low warmth parenting style-
- Effects caring for a family member may have on the education, mental and physical health, self-confidence and self-esteem of children and young people. The number of young people affected by HIV are unknown.



Shani and Ashley's Story

Shani and Ashley's mother 'Caroline' was diagnosed HIV positive in 1996.

Shani was 3 and Ashley 2, at this time Caroline lived with the children and their father 'John'.

John was unaware of Caroline's diagnosis, until he read a letter from the social services department. Their relationship broke down quite quickly, Caroline was very ill at this time. The children continued to see their father, though Caroline found this hard to manage.

Over time the impact was evident on the children, disrupted schooling, lack of boundaries. Shani displayed angry and defiant behaviour, Caroline could not cope with this. John continued to support the children though he remarried.



Shani went into Local authority care aged 9, I began working with Shani when she left care to live with her Godmother aged 11. Ashley stayed living with mum.

Ashley's behaviour was much more passive unlike his sisters.

Caroline's health continued to fluctuate with several periods of hospital admission. Both children struggled to achieve at school.

Caroline had always refused point blank to disclose her status to the children to explain her illness in any way. Caroline would resort to anger and tears when pressed. Shani does not complete her compulsory education, Ashley does, although struggles significantly. Early 2010 Caroline becomes very ill, Shani is expecting twins, Ashley is living at home still, both are still unaware of mums HIV.

Ashley went to live with John, Shani continued to live at her Godmothers.
Child protection proceeding's took place for Shani's unborn twins -category of neglect emotional harm. Shani reacted badly to that decision.
The hospice contacted PPC to help with video dairy for Caroline to share and tell.
Negotiations on how best to do this within the time frame.
Caroline died the day after Shani had the twins. Shani was 17 Ashley 16 .
The video diary remained unfinished. Shani and Ashley still unaware of HIV.....

Shani had a breakdown and was unable to comply with social services expectations.
The twins were adopted.!

Shani and Ashley are finally aware of HIV. Both have been remarkable in sharing their journey, which now you also know, and can agree is a worse case scenario for any child affected by HIV. They are over the worst but not out of the woods yet.



References

- (Kübler-Ross, E. (2005) *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss*, Simon & Schuster Ltd)
- *HIV-positive Mothers' Disclosure of Their Serostatus to Their Young Children: A Review*, Debra A. Murphy
- Clinical Child Psychology Psychiatry. 2008 January; 13(1): 105–122.
- <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2936671/>
- <http://www.ncb.org.uk/hiv>- accessed October 3rd 2015
- <http://aids.about.com/od/hivseniors/a/aginghiv.htm>- accessed September 26th 2015
- <http://www.youngcarer.com/influencingchange>
- <http://ppclondon.org.uk/cant-explain-question-ft-delilah/>
- Bluesky Trust – an HIV support and training organization who have written ‘Do you know it all?’ - An information booklet about HIV for young people. <http://blueskytrust.org/doyouknow.htm>