

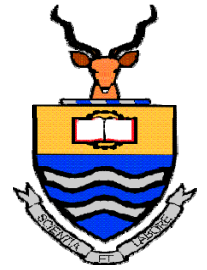


# Growing up in a Positive World: The Challenges of HIV in Childhood

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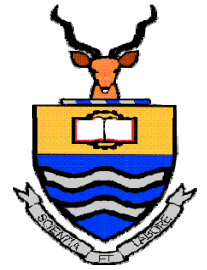
# OUTLINE



- The Scope of the Problem
- Children Infected with HIV
- Children Affected by HIV
- Other Psychosocial Factors for Consideration
  - Stigma
  - Disclosure
  - Adherence
- The Way Forward



# THE SCOPE of the PROBLEM

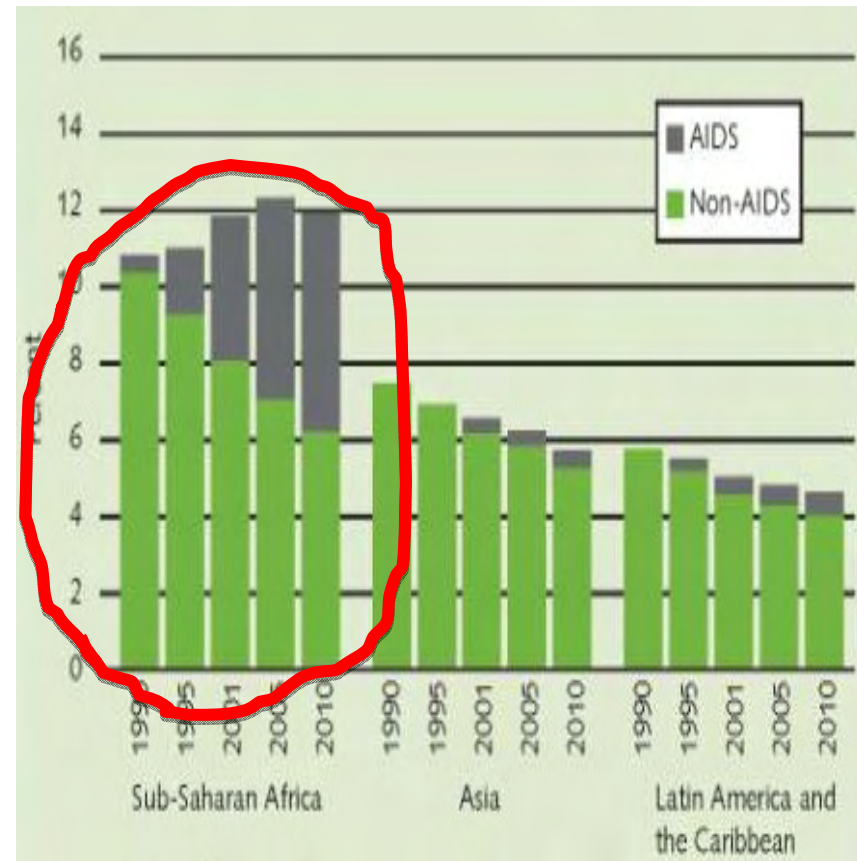
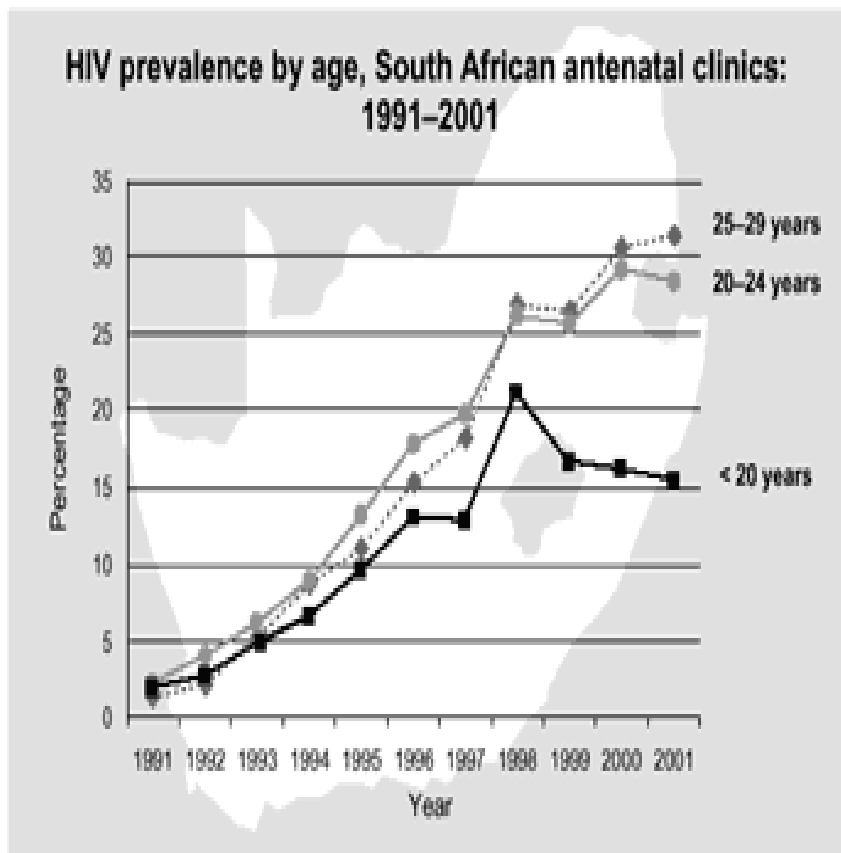
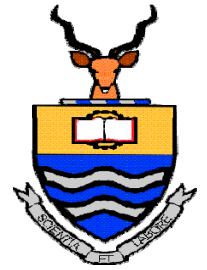


- 2007, estimated 33.2 million living with HIV (UNAIDS, 2007) world wide
- Children are not only infected, but suffer vicariously
- Number of children expected to have been orphaned by 2010 was  $\pm$  25 million (UNICEF)
- HSRC study found that 13% of children aged 2 to 14 years had lost a mother, father or both parents. In addition, 3% of households were found to be child-headed (2002)

(Children Affected by HIV/AIDS in South Africa, Save the Children SA Programme, 2003)



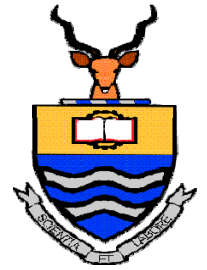
# THE SCOPE of the PROBLEM



(Children Affected by HIV/AIDS in South Africa, Save the Children SA Programme, 2003)



# In the Beginning....



**MATERNAL  
PHYSICAL HEALTH**

**EXPOSURE TO  
'TOXINS'**

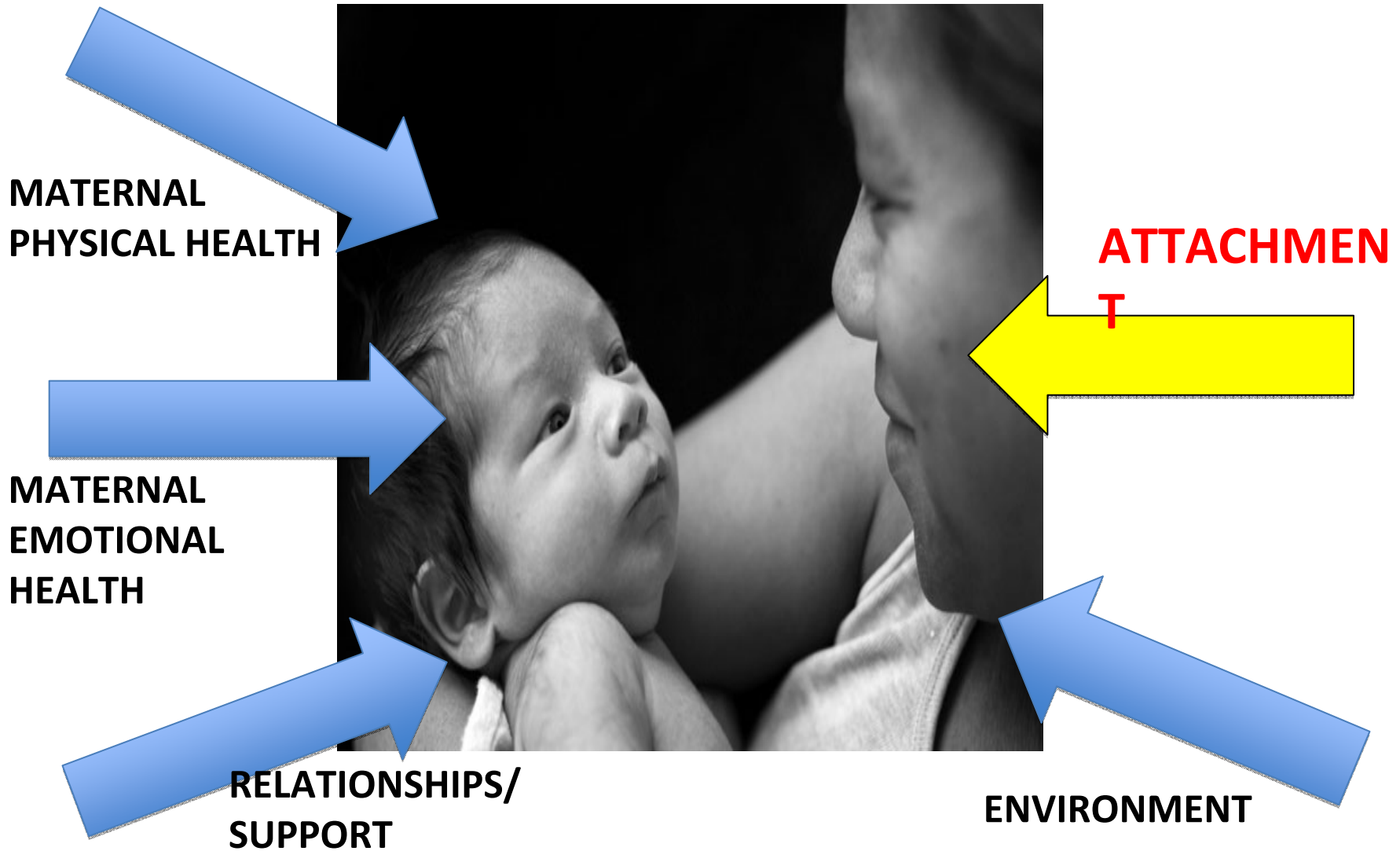
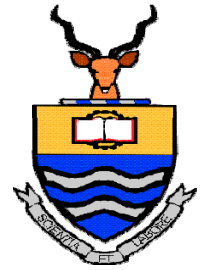
**MATERNAL  
STRESS LEVELS**

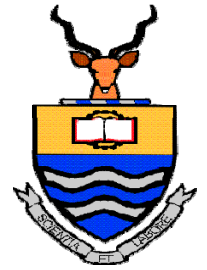
**NEIGHBOURHOODS  
and  
RELATIONSHIPS**



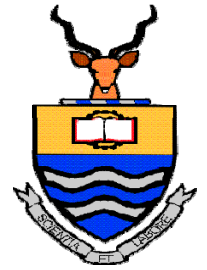


And then.....





..... and love DOES matter



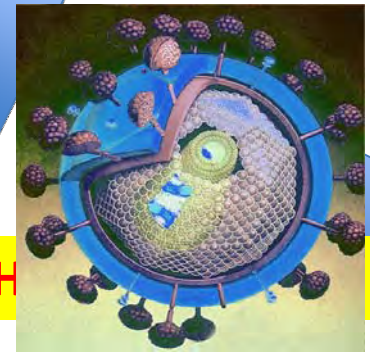
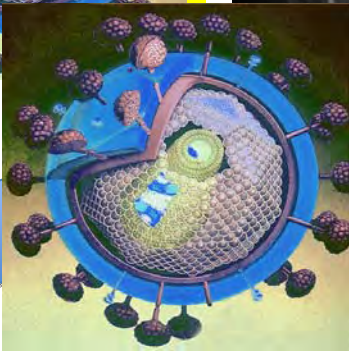
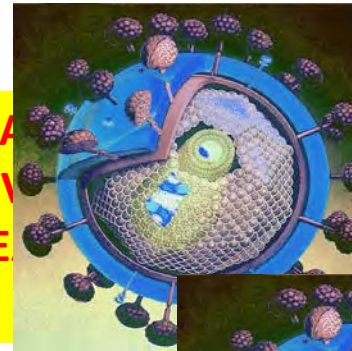
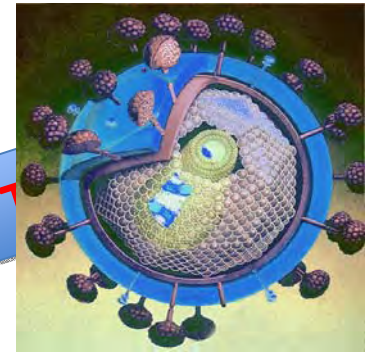
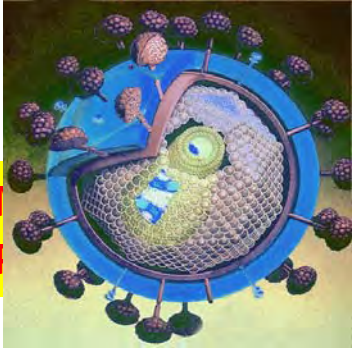
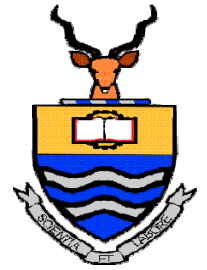
**MATERNAL PHYSICAL HEALTH**

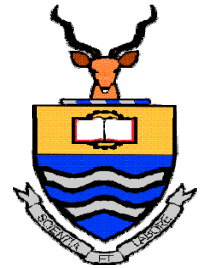
**MATERNAL STRESS**

**NEURAL REGENERATION and**



And then.....





## CHILDREN INFECTED WITH HIV

- Physical health, growth and development
- Impact on the Central Nervous System

**BIOLOGICAL**

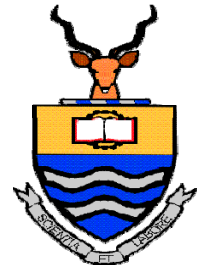
- What about HAART?

## CHILDREN AFFECTED BY HIV

- Physical health, growth and development
- Impact on the Central Nervous System

**PSYCHOSOCIAL**

“PATHOGEN”



- “one of the challenges of understanding HIV in children (and adolescents) is determining which of the biological, psychological, neuropsychiatric, and social factors is most relevant at any given moment”.

(Brown, Lourie & Pao, J Child Psychol Psychiatr, 2000)



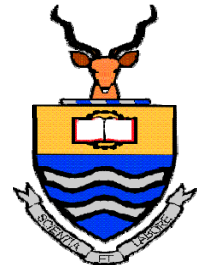
## NEUROCOGNITIVE DEVELOPMENT and HIV



- Neurological, neuropsychological and developmental manifestations
- May be CNS infection, perinatal insults, other disease or environmental circumstances
- HIV-associated encephalopathy: progressive or static
  - Impaired brain growth
  - Progressive motor dysfunction
  - Loss or plateauing of developmental milestones
- Language delays
- Impaired visuo-motor and spatial learning
- Below-average intellectual ability



# HAART and NEUROCOGNITIVE FUNCTIONING



- Improved neurocognitive abilities\* \*\*
- Findings suggest that a CNS penetrating agent is a critical component of HAART \*\*
- Notable decline in the incidence of progressive encephalopathy \*\*
- “the relationship among combination therapy, improved virologic control, and neurocognitive abilities and the mechanisms involved needs further study” – Willen, 2006

\*Brown, Lourie & Pao, J Child Psychol Psychiatr, 2000

\*\*Willen, MR & Develop Dis Research Reviews, 2006



# PSYCHOLOGICAL PROBLEMS in HIV POSITIVE CHILDREN



- Subjectively more distress than their non-infected peers, and multiple associated stressors:
  - Disclosure of HIV infection
  - Social ostracism
  - Fears of death
  - Pain and problems with physical health
  - Hospitalizations, disruptions 2° to appointments, isolation from peers
  - Concerns about body image (wasting, lipodystrophy)
  - Possibly having a chronically ill parent



# PSYCHOLOGICAL PROBLEMS in HIV POSITIVE CHILDREN

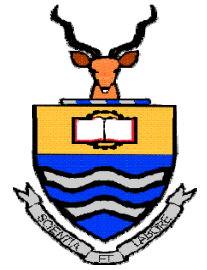


- As a result, generally they have higher rates of
  - Dysphoria (unease, generalised dissatisfaction with life)
  - Hopelessness
  - Compromised sense of self-worth
- And lower rates of
  - Social activity
  - Academic success





# PSYCHIATRIC ILLNESS in HIV POSITIVE CHILDREN

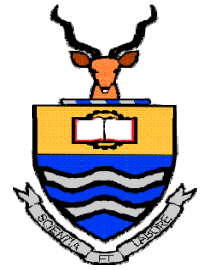


- Higher risk for psychiatric illness than non-infected peers
- Increased risk for psychiatric hospitalization
- Most commonly occurring disorders include
  - Depression
  - Anxiety disorders
  - Disruptive behaviour disorders, incl ADHD, CD
- (NB to consider that many of these conditions occur in context of the multiple environmental stressors found in HIV +ve children)

(Benton, Child Adolesc Psych Clin N Am, 2010)



# PSYCHIATRIC ILLNESS in HIV POSITIVE CHILDREN



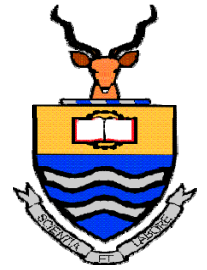
- DEPRESSION

- 25 – 47%
- Increase in frequency from childhood to adolescence
- Diagnosis made difficult by overlap with somatic manifestations
- Higher rates of suicidal ideation
- Poor compliance with medical treatment
- Worsening somatic symptoms
- Treated with SSRIs, NB drug interactions!

(Benton, Child Adolesc Psych Clin N Am, 2010)



# PSYCHIATRIC ILLNESS in HIV POSITIVE CHILDREN

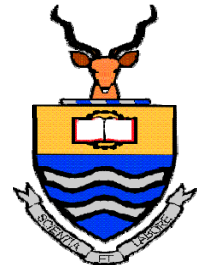


- ADHD and BEHAVIOUR DISORDERS
  - ADHD occur at higher rates, up to 28% noted
  - Frequently documented attentional difficulties
  - Co-occurring risk factors make it difficult to establish causal relationships
  - Using WITS data, Mellins *et al*, showed no link to HIV disease\*, i.e social adversity contributed (WITS – The Women and Infants Transmission Study)

(\* Mellins et al, Pediatrics, 2003)



# PSYCHIATRIC ILLNESS in HIV POSITIVE CHILDREN



## ANXIETY DISORDERS incl PTSD

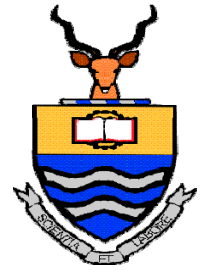
- Common, frequently co-morbid
- May be related to intra-familial stress
- Trauma related to distressing events in child's world, and to medical procedures
- Treatment as for non-infected children

## OTHER PSYCHIATRIC PROBLEMS

- Substance Use Disorders
- Bipolar Disorder
- Psychotic Disorders
- Delirium



# CHILDREN AFFECTED by HIV

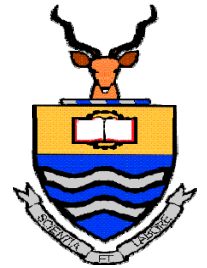


- Impaired or disrupted attachment
- Repeated episodes of incapacitating parental illness
- Parental preoccupation and instability
- Anticipation of death, accompanying uncertainty
  - Sorrow
  - Anger
  - Guilt
  - Confusion
- “disenfranchised grief”

(Murphy et al, Psychosocial Aspects of HIV/AIDS, Eds. Martin & Volkmar, 2007)



# “AIDS ORPHANS”



- Any child under 18 years, whose mother OR father has died (USAID, 2004). Not necessarily both parents.

- “Vulnerable household” when the household head is an orphan.

- Cautious research

- “Corruption”

- 

of Child Res, 2006)

- 

(Sherr et al, AIDS Care, 2008)

**“IRRESPECTIVE OF DEFINITIONS  
HIGH NUMBER OF PSYCHOLOGICAL  
AND PHYSICAL NEGATIVE IMPACTS”**

Global J



# PSYCHOSOCIAL FACTORS IMPACTING CHILD DEVELOPMENT



- Economic impact
- Migration
- Changes in Carer and Family Composition
- New responsibilities and work
- Education
- Loss of home and assets
- Health and Nutrition
- Vulnerability to infection
- Long-term effects of emotional deprivation

(Linda Richter, HSRC)

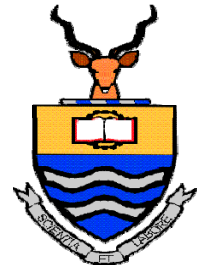


# PSYCHOSOCIAL FACTORS IMPACTING CHILD DEVELOPMENT



- Effects vary by age
- Poverty **AMPLIFIES** the impact
- Risks of
  - Child-headed households
  - Child labour
  - Sexual exploitation and trafficking

(Linda Richter, HSRC)

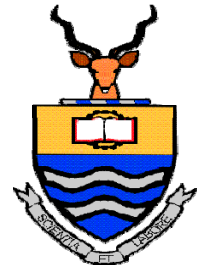


*“The common impacts [of HIV/AIDS] include deepening poverty, such as pressure to drop out of school, food insecurity, reduced access to health services, deteriorating housing, worsening material conditions, and loss of access to land and other productive assets. Psychosocial distress is another impact on children and families, and it includes anxiety, loss of parental love and nurture, depression, grief, and separation of siblings among relatives to spread the economic burden of their care”.*

(Williamson, J in Richter)



# RISK FACTORS for the ADVENT of PSYCHIATRIC ILLNESS



- Depression
- Anxiety disorders, including PTSD and childhood traumatic grief (CTG)
- Disruptive behaviour disorders
- Substance Use Disorders
- Disturbed attachment, maladaptive coping styles and personality disorders
- (Dissociative Disorders)
- Learning Disorders
- **Attachment Disorders**



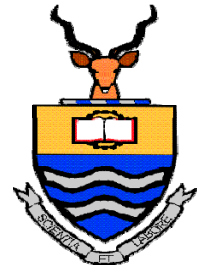
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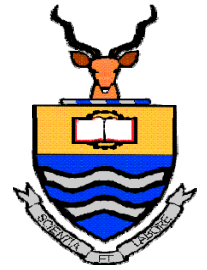
# STIGMA



- Although children may know about their parent's illness they are often not provided with opportunities to identify the illness and discuss its ramifications
- Parents reluctant to inform children of their own HIV
- May prevent accessing adequate, appropriate resources, permanency planning and social support



# DISCLOSURE



- May compel parents to confront personal sense of responsibility
- May attempt to protect the child – “child cannot understand”; but may indeed be able to confront potentially fatal implications
- Several phases
  - Secrecy
  - Exploratory
  - Readiness
  - Disclosure



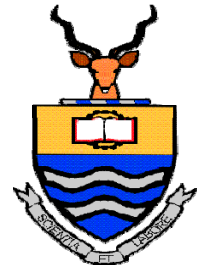
# DISCLOSURE



- Ambivalence because of concerns wrt stigma
- Impact of disclosure
  - report higher esteem, promotion of trust, improved adherence, better health and well being
  - increase distress and contribute to the development of depression, anxiety, and behavioral problems
- Should be planned and structured with preparation for post-disclosure responses (immediate or delayed)
- Opportunities for discussion and expression; “alleviate the burden of unspoken fears”
- American Academy of Pediatrics (1999) policy



# ADHERENCE

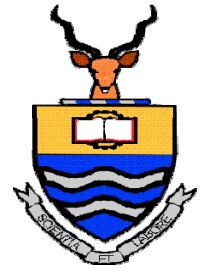


- To gain optimal benefit from these medications, compliance must be near 100%
- Poor or inconsistent adherence can result in increasing viral loads, progression to AIDS, the development of resistance
- Depression associated with poor adherence to medications
- Other factors included
  - Later stage disease were less adherent
  - Increased age in years
  - Female gender
  - Detectable viral load
  - Recent stressful life events
  - Grade retention

(Benton, Child Adolesc Psych Clin N Am, 2010)



# RESILIENCE



- As part of the intrinsic processes which drive child development, children actively seek out experiences— even in great adversity
- Compensatory responses may be enabled
  - Personality and temperament,
  - Learned coping style,
  - Age of exposure,
  - Availability of caring adults and social supports
  - Opportunities for recovery afforded by achievements and new relationships



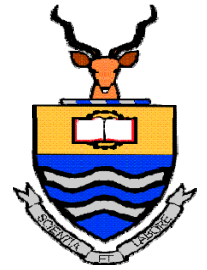
# UN Convention on the Rights of Children



- **Article 24** – .. recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services
- **Article 27** - .. recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development



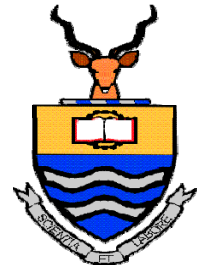
# THE WAY FORWARD



- **Interventions for improving the psychosocial well-being of children affected by HIV and AIDS – Cochrane Collaboration (2009)** (King et al)
  - No studies found that rigorously evaluated interventions improving psychosocial well-being of children affected by HIV and AIDS
  - Implications for practice
    - Consider child psychological theory, as well as “lessons learned”
    - Monitor, Evaluate, Intervene
    - Opportunity for donors and funding
  - Implications for research
    - Collaboration in high quality interventional studies



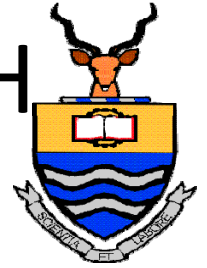
# PREVENTIVE INTERVENTIONS



- “Prevention curricula” around risk taking behaviours, including problem solving approaches and skills based focus
  - Condom usage
  - Sexual debut and behaviour etc..
- The role of the ante-natal clinic ?



# EVIDENCE BASED MENTAL HEALTH INTERVENTIONS



- Targeting specific psychological or psychiatric presentation with evidence-based Rx
- Long-term cognitive-behaviourally oriented coping interventions have been piloted for older children
- Strategies to address bereavement and grief



# COMMUNITY BASED MENTAL HEALTH INTERVENTIONS



- Traditional 'office-based' modalities of care and treatment may not be suitable for families affected by HIV/AIDS
- Home and community-based services, which are flexible and comprehensive in nature
- Directed towards compliance, family and psychiatric stabilization
- Collaboration with paediatric HIV clinicians and social service infrastructure



# Mind, Body and HAART

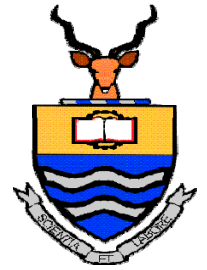


- HAART has positively impacted the body and the brains of children with HIV
- BUT despite HAART the rates of children orphaned by HIV, and AFFECTED by HIV continue to increase

**These effects continue to impact the SPIRIT and the SOUL of the Nation**



THANK YOU



I am not a burden.  
I am just a child.

