

Study 1:
Improving the
Care of HIV +
Children in
Hospital

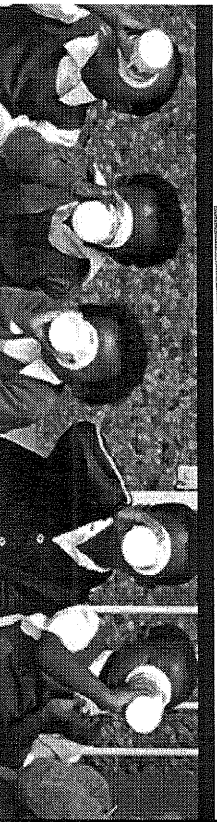
Presented by **Andy Daves** on behalf of:

Linda Richter, Celia Hsiao, Tamsen Rochat & Nigel Rollins

ICDP Oslo July 2005

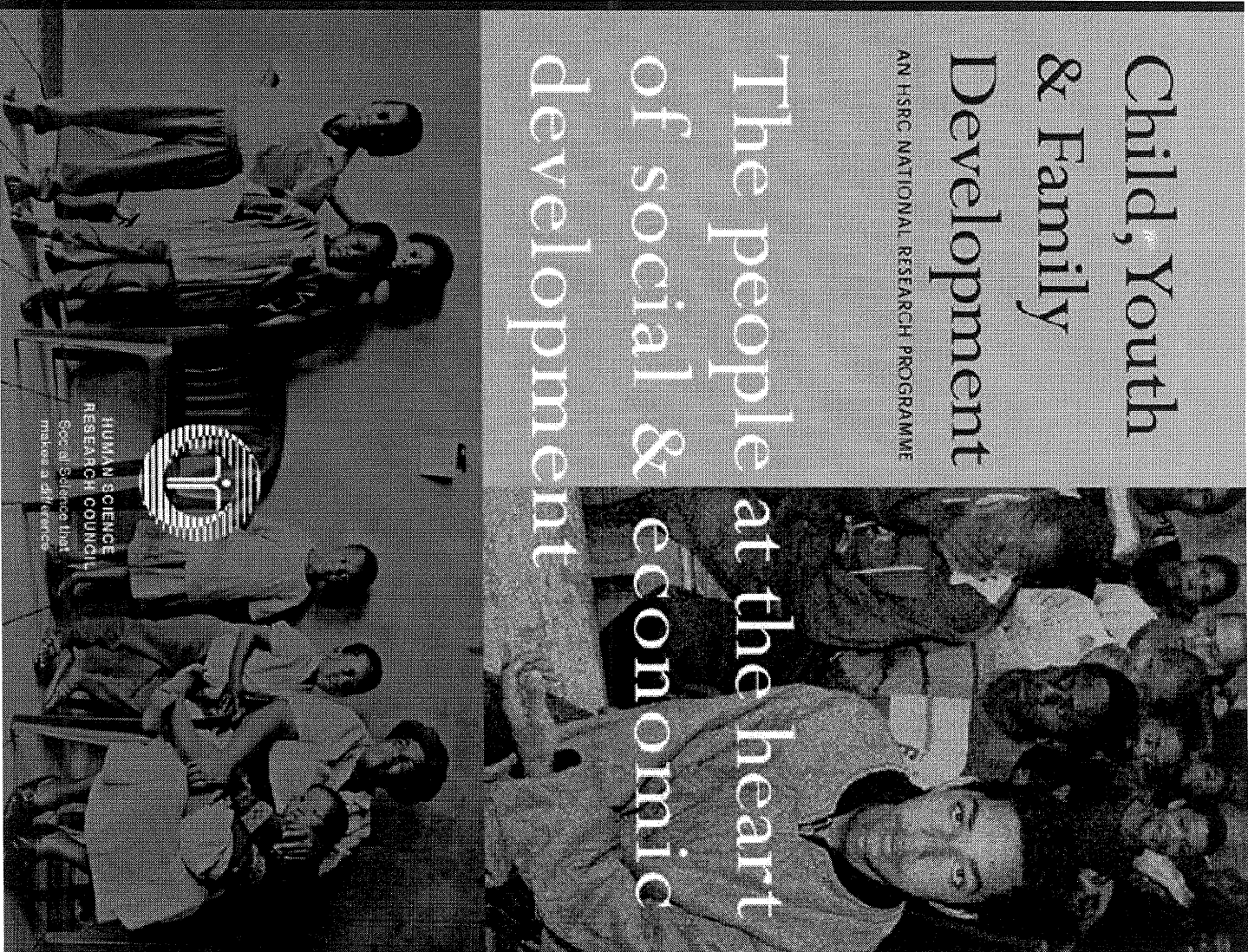
HSRC RESEARCH OUTPUTS

3548



Child, Youth
& Family
Development
AN HSRC NATIONAL RESEARCH PROGRAMME

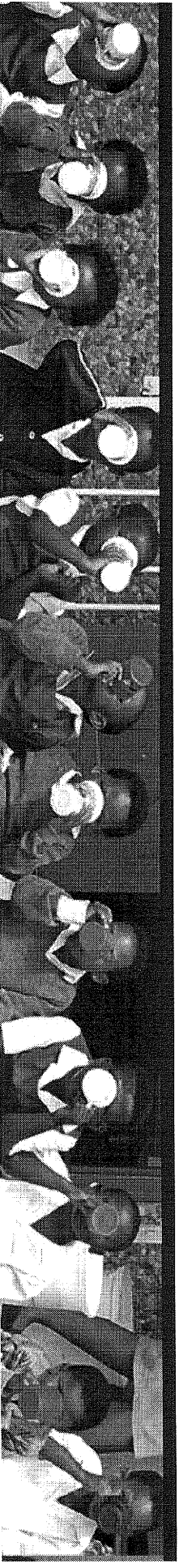
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HUMAN SCIENCE
RESEARCH COUNCIL
Social Science that
makes a difference

South Africa: 2 Projects

- 1. To devise a method of improving empathic care in a pediatric HIV ward, and develop a training tool for hospital staff**
- 2. To pilot a multi-method research approach to understanding the impact of being HIV+ on child care in poor households so as to broaden the base of ICDP method and deepen contextual understanding of the care niche**



Project 1: Points to be Covered

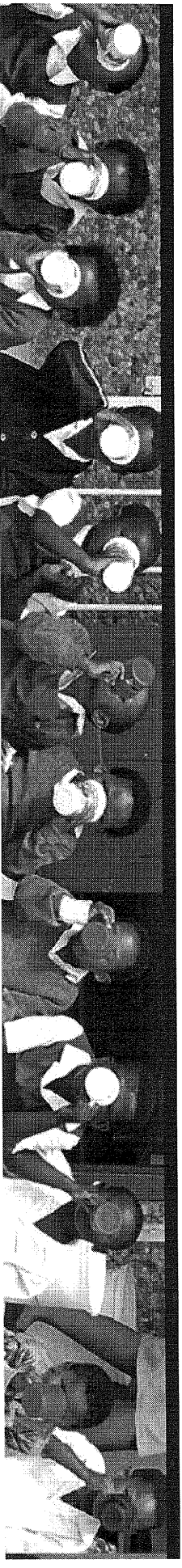
- 1. Background**
- 2. Significance and project aims**
- 3. Demonstration of ICDP principles in a paediatric setting**



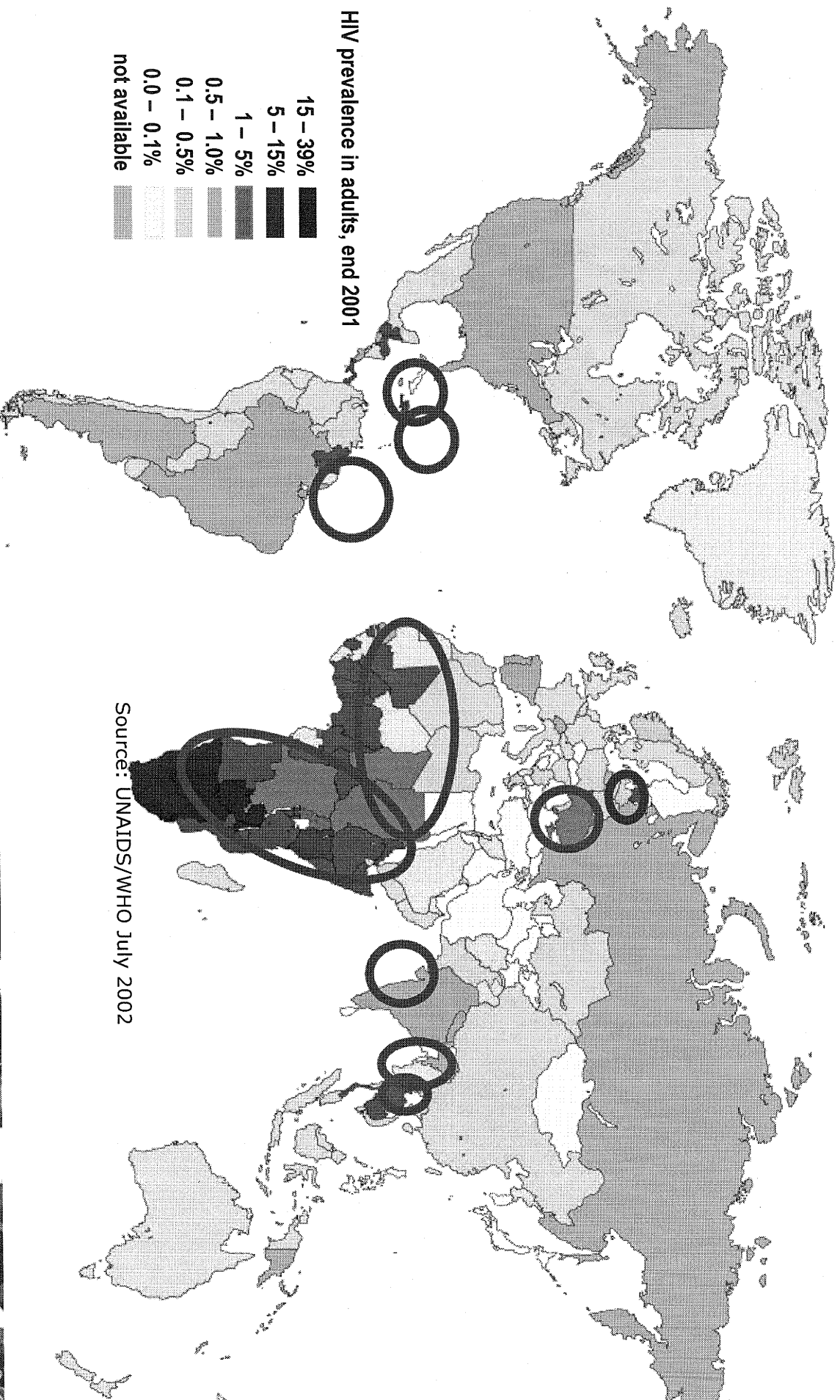
Study 1 Background

Study Context:

**A Pediatric infectious diseases
ward in a large public hospital
in Durban South Africa**



Background: The global burden of HIV/AIDS



Background: Infected Children (SA)

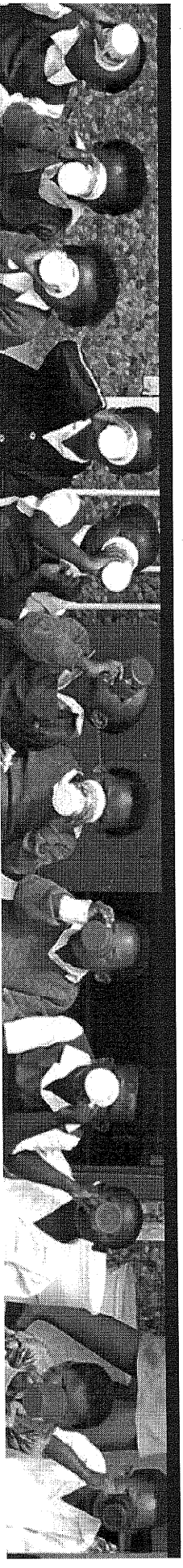
Up to 1/3 of children vertically infected (in SA 100 000 p.a.)

- Can be dramatically reduced with intrapartum Anti-Retroviral Therapy**
- About 10% infected through (“mixed”) breastfeeding**
- Prolonged illness and multiple hospitalizations under poor conditions occur**
 - they are known as “dying wards”**



Background: Signs and Symptoms HIV+ child

- Diarrhoea – Rotavirus and bacteria
- Malnutrition associated with:
 - Reduced intake – anorexia, ulcers, thrush
 - Nutrient loss – malabsorption, diarrhoea
 - Increased metabolic rate – infections
- Neurological manifestations – encephalopathy
- Dermatitis
- Malignancy, etc

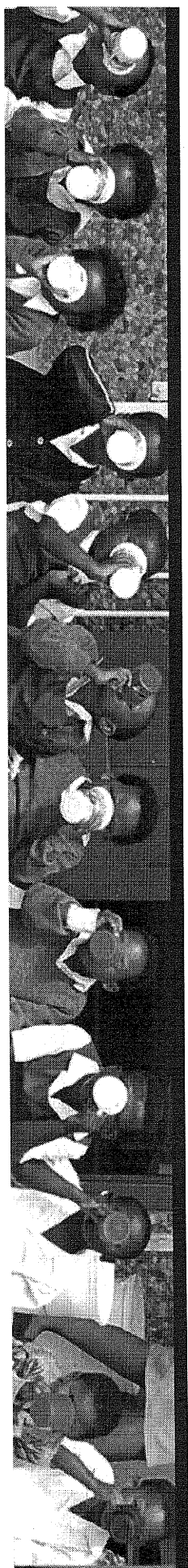
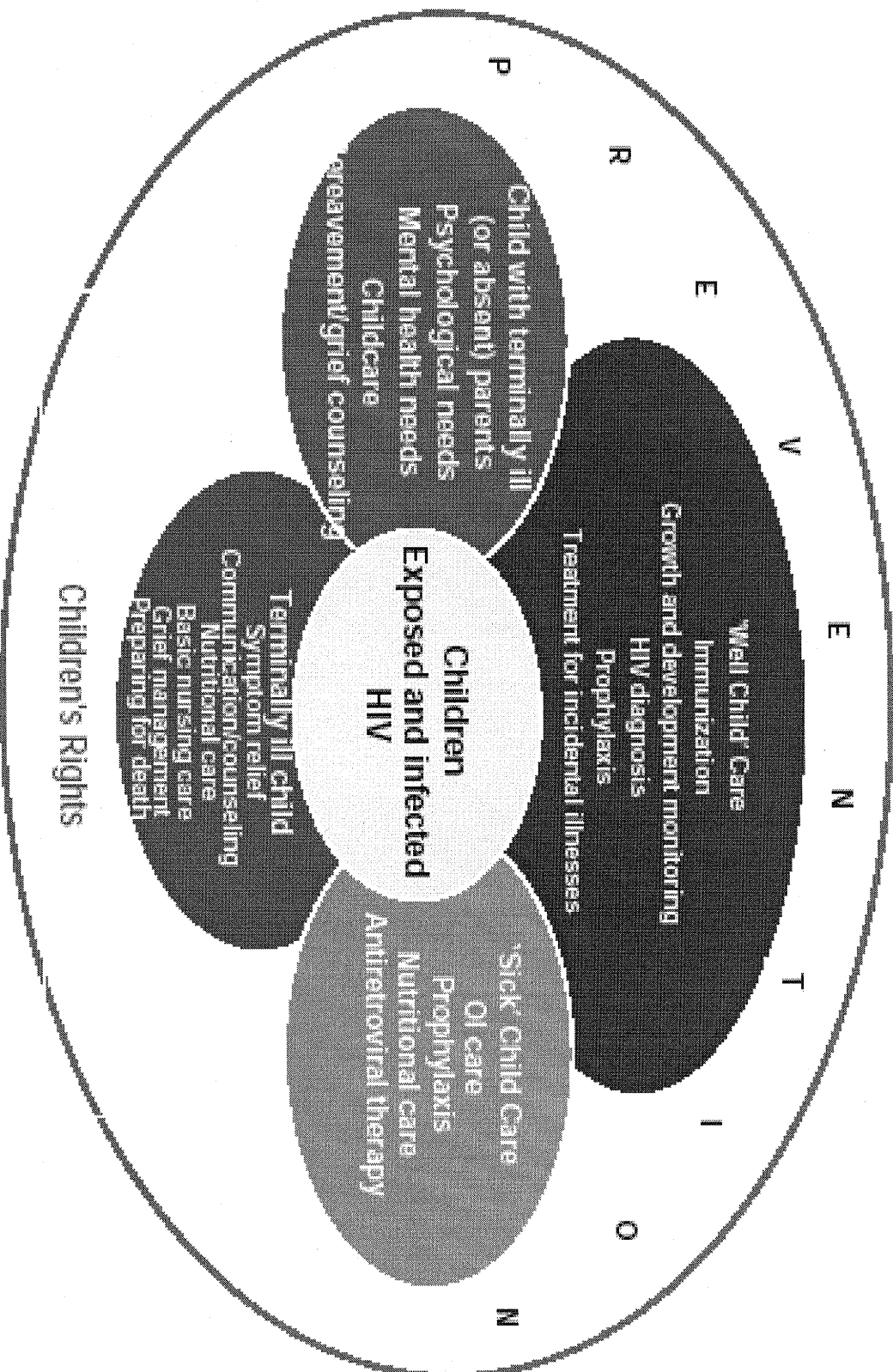


Background: 3 Categories of Infected Children

- **Category 1: Rapid progressors who die by age 1 (25-30%)**
- **Category 2: Children who develop symptoms early and who die between 3-5 years of age (50-60%)**
- **Category 3: Long term survivors who live beyond 8 years of life (5-25%)**



Long-Term Care Planning for Children with HIV



Very Vulnerable Children

Amongst others:

- Children in group / institutional care
- Sick children, infected or *uninfected with HIV*
- Displaced children



Care of Sick & Dying Children

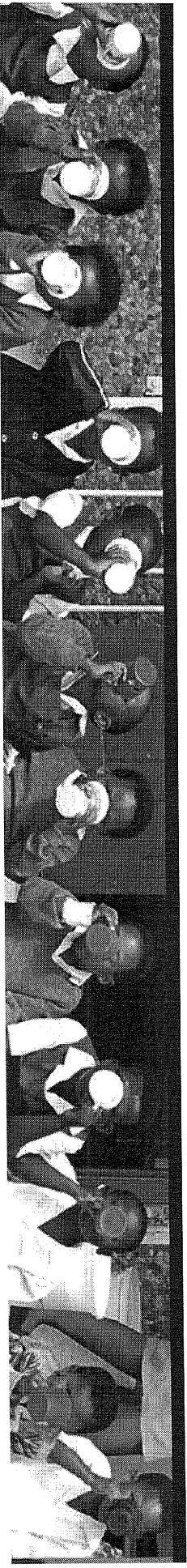
ICDP-informed work in hospitals ...

- **Separation**
- **Infant pain and distress**
- **Maternal preoccupation & withdrawal**
- **Invasive procedures**
- **Active feeding**
- **Preparation for home**



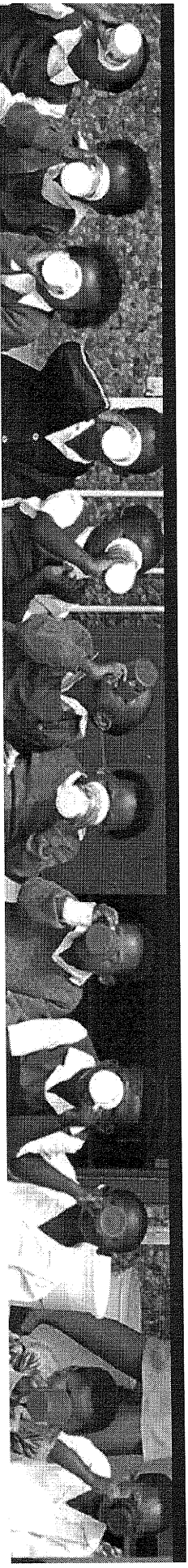
Children in Hospital

- **Separation from caregivers**
- **Strange environment**
- **Illness and discomfort**
- **Painful procedures**
- **Caregiver distress, withdrawal**
- **Staff distress & withdrawal**
- **Children need assistance to cope**



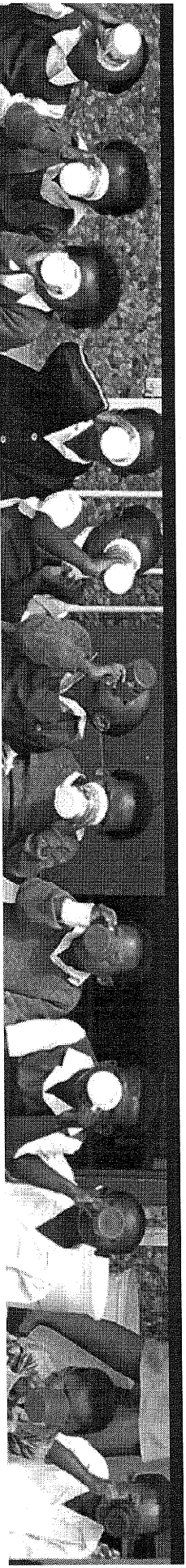
HIV Infected Children in Hospital

- **Occupy >60% paediatric beds**
- **Failure to thrive, lower respiratory tract infection, acute or recurrent diarrhoeal disease, severe sepsis and HIV encephalopathy**
- **Multiple admissions**



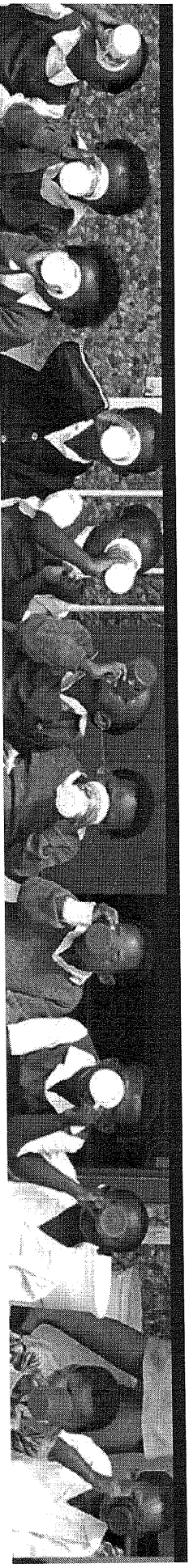
Approach to the Intervention

- 1. Working together to avoid blame & to create “own” solutions**
- 2. Be action-oriented & solution-focused**
- 3. Have a larger goal - to help other staff & caregivers while reducing risk to children**
- 4. Start from the concerns of staff**



Working Together on the project

- Meeting to discuss issues
- Sharing expertise
- Being frank about difficulties
- Framing the issues jointly
- Filming in ward (+ 6 weeks)
- Communicating and informing



Being Solution-Focused

- **Describe conditions, problems**
AND
- **Devise & discuss interventions**
AND
- **Test, describe & train**
AND
- **Disseminate our learning**



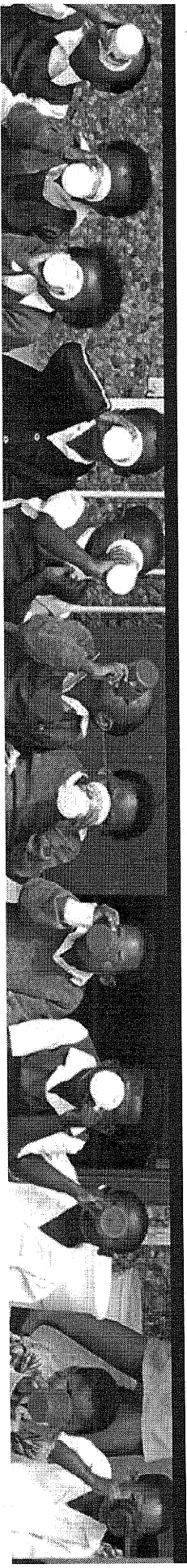
Starting from Staff Concerns

1. **Assisting HIV+ caregiver cope**
2. **Reducing the pain of procedures**
3. **Active feeding**
4. **Preparation for return home**
5. ***Address child distress & crying***



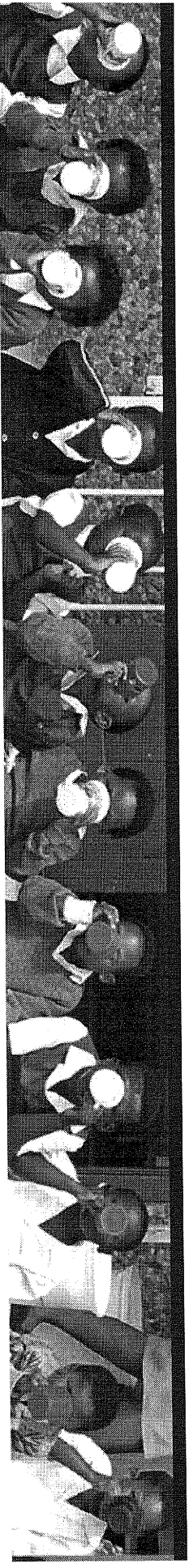
Child Distress & Crying

- **Very distressing for staff & caregivers**
- **Some crying is inevitable**
- **Children can be helped to cope better with difficulties**
- **Can reduce pain of procedures**



Crying can be Reduced by:

- Rhythmic movement
- *Transitional objects* – comfort objects that bridge gap in space/time to caregiver
- Non-nutritive sucking
- Touch, holding & massage



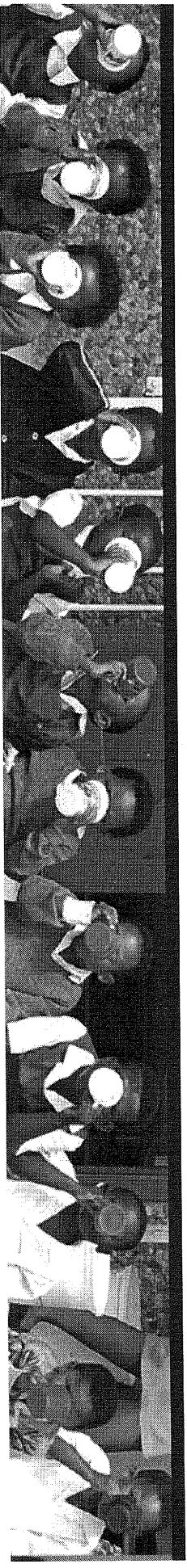
Rhythmical Movement

- **Body contact**
- **Soothing, reduces distress**
- **Regular, *andante* (slowish movement)**
- **Horizontal rocking**



Transitional Objects

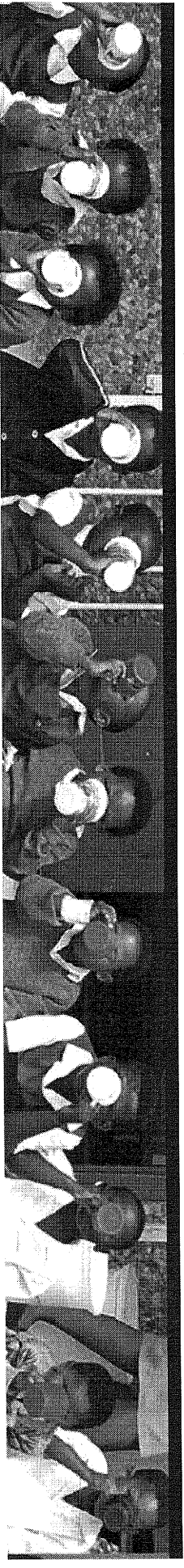
- At home often a soft cloth, blanket
- In interventions often a doll or fluffy toy
- Found to be effective soothers for children





Non-Nutritive Sucking

- **>60% of infant sucking is non-nutritive**
- **Releases endorphins, other pain-reducing neurotransmitters**
- **Can reduce stress**
- **Knock on benefits – better feeding, heightened attention to the environment**



Massage

- **Stimulates tactile & pressure receptors**
- **Decrease pain, increase alertness**
- **Demonstrated impact on at-risk neonates, drug-addicted babies**



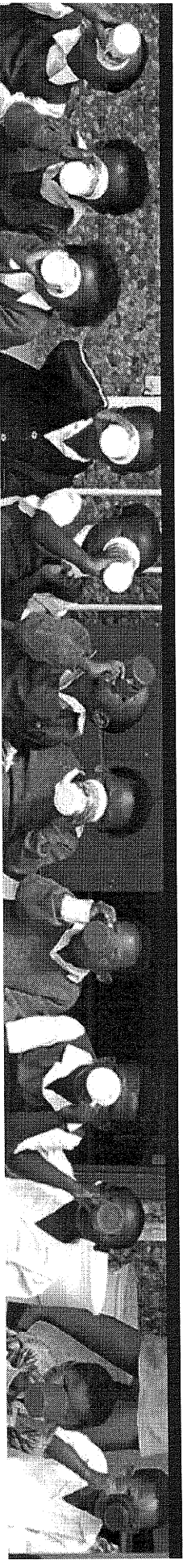
Examples - In Situ Solutions

1. Transitional object – the green cloth

A baby shows us how

2. Massage – changing a nappy

A mother shows us how



“Must Have the Green Cloth”

Mom visits, gently wipes child with green cloth

Mom leaves, child very distressed

Finds green cloth, cries in protest for mother

Child uses the cloth as comforter, returning to it again and again

Refuses other distractors – the balloon

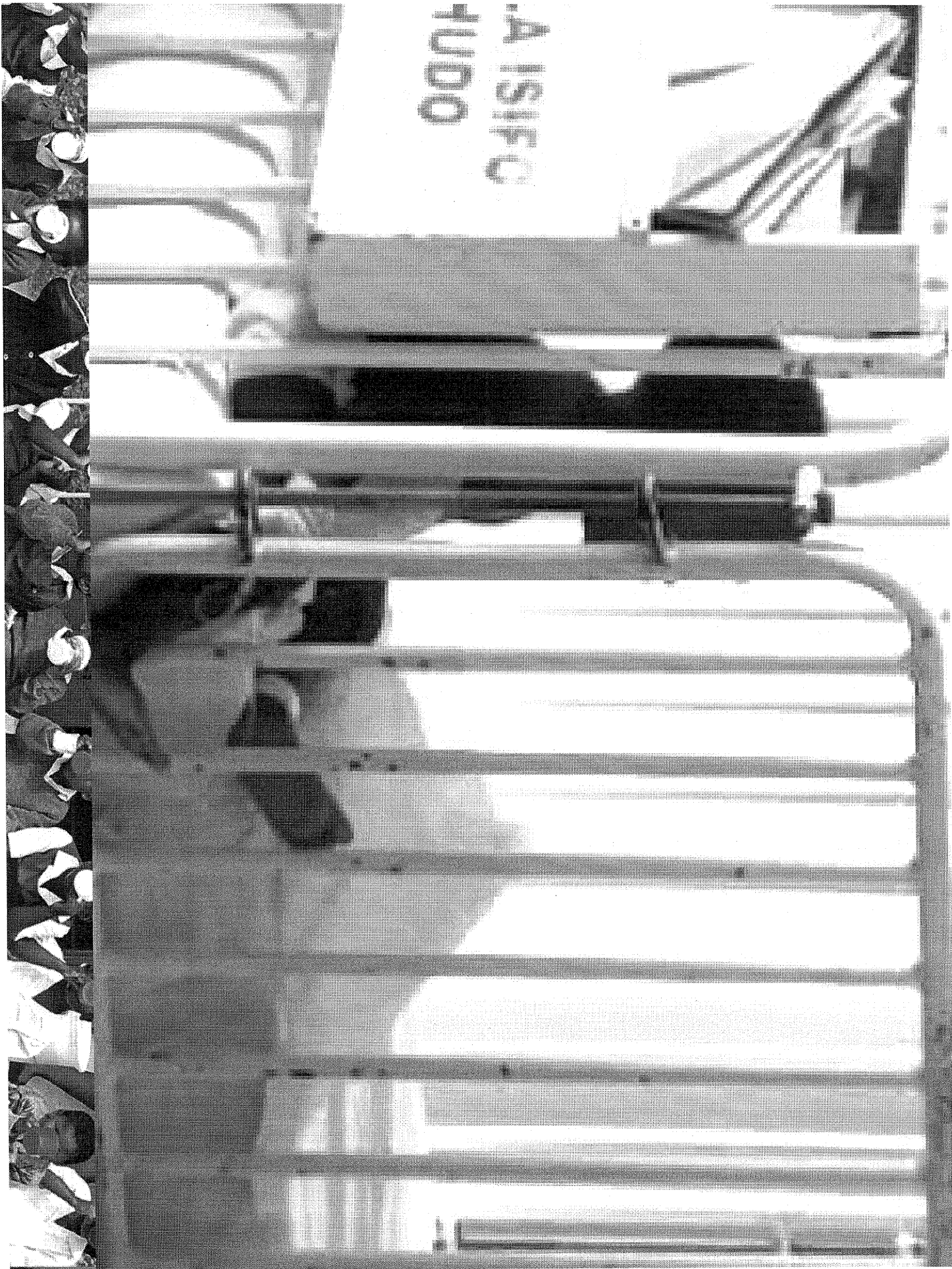
Nurse puts cloth away twice, not understanding

Celia explains - nurse wipes child's face with cloth & this brings some relief to child





AISFC
JUDO



Changing the Nappy

Child has painful associations

Protests, mother rubs arms gently

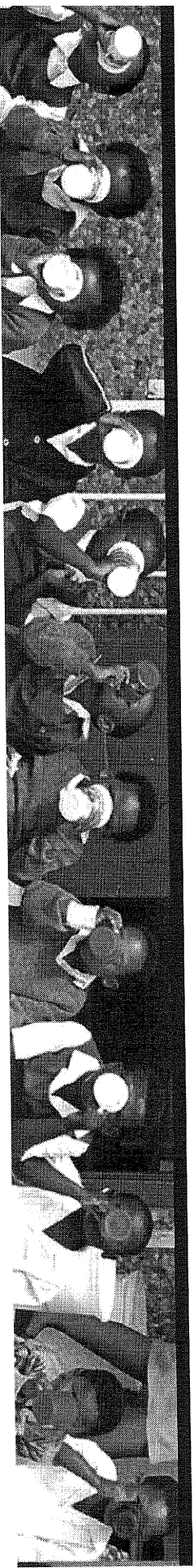
Wipes bottom, child protests

Mom rubs arms again

**Lets child put on cream (child gains
some control over discomfort)**

Nappy changing causes distress

Mom holds and comforts the child





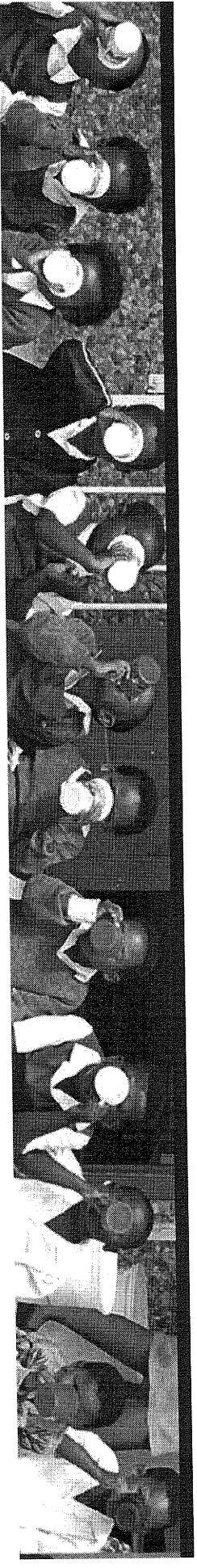
Processing What We See

- Evokes personal memories
- Activates empathy for the child
- Deepens appreciation of the work done
- Increases motivation
- Generates enthusiasm & leads to plans



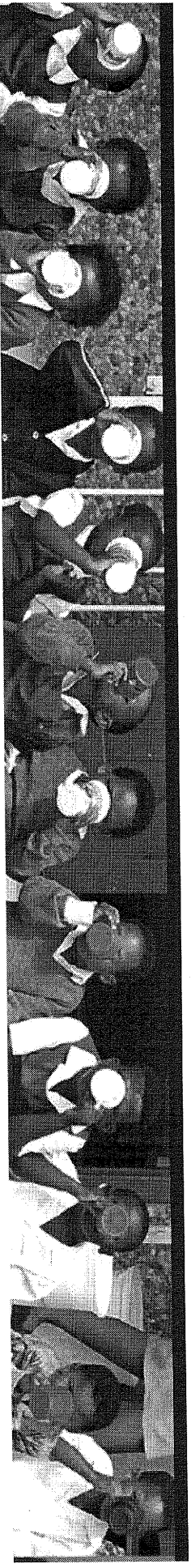
Next Steps 1

- **Systematically introduce familiar cloths & clothing**
- **Train two nurses in massage to train mothers/caregivers**
- **Filming**
- **Develop scripts, acting, complete videotape**



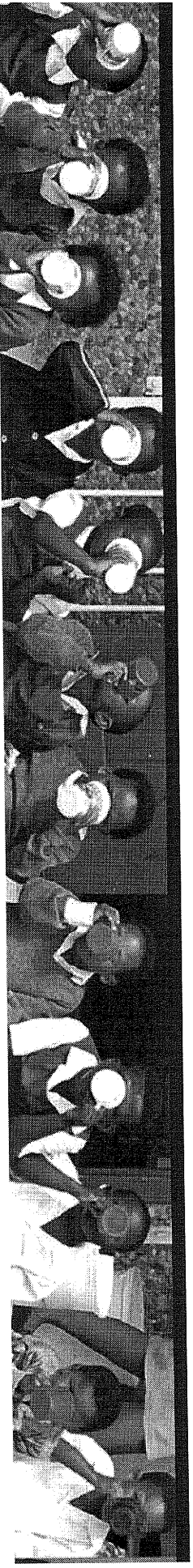
Next Steps 2

- **Complete all videotapes – supporting mothers, painful procedures, feeding, discharge**
- **Set up study to evaluate the impact of one or more of the intervention-domains on children & staff**



Moving toward the Larger Goal

- **Make 5 20-minute videotapes on topics of staff concerns**
- **Some real sections, some acted**
- **Scripted together - storytelling**
- **Distribute to other hospitals**



Conclusion: The co-Creation of Hope

- **Assist staff to cope with distress & disengagement**
- **Assist caregivers & children with distress & withdrawal**
- **Promote, enable empathic care**
- **Re-humanise ourselves in the face of the epidemic**

