Communities Coping with Children Living with HIV and AIDS –

Bridging the Gap between the Ideal and the Reality

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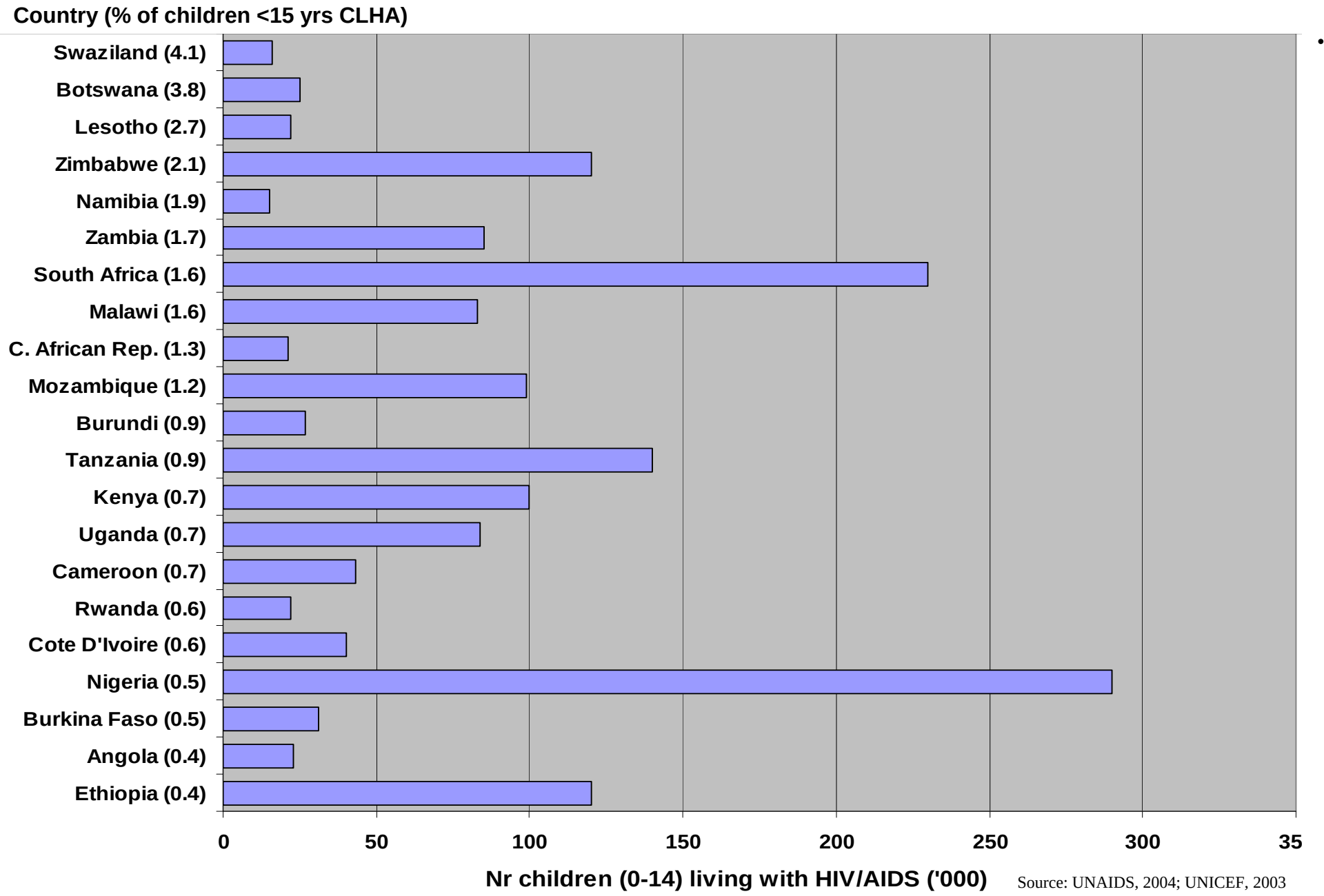
Background

- Based on findings from a regional workshop, including both paediatric ART and community care programmes
- Held in Harare, 8 - 12th November 2004; participants from 9 countries; sponsored by SAT with EGPAF involvement
- Intended as a ground breaking workshop to define how community are coping with “CLHA” (NB. NOT “Paediatric AIDS” or “Children infected with HIV”)

Workshop Format

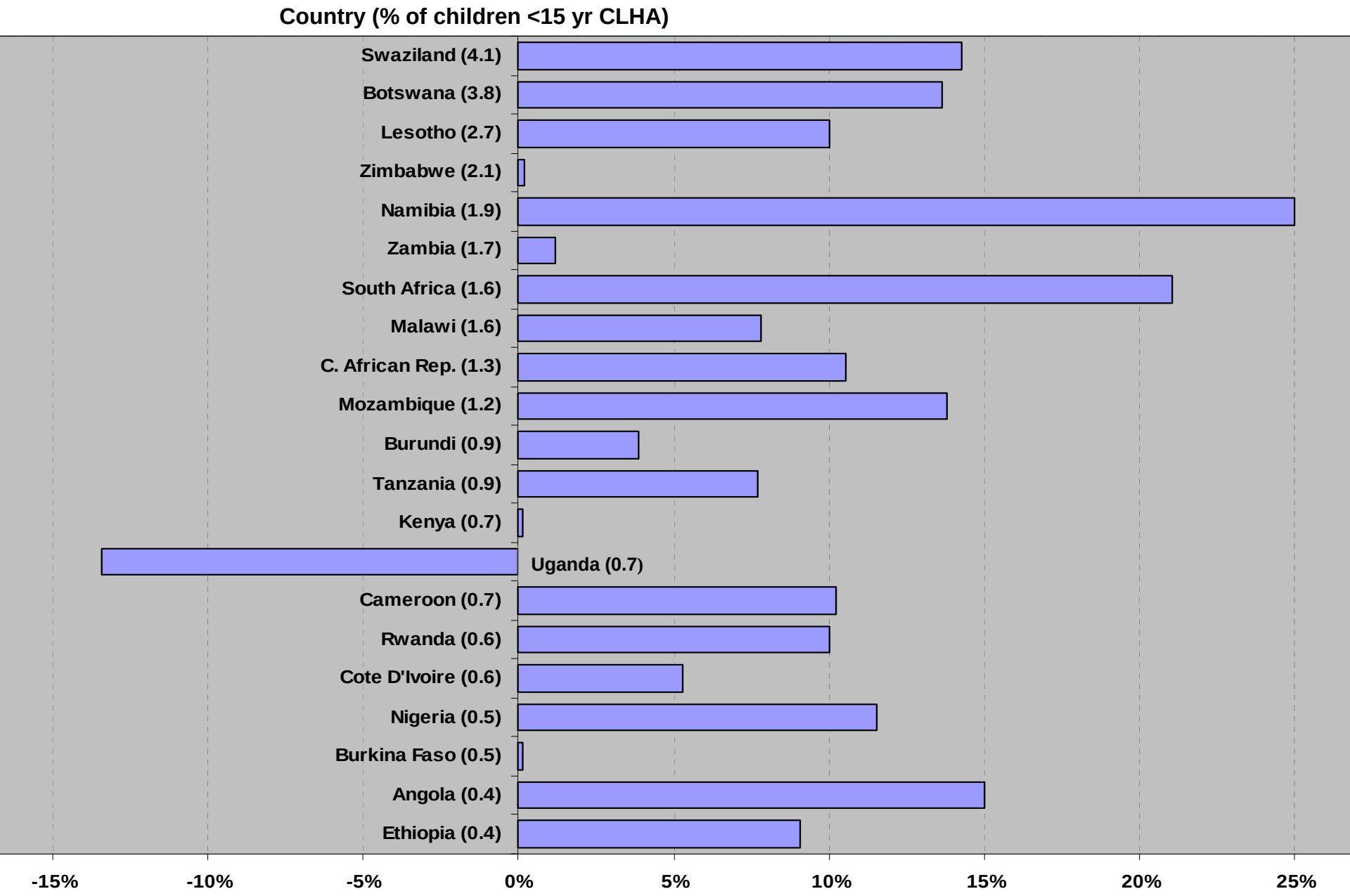
- Plenary presentations, group work and powerful testimonies from parents
- African-specific with Africa-based participants
- Two tracks – community and medical
- Examining ‘the ideal’ and ‘the reality’ and how to bridge the gap between the two

Number of CLHA in sub-Saharan African countries



Source: UNAIDS, 2004; UNICEF, 2003

Change in number of CLHA in African countries, 2001-03



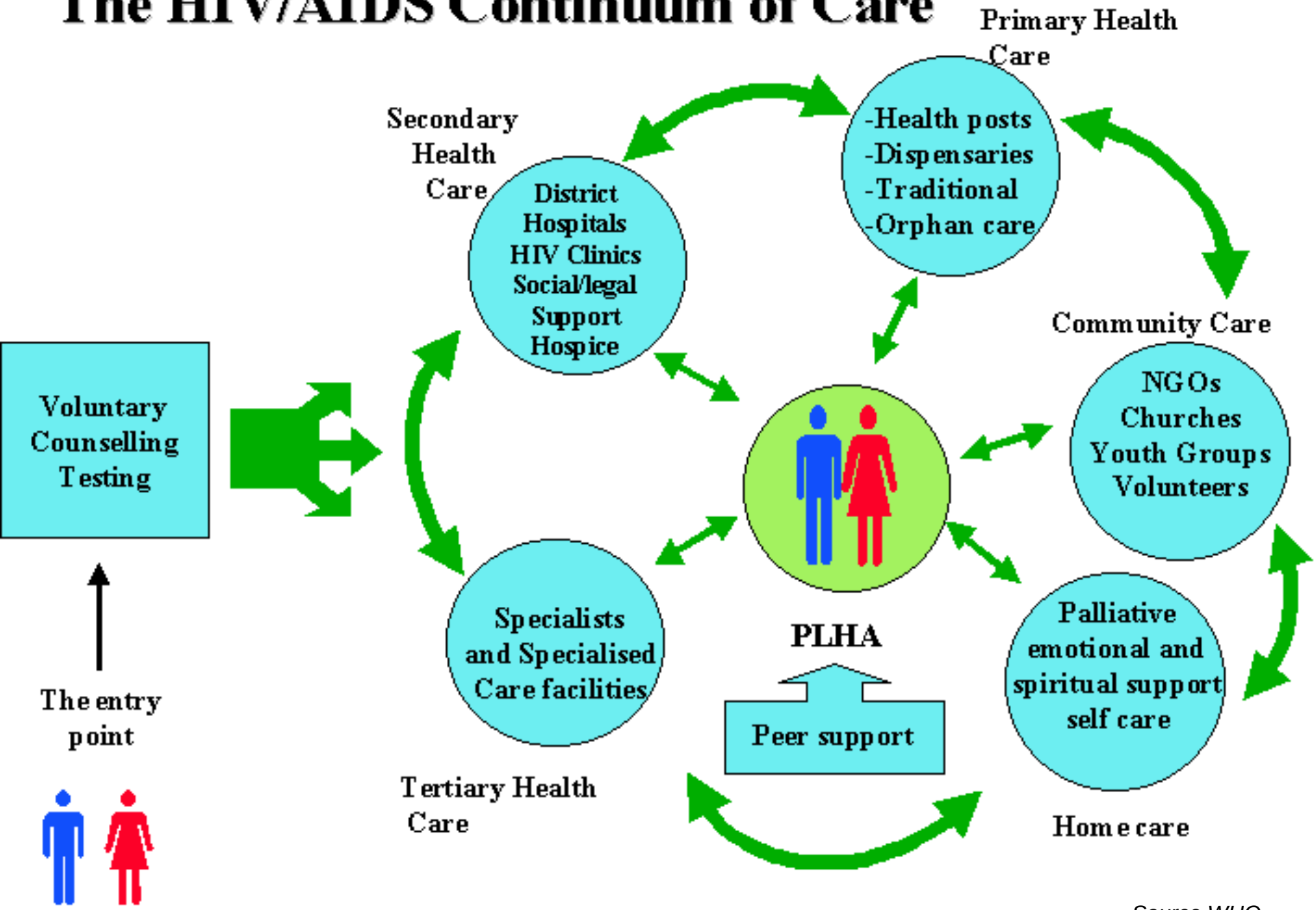
Source: UNAIDS, 2004; UNICEF, 2003

Critical Issues around CLHA (1)

Neglect of right to life of CLHA

- Mean survival time for CLHA in Africa 2-3 years compared to 8-10 years pre-ART in the West
- Discrimination and stigma (at all levels and in all settings) prevent addressing the issues for CLHA
- Prevailing attitude concerning CLHA of “They’re just going to die anyway”
- CLHA die mostly from treatable non-AIDS infections and malnutrition
- CLHA are not included in many ART programmes, and are overlooked in community care programmes

The HIV/AIDS Continuum of Care



Source WHO

Critical issues around CLHA (2)

Lack of model programmes supporting CLHA

- Lack of model programmes that provide both care and treatment through the continuum of care (COC) for CLHA

  Model = replicable and sustainable;
  COC implies institution and community linkage

- The continuum of care is:
  - poor within the health delivery system,
  - inadequate into the community
  - poorly defined within the community

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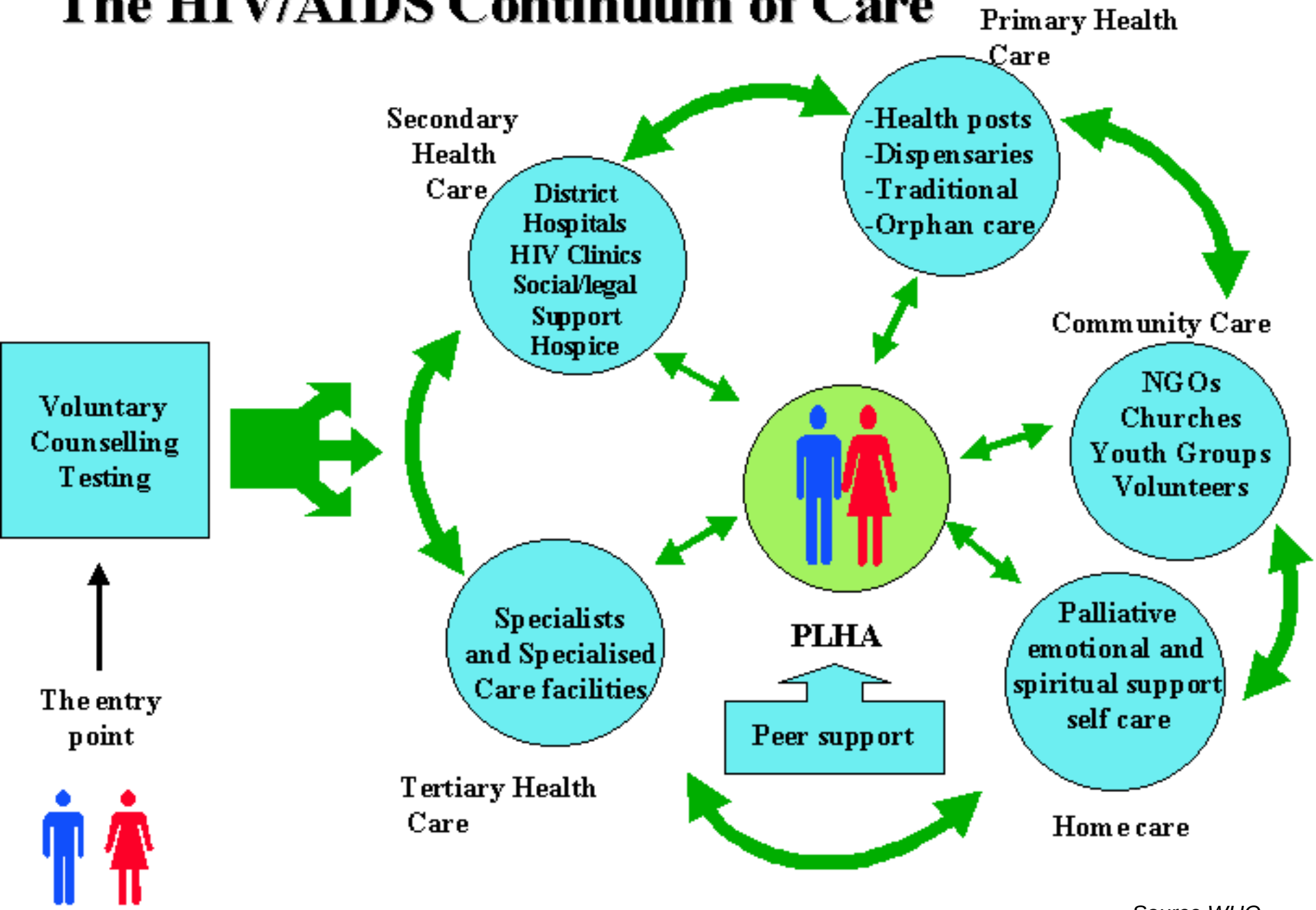
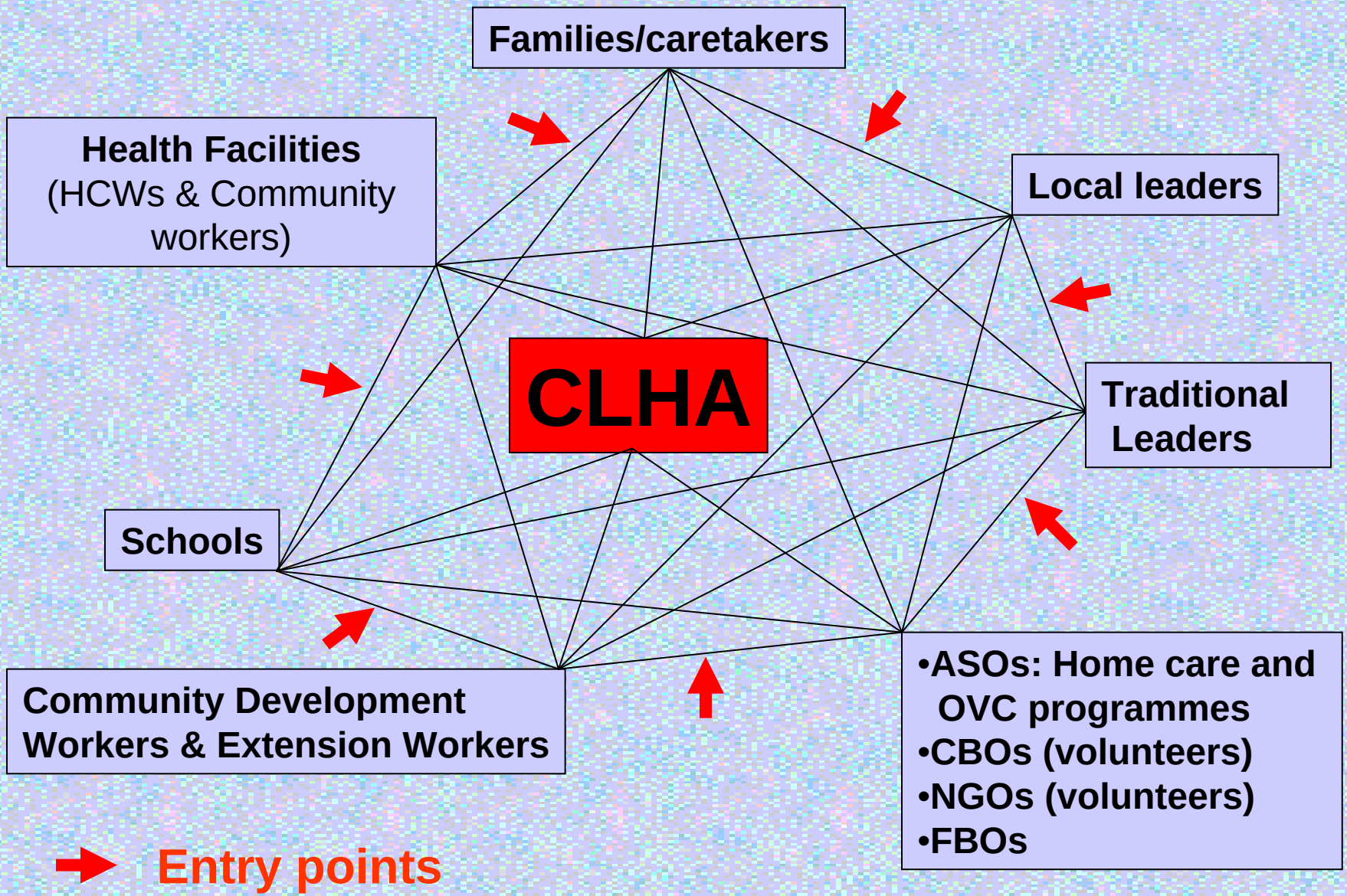


Source WHO

Continuum of care for CLHA



Entry points to COC are community and institutional levels

- Responsibility of communities, families and health workers to have clinical suspicion of HIV infection, and discuss and refer appropriately.

  For programming purposes:
  - OVC programme volunteers
  - CHBC programme volunteers
  - Traditional healers and midwives
  - Schools
  - Health service delivery points (including community based Development & Health Workers)
  - Responsibility of health workers and health facilities to make laboratory/confirmatory diagnosis of HIV

Comprehensive Care Package for CLHA

- Basic medical care
- Prophylaxis against OI
- Early diagnosis and appropriate management of HIV and OI (including ARVs & complementary traditional treatment)
- Good nutrition necessary for appropriate growth and development
- Social support (meeting needs of child – food, clothing, shelter, love)
- Spiritual & Psychosocial support (SPSS)
- Competent caretakers with best interests of child at heart
- Caring for carers
- Maintaining schooling
- Education and information around illness
- Rehabilitation services
- Palliative care services when the time comes

Critical Issues around CLHA (3)

Comprehensive care and treatment for CLHA

- Care and treatment for CLHA is much more than just ART
- Provision of comprehensive care package should combine to allow the child “the right to be a child” and to fulfill their individual potential
- How to measure success in this provision of care?

→Need wider definition of indicators than just number of children on ARV treatment

Critical Issues around CLHA (3)

Ambivalence towards ARV treatment roll out:

- Life saving and life enhancing health benefit
- Opportunity to reverse stigma and discrimination
- ART as a platform for global equity and rights discussions

BUT

- May disempower non-ARV treatment and care of CLHA and distort the balance between care and treatment
- May reinforce the “CLHA are going to die anyway” viewpoint by discouraging treatment of CLHA that are not on ART programmes
- Distorts development priorities in resource poor settings

Critical Issues around CLHA (4)

Lack of emphasis on SPSS needs of CLHA

- Stigma exists for CLHA – it is very real
- Many barriers to care through stigma and discrimination and lack of family communication
- Disclosure issues of CLHA in non-ART settings largely overlooked
- Few support groups for CLHA and guardians of CLHA in SSA
- SPSS needs of school-age and adolescent CLHA virtually ignored