

Family-centred services for children affected by HIV and AIDS

Linda Richter

The Road to Vienna

CCABA & IAS

Children and Especially Marginalized Populations

Geneva

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HUMAN TOUCH

Outline

- Children – a marginalized group
- Shifting ground (JLICA, CCABA, Mexico)
- Strengthening families – social protection
- The Road to Vienna
 - Family-centred services for children
 - Children and especially marginalized groups

Children - Marginalized

- Denial of & resistance to heterosexual, including paediatric, AIDS
- Delayed response to children
- Prevention, treatment & support for children lag behind efforts for adults
- Small scale, sometimes ineffectual efforts to protect children from the worst effects of the epidemic & provide care/support

Delayed Prevention

- 1985 - first USA recommendations for PMTCT
- 1991-1993 - definitive AZT trials
- Rapid decline in vertical transmission in Europe and the USA
- 1998 – first WHO recommendations for developing countries
- 2010 - most developing countries still using less effective regimes

Delayed Treatment

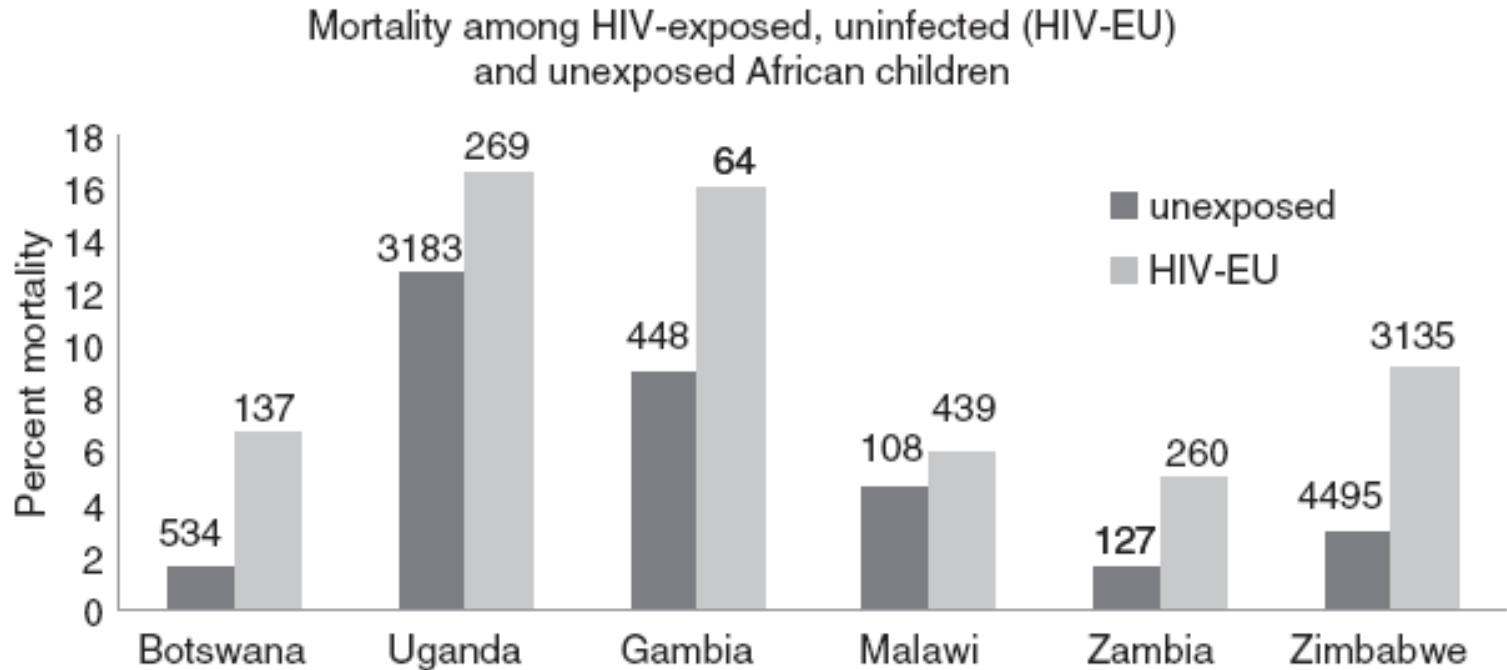
- 1995 – survival of children through preschool years acknowledged
- PMTCT success reduces incentives for paediatrics ARVs
- Lack of research on paediatric treatment
- Lack of political will – MDGs?

Lagging Prevention

- PMTCT most effective prevention of HIV available, but roll out is disappointing
- Eg South Africa, 81% of pregnant women tested nationally; 2/3 receive test results
- 57% of those with results took ARVs for PMTCT in 2007
- = 31% of pregnant women in PMTCT
- Very poor follow-up of mother & child – father and other family?

Unanticipated Effects

Problems experienced by exposed, uninfected children – heightened mortality, morbidity, developmental problems



Mortality among HIV-exposed, uninfected and unexposed African children. Data are percentages of deaths among

Filteau, 2009

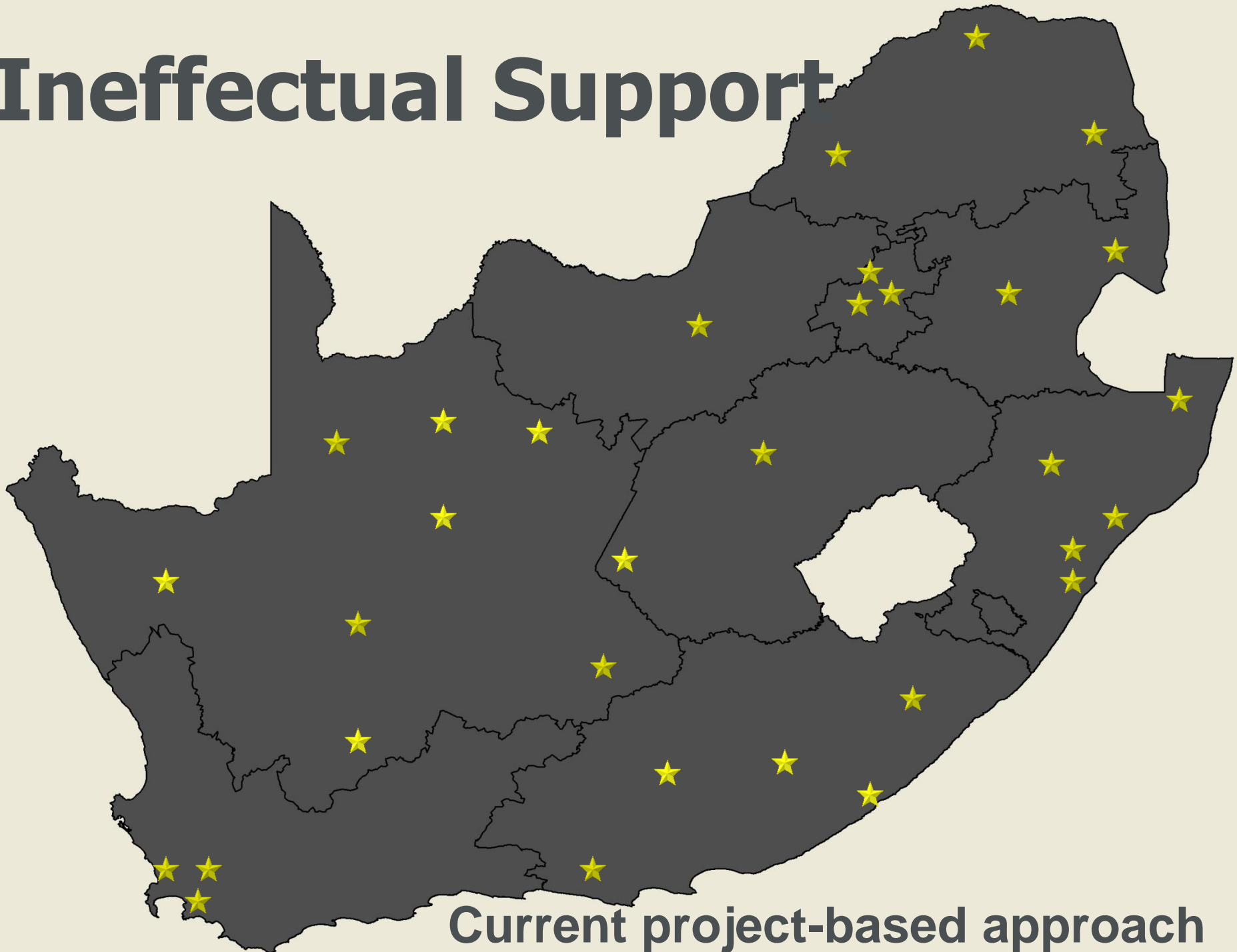
Lagging Treatment

- Children
 - 6% of all people living with HIV - about 2 million children
 - 17% of new infections
 - 4% of those receiving treatment, but 13% of those requiring it
 - 16% of AIDS-related deaths
 - 8% of children in developing countries who need treatment, are receiving it

Inadequate protection?

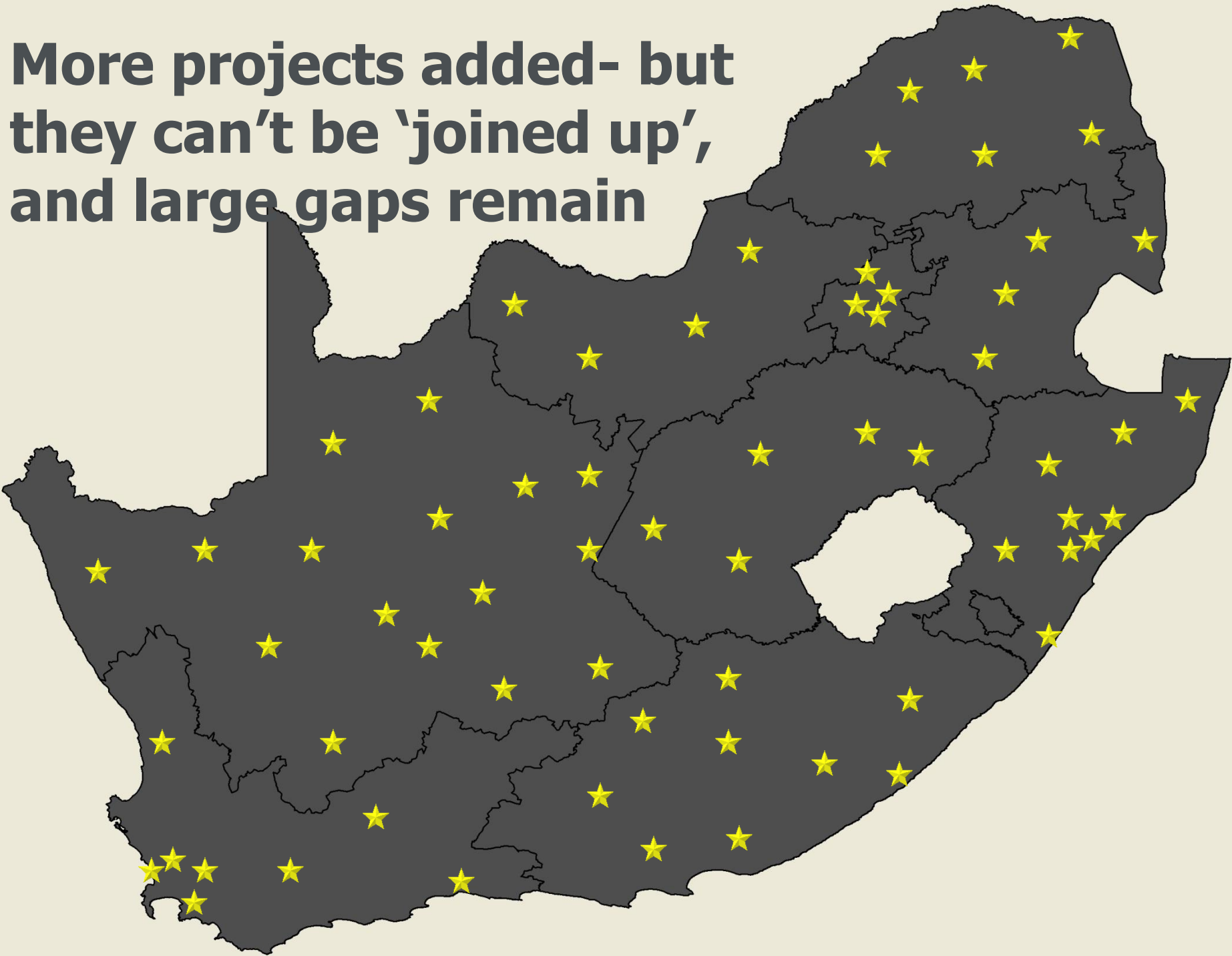
- Project-based, case management approach
- Lack of comprehensive “public health” interventions
- Lack of policy interventions
- Lack of appreciation of effects across generations

Ineffectual Support



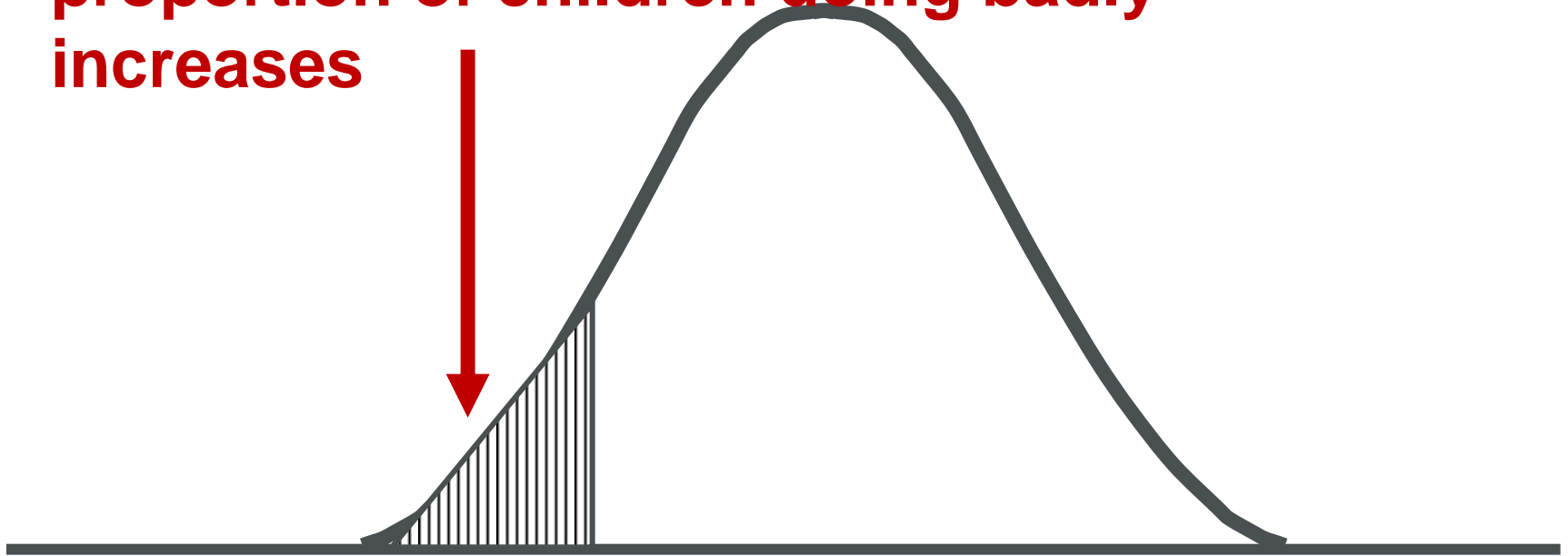
Current project-based approach

More projects added- but they can't be 'joined up', and large gaps remain



Public Health Approach

Under adverse conditions, the proportion of children doing badly increases

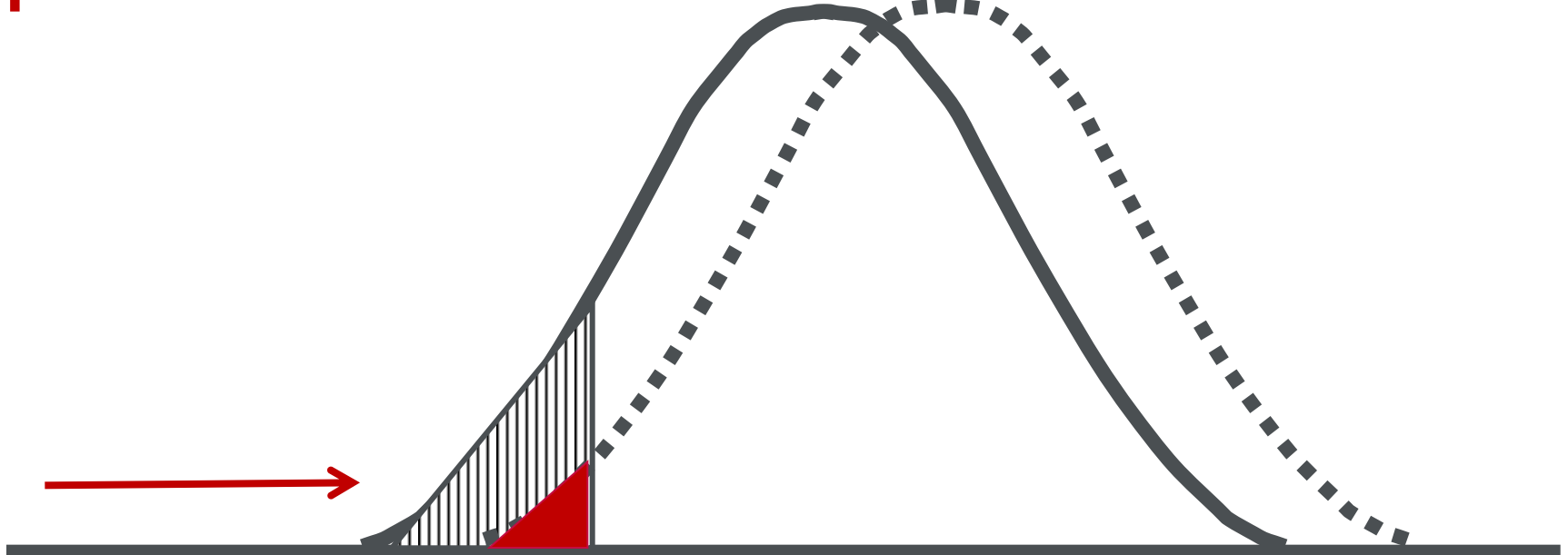


This means there are more children needing non-specific support & more children needing help

It becomes more difficult & less cost-efficient to try & reach these children one-by-one

Policy Interventions

Shift the curve to the right by beneficial provision for ALL children →→→→



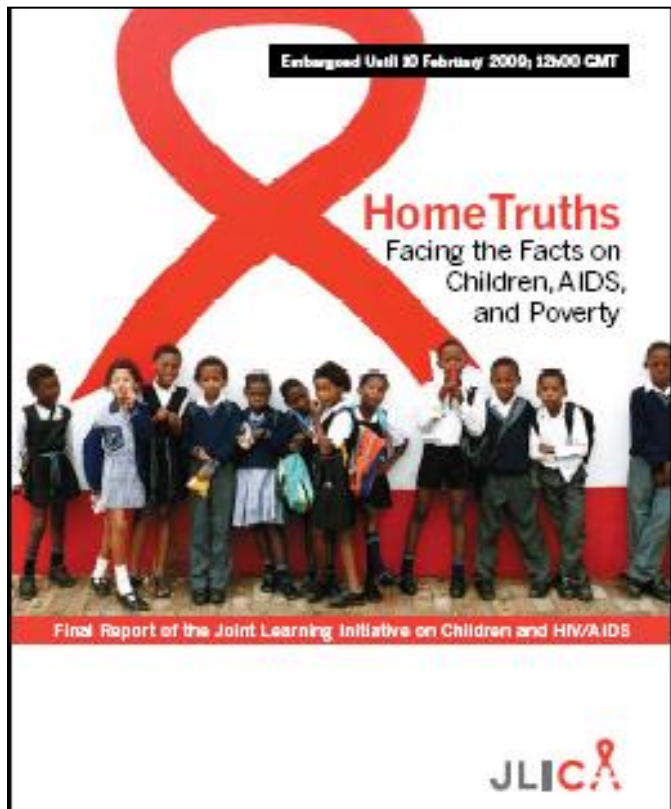
If we could do things that benefited ALL children, the number of vulnerable children would decrease

There would be fewer children needing help & we could feasibly reach them with appropriate intervention

Shifting Ground

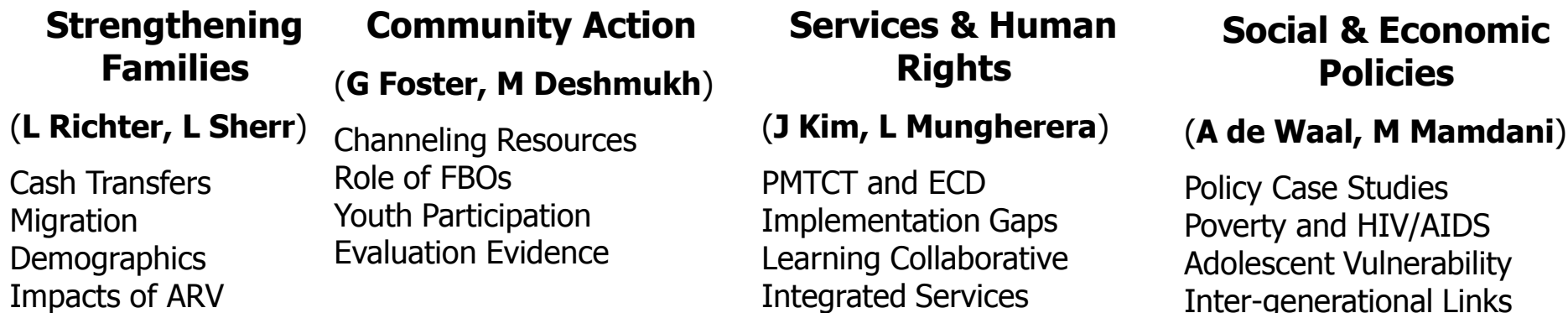
- Joint Learning Initiative on Children and AIDS (JLICA) 2006-2008
- Coalition on Children Affected by AIDS (CCABA) 2004 -
- Plenary on children in Mexico 2008

JLICA



- Independent, time-limited global alliance of researchers, implementers, activists, policymakers, and people living with HIV
- Hundreds of individuals and organizations involved in process of analysis and joint learning
- Mobilized evidence, facilitated new thinking and advanced action for children

JLICA Working Groups



Learning Group (LG) Synthesis



JLICA Final Report

Home Truths: Facing the Facts on Children, AIDS and Poverty

JLICA Recommendations

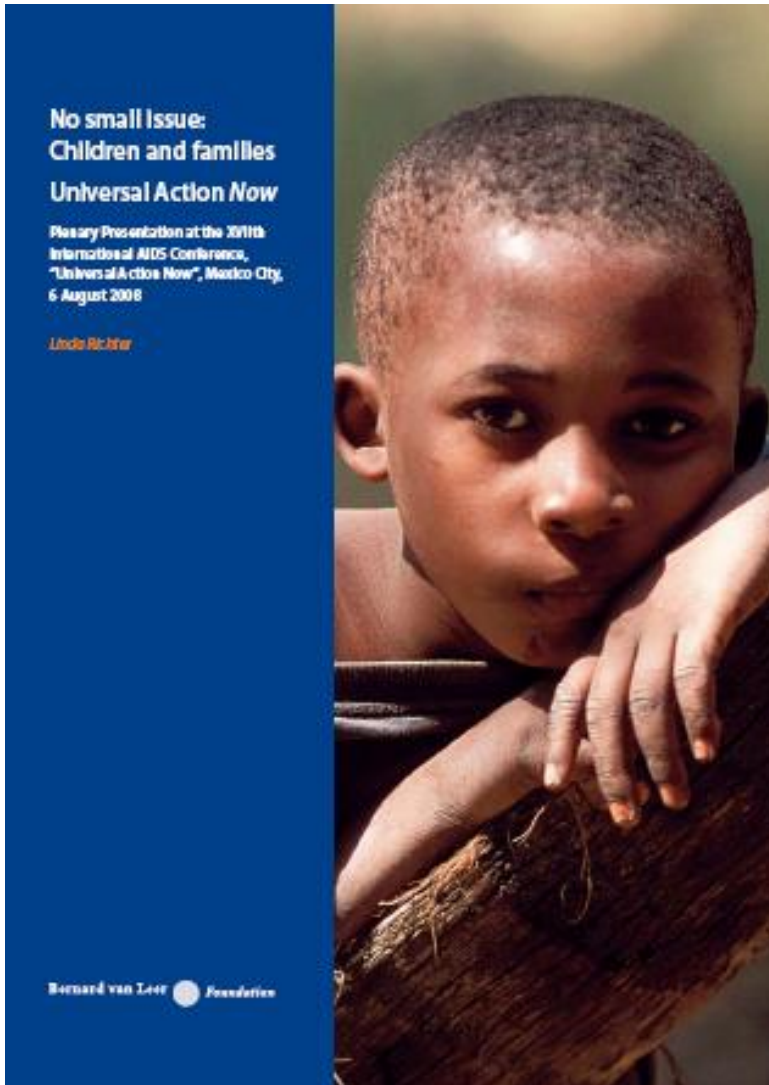
- Support children through families
- Strengthen community action that backstops families
- Address family poverty through national social protection
- Deliver integrated, family-centred services to meet children's needs

CCABA



- Formed in 2004
- Collective of private and public foundations and re-granting organizations in the North and South
- Taken on advocacy of JLICA recommendations

Mexico Plenary 2008



- Support children through families
- Develop comprehensive & integrated family-centred services
- Create social protection for the poorest families
- Expand income transfers to poor families

Strengthening Families

- **Acknowledge** families in the lives of children
- **Strengthen** families
 - Economic strengthening – social protection
 - Universal access to services
- **Family-centred services** for children affected by HIV and AIDS

Acknowledge families

- Families = long-term, mutually supportive relationships
- Intrinsic to human life – for children and adults
- Wide diversity of biological, adoptive, elective families
- Continually recreated – “breakdown” is not an end state
- Need for families greatest during times of stress

Families Key in HIV/AIDS

- A “family disease” in high prevalence settings eg southern Africa
- As a result of transmission in families, between:
 - long-term partners
 - parents and children
- Experience repeat morbidity & mortality
- Bear greatest burden of care
- Context for new infections eg orphan risk

Family Impacts

- Up to 60% of families in high prevalence countries are affected
- 95% of “orphans” live with family, most with their surviving parent
- Increased poverty, decreased consumption – food, education, health
- Fewer than 15% of families receive outside assistance

Economic Strengthening

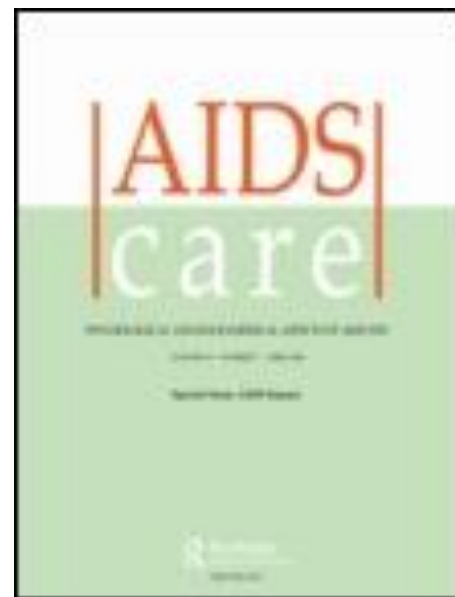
- Access to services – health, education, social welfare, justice
- Direct income transfers – old-age pensions, disability grants, child grants
- Demonstrated benefits – children, families
- Coincides with development agenda (esp Africa - AU, SADC, donors)
- UNAIDS Business Case on Social Protection (in progress)

Family-Centredness

- Orphanhood → “individual frame”
- Keep children and parents alive
- Keep children in families
- Build family caring capacities
- Empower families to educate and protect children and keep them healthy
- Backstop families with social protection

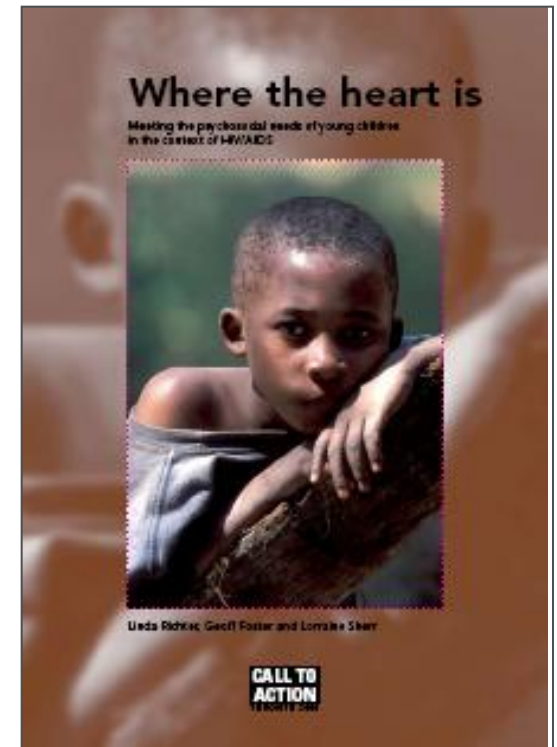
Family-Centred Services

- Home visiting
- Early childhood development = food and stimulation
- Treatment for parents
 - Preserve child care & security
 - Benefits growth, school, labour & wellbeing of children
- PMTCT+



CCABA Initiatives

- 2004 - CCABA formed in Bangkok
- 2006 - Road to Toronto; Teresa Group/CCABA – Children’s Pre-Conference Symposium
- 2008 - Mexico Plenary on children
- 2009-2010 – Family-centred services



“Road to Vienna”

- Proposed in Mexico Aug 2008
- Meeting 1 – Nairobi Sep/Oct 2009
- Meeting 2 – Geneva Feb 2010
- Events at 18th IAC, Vienna
 - Satellite, Non-Abstract Session
 - Launch of Special Issue of JIAS
- → Advocacy eg “End or Virtual Elimination of Pediatric AIDS”
- → Funding for effectiveness studies?

Nairobi Meeting #1

Mary Jane Rotheram-Borus (UCLA) HIV and AIDS: The case for family-based programming for children and youth and inter-generational benefits: Evidence and experience

Theresa Betancourt et al (Harvard, Columbia) Family-centred approaches to PMTCT/ Prevention of Mother to Child Transmission Plus

Arvin Bhana et al (HSRC, Mt Sinai) The Collaborative HIV Prevention and Adolescent Mental Health Project (CHAMP) family-based HIV prevention approach

Sarah Leeper et al (Brown) Anti-retroviral treatment for children

Daniel Kinoti et al (Kenya, USAID) Care and support

Nairobi Meeting #2

Mark Tomlinson (Stellenbosch) Parental depression: The case for family-centred approaches

Charles Bruner (Harvard) Family strengthening strategies: What do we know from early child development programmes?

Sangeetha Madhavan (Maryland) & **Vicky Hosegood** (LSHTM) A demographic view of families and households in Africa: Implications for family-centred approaches

Linda Richter (HSRC) Models for family-centred approaches: Implications for children affected by HIV/AIDS and poverty

What Does it Mean?

Family-centred?

- Juncture box, telephone exchange – point of connection for reach and services
- Task shifter, adjunct to health services
- Ally, collaborator (or reduce harm) in prevention, treatment & care
- Build family capital (relationships, resources, resilience) across generations

Overall Strategies

Ecological approach to child wellbeing

- Keep children in families
- Keep family members together or at least connected
- Keep families in their homes
- Keep families in communities and interacting
- Enable families to keep and build on their assets

Forms of Services

- Based on place eg children & parents get tested or treated together
- Relationships (no single individual eg HIV/AIDS is a family disease) – “mindshift”
- Incremental – radiate services to others who may need them or hotspots for prevention
- PMTCT+ as a start

Marginalized Groups

- Shared platform in Mexico - Elena Reynaga (Argentina) Redtrasex
- History and the early association of HIV/AIDS with marginal groups – human rights, a social disease (Mann)
- M J Rotheram-Borus 2005 paper – families are affected by HIV/AIDS
- Franco review – children in low prevalence settings

Children and EM Groups

- Their children are the most marginalized of all, frequently excluded from services
- Family strengthening is critical for children's long-term wellbeing
- People in EM groups often depend on families in the absence of services
- Families who support people in EM groups receive little help

Some Oral History

- Geoff Foster
- The early 1990's
- Inter-Agency Coalition on AIDS and Development (ICAD)
- The role of gay groups in promoting responses to children

Neglect of Family Issues

- Search 2007-2010 – CSW, IDU, MSM – *non-biological, family, partner, child* – only 27 papers
- Many/majority had partners (married) and/or children
- Families a source of risk (eg male MSM, male IDU, sexual abuse)
- Families often a source of valued support (not female IDU)

Family Findings #1

- Disclosure to family was a help, increased support
 - IDU (Ko et al 2007, Li et al 2007, Valle & Levy 2009)
- Families generally accepting
 - MSM (Garofalo et al 2008; Meyer & Champion 2009)
- Need family support
 - IDU (Gu et al 2009, Wohl et al 2010)

Family Findings #2

- Want assistance with family issues
 - MSM (Tsui et al 2008)
- Intervention improved family life
 - IDU (Kermode et al 2008)
- Among IDU, increased adherence to exchange programmes (Fitzgerald, 2008)
- Submitted an abstract for Vienna on broader review 2005-2010

Geneva 10-11 Feb

- Called for paper proposals, then papers
- To advance our understanding of family-centred services for children
- Among especially marginalized groups
- Asking the questions:
 - What are the needs of children and families?
 - What forms could services take?
 - How to move forward with a shared agenda?

What to Achieve?

1. Greater awareness of difficulties children and families experience among especially marginalized groups
2. Shared agenda of action, advocacy and research to push for family-centred approaches to prevention, treatment, care and support for **all** children

HUMAN TOUCH



Thank you!