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# **Young Carers for AIDS-unwell adults: developing a support programme in South Africa**



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# Orphaned children: health risks

**Physical health** (Ainsworth & Semali 2000; Nyamukapa, Gregson et al. 2006; Watts, Gregson et al. 2007)

**Malnutrition** (Ainsworth & Semalil. 2000; Lindblade et al. 2003; Gray et al. 2006; Cluver, Gardner et al. in press)

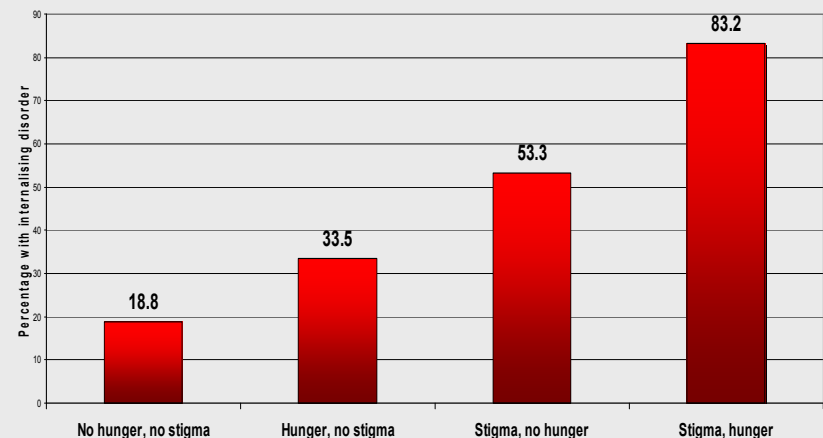
**Mental health** (Atwine et al. 2005; Bhargava 2005; Watts et al, 2008, Cluver et al. 2007a, Cluver et al, 2007b)

**HIV risk** (Gregson et al. 2005; Kissin et al. 2007; Operario et al. 2007; Birdthistle et al. 2008; Cluver & Operario 2008)

**Education** (Muller et al. 1999; Case & Ardington 2005; Mishra et al. 2005; Gray et al. 2006; Operario et al. 2008)

Cumulative mechanisms:  
poverty, stigma,  
caregiver illness

Orphanhood:  
effect or process?

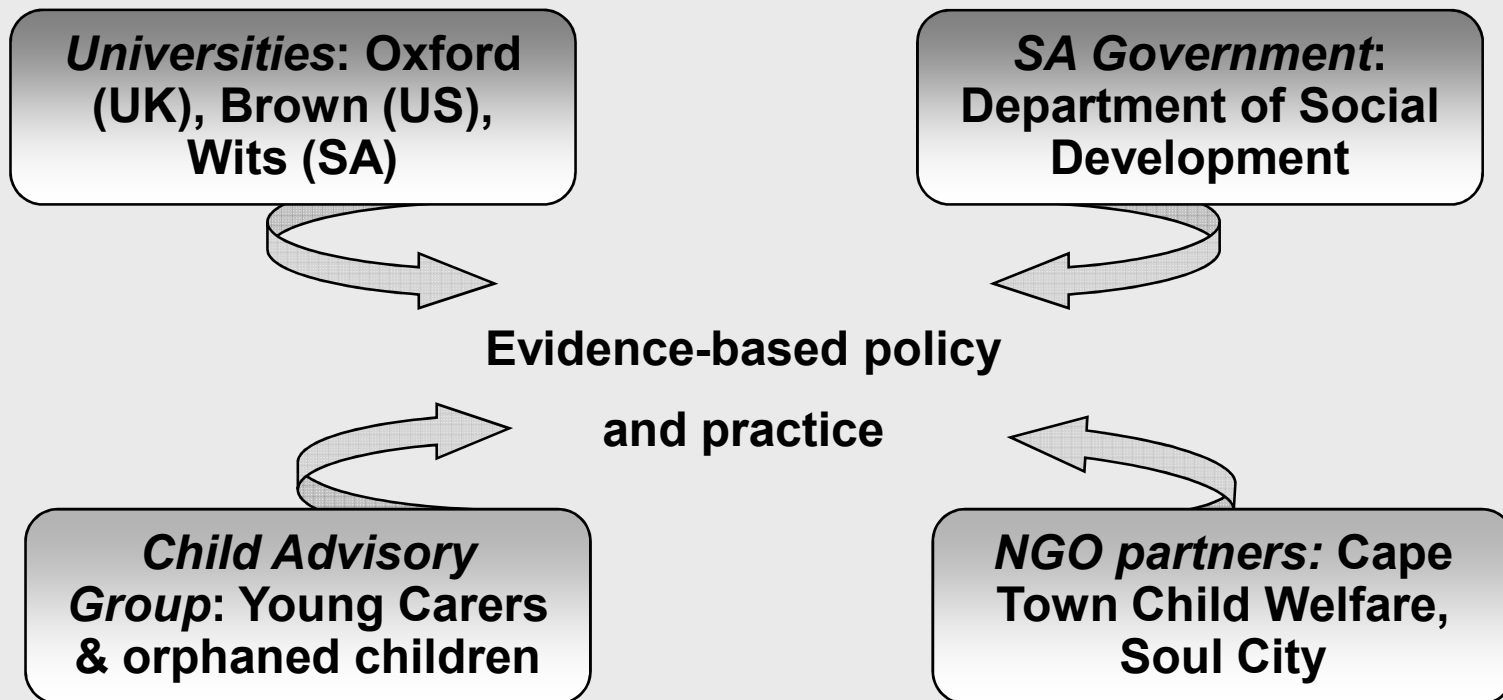


# The 'invisible children' in OVC

- Domestic tasks
- Sibling care
- Medical care
- Emotional support
- Intimate care
  
- Extent
- Outcomes
- Risk & protective factors
- Intervention effects



# Collaborative research



# Young carers: health risks

## ***Physical Health:***

Anthropometrics

Nutrition

TB

Upper respiratory infections

Alcohol and substance use

## ***Sexual Health:***

Sexual debut

Unprotected intercourse

Forced sex

Pregnancy

HIV knowledge

Transactional sex

Multiple partners / concurrency

STIs and HIV

## ***Mental Health:***

Depression

Post-traumatic stress

Behaviour problems

Other emotional problems

## ***Social Health:***

Peer relationships

Family problems

## ***Educational / Cognitive:***

School enrolment

School attendance

School / cognitive performance

# Mechanisms of risk and protection

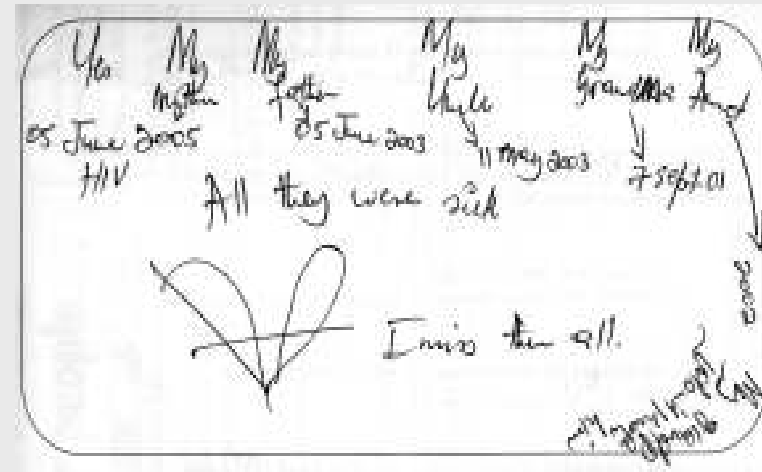
- Gender
- Poverty
- Education
- Carer illness
- Caregiving tasks
- Stigma
- Family processes
- Parental monitoring
- State support
- NGO support
- Peers
- Succession planning



**'She is very ill and I assist her in all her requirements: bathing, feeding, toileting needs.'** (Robson, 2000)

# Support programme

- National NGO
- Non-technical, non-reliant on professionals
- National Action Plan priorities
- Scalable



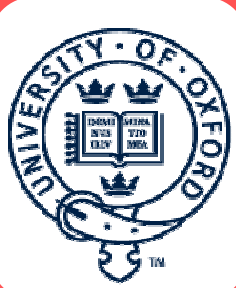
- Peer support network
- School-based programme

- Qualitative stage: 'Market research'
- Quantitative longitudinal stages: identifying mechanisms
- Randomised controlled trial at pilot, adaptation, scale-up

# Methods

- Qualitative and quantitative, longitudinal
- Standardised measurements, verbal autopsy method
- Intervention pilot and full trial (RCT)
- Age of children: 10-18 at baseline, 3 year follow-up
- i) Young Carers ii) orphaned children iii) children in non-affected households
- Include other chronic parental diseases and disability
- 4 Provinces: Western Cape, Eastern Cape, Mpumalanga, Gauteng
- Sample size:
  - Qualitative, ~150 per province
  - Quantitative, ~1000 per province





# Strengths and suggestions

- Active collaboration of government, researchers, NGOs, affected children
- First quantitative study of Young Carers in sub-Saharan Africa
- Rigorous 2-stage evaluation of NGO programme



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What can we improve?  
All comments welcomed.

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(Evans and Becker, in press)

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Thank you.