

Policy Brief: Evidence to support broad-based responses to children living with AIDS in the family

Source: Bray, R (under review) 'Young Carers': Ambivalence and contradiction in a South African peri-urban settlement.

Recent in-depth qualitative research amongst children living with sick adults has exposed how they cope and why they become vulnerable, as well as how they respond to neighbourhood resources and specific AIDS-related intervention.

This study is part of the Young Carers project designed to question whether and how living with AIDS triggers different vulnerabilities in children to those arising from other illnesses. Young Carers is a collaboration between South African government, the National Action Committee for Children Affected by AIDS (NACCA), Oxford University and the University of Cape Town. A full report of research methods and findings from this and related research is on www.youngcarers.org.za

The Questions

- What aspects of living with and caring for sick adults do children feel equipped for, and derive benefits from?
- What aspects of caring are beyond children's abilities, add to existing vulnerabilities or cause new stress?
- What prevents families and communities protecting children and enabling them to thrive when caring?
- What kinds of services and supports work?

The Research

- Worked intensively in an informal settlement outside Grabouw, Western Cape province with 14 children aged 9-17 years whose adult relatives have been seriously ill (or died) owing to AIDS or other illness.
- Engaged children in art, drama, video-making and conversational interviews.
- Observed neighbourhood relationships and family life; interviewed adult relatives and social workers.

Finding 1: Children want to care for adults, but face limits to their knowledge and capacities:

- Children are confident in their ability to keep sick adults company, give them food, drink and medicines, and to monitor their well-being.
- Children derive greater personal satisfaction and social value from giving care than from other domestic roles.
- Children live with and care for relatives knowing only some of the causes behind their illness, and little about its prognosis.
- Children often keep silent about sickness at home because they need to be careful about who knows what regarding their own situation and the situation of those close to them, in order to protect the family reputation and to avoid being alienated from their sources of support.
- Cleaning up body fluids is difficult for children and poses health risks when there is no access to clean water or sanitation.
- As adult sickness worsens, children see limits to their abilities to care and rely on trusted neighbours or kin to:
 - Access transport to hospital,
 - Provide adult company prior to, and during, a death.

Finding 2: Caring poses less of a threat to children's well-being than social violence and ineffective schooling

- Frequent violence (muggings, rape, assault) in the neighbourhood prompts parents to try to keep children at home to ensure their safety, a strategy that largely fails and further reduces children's abilities to befriend adults in the vicinity who can support them when caring;
- Efforts of children and adults to protect each other are undermined by the inability of schools to deliver the level of education that is expected to provide a route out of chronic poverty.

Finding 3: Targeting 'young carers' or 'AIDS-affected children' cannot address the core issues:

- When children live with severe sickness (in a parent-figure or sibling) their strengths and vulnerabilities are not determined by their caring role, but by the qualities of their relationships with family and specific community members;
- Services explicitly geared towards AIDS (or families in crisis) may fail because they threaten these small protective networks and will be avoided by children and adults who fear attracting stigma.

Conclusion: The well-being of children living with or caring for sick adults (regardless of illness cause) is best protected through:

- Locating care and services in hubs accessible to all children & families,
- Adults who listen carefully to children & act upon what they have heard,
- Free and available transport to health facilities, & adult access to medicines,
- Food security,
- Functioning schools able to provide quality, relevant education & support,
- Safer neighbourhoods.