

## This Little Light of Mine...

### Caregivers of children affected by HIV speak out at the National Children's Forum

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*"I will brave all the elements to reach anyone who calls on me for care".*

In this statement Penelope<sup>1</sup>, a caregiver from the Northern Cape, captured the commitment of the 18 caregivers that accompanied 90 children infected and affected by HIV/AIDS to the National Children's Forum (NCF) in Cape Town in August.

The Forum was organised by the Children's Institute, in collaboration with Soul City, the Child Rights Centre, the National Department of Health and the Joint Monitoring Committee on Children, Youth and Persons with Disability. One of the aims of the Forum was to provide a window into the worlds of the children and their caregivers and to establish the requirements for improving their situation. At the Forum the children and caregivers participated in groups where they discussed the circumstances of their lives, their joys, and their fears, and then presented these to MPs and decision-makers.

Nearly half of the caregivers were younger than 35 years of age, showing the commitment of young South Africans to the plight of HIV-affected children. Most of the group were women, and had a professional background. When one listens to their stories of how they became caregivers it is quite clear that for each of them it is not just a job but a calling to which they have committed their lives. Two of the caregivers, an environmental health officer and a psychiatric nurse, left their professions to follow their calling to care for children and families infected and affected by HIV/AIDS.

A number of caregivers started out by caring for relatives and friends suffering from AIDS-related illnesses, but the huge need in their communities led to many requests for support from others affected by AIDS. Caregivers told their stories of taking patients into their homes and tending to them day and night: *"There are no office hours for us as there are for decision-makers and politicians. Desperate people knock on our doors day and night."* Caregivers subsequently underwent training for home-based care and counselling which equipped them better for their difficult tasks.

All the caregivers that participated in the NCF are affiliated to community-based or non-governmental organisations. The services provided by these organisations range from home-based care, assistance for rape survivors, foster care placements, and trying to re-unite abandoned and orphaned children with their extended families.



The resounding message of the caregivers was that people with HIV and AIDS need food, love and support: *"Those infected with HIV are often rejected and thrown out of the family homes. When they come to us they are ill. They have had nothing to eat and have been unable to wash or get clean clothes for days. The first thing I do when I see them is to hug them and hold them"*.

The greatest concern expressed by caregivers was the need for financial support that would ensure that the children with whom they worked received food and care. The situation of these children could be improved through access to the social security grants for which they qualify but are unable to access due to constraints of the current social security system. The caregivers were also concerned for the safety

of some of the children who were being abused in the homes and communities in which they lived, due to the stigma attached to HIV.

Caregivers themselves receive little emotional support or debriefing. They described the opportunity to meet and share information with caregivers from other parts of the country as one of the greatest benefits of participating in the Forum: *"At least we know that we are not struggling alone"* was the ironic relief that reverberated from across the room. They were keen to establish support networks and a newsletter in which they could share experiences and information.

Caregivers are the unrecognised beacons of hope in this devastating epidemic. The group at the NCF represented a small part of formal caregivers. There are thousands of other caregivers such as grandparents, neighbours and friends of affected HIV children that do their utmost to support the children under very difficult circumstances. Tangible support from government and society in general is essential to enable them to continue and extend their work. Their plea to government was that it should fund non-governmental organisations that are providing care to children infected and affected by HIV/AIDS. They felt that this was the best way to ensure that the money reached the children.

*If you would like more information about organisations in your area that work with children affected by HIV, contact Charles Mandivenyi at Save the Children (UK) in Pretoria (Tel. 012 341 1889 Email: cmandivenyi@scfuk.co.za) for a copy of the Directory of Services of Organisations working with HIV-affected children or visit the website at [www.childaidservices.org](http://www.childaidservices.org)*

1. Name has been changed