

Treatment and support: a double-edged sword

She stops mid-sentence. Her body remains still as the woman passes by the open door. As soon as the woman's silhouette is no longer visible through the net curtain, Stella leans closer and speaks in a conspiratorial whisper.

"I'm worried about what will happen if I get sick. I'm worried that when I'm seriously ill or pass away without my own place, what will happen to my children. The owner will come and ask many questions. That woman," she says, pointing with her chin to the open door, "is the owner."

Stella pays R300 each month for the two-room house she shares with one of her two daughters and seven-year-old son. The family's sole income are two grants: the R780 care dependency grant for her HIV-positive son and her R780 temporary disability grant. Food, clothes, school fees, supplies and uniforms, transport all eat away at her tight budget.

When she first applied for the disability grant she was too ill to work. Access to the grants has improved her and her children's nutrition. With better nutrition came better health and resilience.

"I don't feel like staying the whole day doing nothing. I want to work. I'm not sick like before."

If their grants come up for review, her and her son's health may mean the loss of the family's only source of income. For Stella and her children the grants are currently their only means of survival.

Stella's situation is the norm for the majority of households affected by HIV in South Africa, described by one researcher as "the socially weakened". The disability grant, designed for people too ill or disabled to work, has come to be known as the HIV grant and, together with the care dependency grant for children, function as de facto poverty-alleviation measures.

With the high level of unemployment and the added burden placed on family networks by HIV/Aids, grants are a key source of survival for those households able to access them. More than 1,3 million people receive a disability grant. Recently, in a crackdown on fraud, the department of social development cancelled 269 000 temporary disability grants. There are no estimates of how many of the recipients were getting the grant because of Aids-related disability.

Stella hasn't had a job since 1997 when the factory that employed her shut down.

"I'd like to work but I hear they ask for a blood test first before you go to work. If they find out you're HIV-positive you don't have a job."

She also worries who will care for her HIV-positive child while she is at work. Since she heard that she may lose the disability grant, Stella has started looking for a job again.

Studies have shown that HIV/Aids drive poor people deeper into poverty with a string of consequences, including a decrease in nutrition as less money is spent on food, the loss of secure accommodation, and children, particularly girls, dropping out of school.

According to a study by the Institute for Democracy in South Africa, about 14 million children live in households with an income of less than R400 a month. The authors of a working paper by the Children's Institute and the Centre for Actuarial Research refer to the Idasa study to point out what they and other researchers have found: that households directly affected by Aids are among the most vulnerable to rapid socio-economic decline.

The state support is meant to slow the decline, but children's rights activists argue that they prejudice those adults caring for their biological children. According to the department of social development, almost 7 million children are accessing the child support grant - R180 per child up to the age of 14. Approximately 300 000 foster child grants, designed for those taking care of up to six orphaned or abandoned children, are being paid out at R450 per child up to age 18.

The system seeks to provide assistance to "Aids orphans" but disregards the fact that only a small percentage of South Africa's children are maternal or double orphans while far more children live in poor households made poorer by Aids.

Grant applicants also need to provide identity documents, birth (and sometimes death) certificates and doctor's assessments, all of which require transport to various departments and hours spent in queues - this partly explains why only about half of those families eligible for child support grants actually get them. The department of social development has recently addressed some of these issues by simplifying the application procedure.

"The ethics of the state providing support to poor relatives to care for children, without providing

adequate and equal support to biological parents living in poverty to care for their own children, is questionable. Such a system - like that of the social security provisions currently encapsulated in the Child Care Act, and the Social Assistance Act, and replicated (if in slightly different terminology) in the proposed Children's Bill - is inequitable," argue the authors of "Children - in need of care or in need of cash?"

The absence of an adequate social care system for families affected by HIV/Aids leads to an infringement of a number of children's basic rights, including their right to education, health, parental care and protection, as well as the overriding principle of "the best interests of the child", as laid out in the African Charter of the Rights and Welfare of the Child.

HIV affects children's rights "in every conceivable way, whether seen or unseen", says Cati Vawda, director of the Children's Rights Centre in Durban.

"For HIV-positive children it's very, very direct. It's not just about what happens to them but also about the context in which they exist. The violation of these rights can be multiple and antagonistic."

This context includes whether the child lives in a rural or urban setting, and whether the mother is able to realise her own rights, such as accessing the documents she needs for state support. "Without documents, as far as the government is concerned, you don't exist, you don't get support," Vawda says.

"Given that 70 to 75 percent of children in South Africa live in poverty, chances are not high that mother and child are getting access to health, to security and to identity - all three are interlinked."

There has also been anecdotal evidence of grant recipients on anti-retroviral therapy (ART) going off or considering temporarily stopping treatment, resuming ART only once a grant has been renewed, with dire consequences for the patient's health.

"Mothers will have to choose between their own health and feeding their kids," says Liesl Gerntholtz, director of the Tshwarnang Legal Advocacy Centre.

Gerntholtz points out one positive side-effect of the Aids epidemic: the adoption of a more child-centred approach in South African policy formulation and legislation.

Internationally, she says, the move away from viewing children as passive beings upon whom the law is acted has gained momentum. In South Africa, HIV has forced this more child-centred approach upon policy-makers.

"South Africa is such a patriarchal society and children are part of that authoritarian culture. The Aids epidemic has raised the profile of children."

Because of the epidemic, the Children's Act lowers the age of consent for medical treatment and contraception to 12. The notion that a 12-year-old can access condoms or ask for ART without their permission has outraged many adults, but as Gerntholtz points out: "I wouldn't want my 12-year-old to consent to an HIV test on her own - but she has not lost a mother or is not living on her own."

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