HIV AND CHILDREN

A family of orphaned children plays outside their home in a shanty compound in Kitwe, Zambia

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PROFILES: COUNCIL RESEARCHER DR. AVINA SARNA AND TRUSTEE JUSTIN ROCKEFELLER
PRESIDENT’S MESSAGE

Globally, over two million children under the age of 15 live with HIV. In sub-Saharan Africa between 1990 and 2007, nearly 12 million children under the age of 18 lost one or both parents to AIDS. It is hard to fathom the gravity of these numbers except when you think that every one of them—parent or child—was a loved and cared-for family member. Most of these families had no access to treatment for these children. Most probably struggled to give them food and care without any other hope to help them to live longer, healthier lives during their short lifetime.

The Population Council’s research and life-saving programs to eliminate HIV infection in newborns and to help HIV-positive children enjoy healthier lives...

This issue of Momentum describes some of the Council’s efforts to stop the deaths of children from AIDS. Council research contributed to ongoing initiatives to increase access to drugs that prevent HIV-positive pregnant women from passing the virus to their child (page 2), to provide HIV-positive children with early treatment (pages 4 and 6), and to develop solid evaluation data on current HIV initiatives to help program managers and health care providers strengthen services for individuals and families living with HIV (page 8). Our research expertise provides governments and communities with information needed to increase the effectiveness of programs that support women, newborns, and children affected by HIV and that help them live longer, healthier lives.

Your support helps make this life-saving work possible. Our programs protect children from the devastating consequences of HIV and AIDS and enable caregivers to offer treatment and hope to young family members who have lost their parents to the disease. Read about one Population Council researcher who gives a personal account of why HIV prevention is so meaningful to her (page 10), and one of our donors (page 11) who talks about why he supports the Council’s worldwide work. Your contribution ensures that the Council continues to address these critically important global health concerns and to make life better for current and future generations.

Sincerely,

Peter J. Donaldson

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HELPING MOTHERS KEEP THEIR BABIES SAFE FROM HIV

Every year, thousands of infants are infected with HIV. It doesn’t have to be this way.

THE POPULATION COUNCIL’S EVALUATION OF m2m PROVIDED SOLID EVIDENCE THAT THE PROGRAM WAS HELPING WOMEN USE SERVICES TO PREVENT TRANSMISSION OF HIV TO THEIR CHILDREN.

PROBLEM Although services to prevent transmission of HIV from mother to child are available in South Africa, they are underutilized. HIV-positive women who face fear of stigma and discrimination, lack of information, limited counseling, and poor support services are often unable to take the necessary steps to keep their babies free from HIV infection. Health care providers are seeking effective strategies to help women overcome these barriers and use the HIV-prevention services that are available to them.

PROGRESS An innovative program, mothers2mothers (m2m), was created in South Africa to support HIV-positive pregnant women. The program trains and employs HIV-positive mothers who have used services to prevent mother-to-child transmission of HIV. These “mentor mothers” organize health talks and conduct regular support groups for their peers. They also reach out to the community to help women follow feeding practices that are best for their baby. They promote safer sex and family planning, and encourage mothers to return for HIV treatment and to bring their baby to the clinic for HIV testing.

SOLUTION Women who participated in m2m were more likely to talk about their HIV status with friends and family members, to receive drugs to reduce the chance that their baby would be infected with HIV, and to follow recommended infant feeding practices. Following the evaluation, the program has expanded to hundreds of other locations in South Africa and beyond to Lesotho, Zambia, Kenya, Rwanda, Malawi, and Swaziland — providing hope and care to HIV-positive mothers across Africa.

PARTNERS Health Systems Trust, mothers2mothers, Elizabeth Glaser Pediatric AIDS Foundation

COURTESY OF m2m

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INCREASING HIV TESTING FOR AT-RISK CHILDREN

In order to test and treat at-risk children for HIV more effectively, we must provide education and support services to elderly caregivers of orphaned children.

PROBLEM South Africa has the world’s largest number of children living with HIV. Many of the most at-risk children live with their grandparents or other relatives. Most caregivers do not know the children’s HIV status, since there are few opportunities for testing children after infancy. A life-saving opportunity is lost because children who are diagnosed with and treated for HIV before their immune systems weaken have a much higher chance of survival. Without treatment, HIV-positive children are frequently sick, and caregivers—the elderly in particular—face an overwhelming burden.

PROGRESS The Council developed The Caregiver Project with a local partner, the Masimanyane Women’s Support Center. The project trains grandmothers (called “grannies”) to serve as peer supporters for elderly caregivers. The grannies provide information about pediatric HIV testing and treatment to elderly caregivers who come to Social Security Agency sites to get grants for social services for children and the elderly. Grannies offer caregivers referral cards that list the locations of pediatric testing services and encourage them to take the children to be tested.

SOLUTION This novel approach of using grannies to promote HIV testing services builds on earlier Council research that demonstrated the critical role elderly caregivers play in caring for children orphaned by HIV. The Caregiver Project is targeting an important gateway to accessing these children, the elderly caregivers, and motivating caregivers to seek care through age-appropriate resources.

PARTNERS South African Social Security Agency, Masimanyane Women’s Support Center

THE CAREGIVER PROJECT IS HELPING HIV-POSITIVE CHILDREN ACCESS LIFE-SAVING MEDICAL TREATMENT AND PROVIDING AN OUTREACH MODEL THAT CAN BE REPLICATED ACROSS AFRICA.
OVERCOMING BARRIERS TO TREATMENT FOR CHILDREN

Only 11 percent of HIV-positive children eligible for treatment in Kenya receive life-saving therapy.

PROBLEM Even in areas where treatment services are available, caregivers of infected children often do not seek care or seek it late in the course of the disease when treatment is less effective.

PROGRESS Through surveys, group discussions, and interviews with families and health workers, Council researchers identified barriers that prevent parents and caregivers from seeking treatment for HIV-infected children. Many caregivers were unaware of treatment for children, or were paralyzed by fear and a loss of hope. They worried about additional costs of the free services, including transportation, medicines, food, and consultation fees. They associated the health clinics and treatments with death, since many children who arrived at the clinic with symptoms of HIV infection did not survive. Family members were also often anxious about how others in the community would react if they found out a child in the family was HIV-positive.

SOLUTION Applying its research findings, the Council and the government of Kenya are supporting community-awareness activities to educate and assist caregivers, inform them of available services, and reduce stigma. The Council is also working with health facilities to improve counseling, support, and outreach services, and to provide Kenya’s government with recommendations for improving pediatric HIV services so HIV-positive children across the country receive life-saving treatment.

PARTNERS Christian Health Association of Kenya, Archdiocese of Nairobi Eastern Deanery AIDS Relief Program, Elizabeth Glaser Pediatric AIDS Foundation, Kenya Network of Women with AIDS

“AFTER COUNSELING AND BEING GIVEN HOPE THAT I AND MY CHILD CAN TAKE DRUGS AND LIVE ON, THE FEAR OF STIGMA HAS SINCE GROWN WINGS AND FLOWN AWAY.”

—Mother of a child living with HIV who participated in Council research activities
**PROBLEM**  Despite high levels of donor spending with the goal of helping vulnerable children, the evidence for building effective policies and programs remains limited. Without solid evaluation data, policymakers and donors are often forced to make uninformed decisions about the implementation and financing of programs. Program managers and health providers lack information about programs that improve the quality of life for children and families.

**PROGRESS**  Council staff members pioneered the development of definitions of vulnerability to help programs identify the neediest children. A Council evaluation of a program in Uganda that helped HIV-infected parents plan for their children’s future became a UNAIDS “best practice” and has been replicated in many settings. Council researchers are evaluating the RAPIDS program in Zambia. This community-led initiative includes a holistic package of care and support services for people living with HIV and for children living in households and communities affected by HIV/AIDS.

**SOLUTION**  The Council’s studies apply innovative research techniques to address complex issues about providing care and services to children affected by HIV. The Council’s evaluation of the RAPIDS intervention has highlighted the effectiveness of program activities and valuable lessons for program managers and providers. A mid-term evaluation in 2007 showed important progress, such as more help with school books, uniform fees, and transportation and improvements in school attendance among vulnerable children. Results from the 2009 data collection promise to provide further guidance to program managers on how to ensure the greatest impact with available resources.

**PARTNERS**  RAPIDS (Africare; CARE Zambia; Catholic Relief Services; Expanded Church Response; RuralNet Associates Ltd, Zambia; The Salvation Army; World Vision; University Teaching Hospital; University of Zambia)

**BUILDING SUPPORT FOR ORPHANS AND VULNERABLE CHILDREN**

We provide solid scientific evidence about programs targeting orphans and vulnerable children to help governments and communities provide better care for these children in need.
Why is it so difficult to get HIV-positive children treatment and services?

Children cannot advocate for themselves, so when the HIV epidemic first hit communities, all the programs and services focused on adults. It took another three or four years before people realized children needed special treatment, including programs that reached out to parents and caregivers who really controlled the care or lack of care the children received. Caregivers come with their own circumstances and feelings. For example, some parents feel guilty about having infected their children. Some caregivers are uninformed about the disease or worry that they and the children they care for will be isolated from the community if people find out the children have HIV. There is a lot of learning still needed in this area to overcome misinformation and get children the care they need.

Is there a particular family situation that you found especially powerful or memorable?

In India, I met a woman who was HIV-positive. She had one child who was HIV-negative but she worried about him and the life he would have once she was gone. She had no one to care for him so she became pregnant again and took precautions to ensure her baby would be HIV-negative. She wanted her son to have a brother or sister so they could look out for one another and take care of each other after she died.

This woman’s story is part of what makes my work so rewarding. We need to understand the decisions people make under these very difficult circumstances in order to design programs and services that will help them and their families live longer, healthier lives.

What motivated you to become a doctor?

I always knew I wanted to be a doctor. There were no doctors in my family; my father was in the Indian military so we moved around a lot to different army bases in India and outside the country. I was born in India but we lived in many other places, including Egypt. Perhaps my mother influenced my interest in medicine. I have always been very focused in my desire to do medicine.

Why did you decide to leave clinical practice for research?

After living and working in many different countries, including Bhutan, Poland, Switzerland, and Iran, I saw systems and programs that worked well in one place and thought these systems and programs could work well in other places too. Being in public health research allows me to help deliver services to more people than I ever could as a physician working one-on-one with patients.
THE POPULATION COUNCIL WORKS WITH HEALTH PROVIDERS, CENTERS, AND COMMUNITIES IN DEVELOPING COUNTRIES TO ESTABLISH SERVICES THAT HELP CHILDREN AND FAMILIES SUFFERING FROM THE DEVASTATING CONSEQUENCES OF HIV AND AIDS.

This issue of Momentum describes some of the Council’s initiatives to increase access to low-cost, life-saving treatments to prevent mother-to-child transmission of HIV, help communities mobilize resources to assist families affected by HIV, train grandmothers to encourage HIV testing for orphans, and build a bank of evaluation data to guide programs and service delivery.

This is critically important work but it is not enough. We need your help. Your support helps us conduct research that identifies ways of getting these medical advances and services to communities that continue to be battered by the HIV epidemic. We firmly believe there will be a day when no child and no family suffers from HIV. You can help bring that day closer. Thank you for your generous support.
The Population Council conducts research worldwide to improve policies, programs, and products in three areas: HIV and AIDS; poverty, gender, and youth; and reproductive health.

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