

## EXPLORING CURRENT PRACTICES IN PAEDIATRIC ANTIRETROVIRAL ROLL-OUT AND INTEGRATION WITH EARLY CHILDHOOD PROGRAMMES IN SOUTH AFRICA: A RAPID SITUATIONAL ANALYSIS

“Exploring Current Practices in Paediatric Antiretroviral Roll-out and Integration with Early Childhood Programmes in South Africa: A Rapid Situational Analysis” is a collaborative research project between the Horizons Program of the Population Council and the Faculty of Health Sciences at the University of Cape Town. The aim of the study is to identify successful programme strategies in paediatric HIV treatment in South Africa and determine priority knowledge gaps to be addressed by operations research. The study objectives are to:

- Identify critical components of paediatric HIV treatment services.
- Determine ways in which children are currently enrolled into antiretroviral therapy (ART) programmes.
- Identify referral links to ART programmes for children.
- Identify factors influencing access to treatment and adherence for children.
- Examine the barriers to treatment/issues of equity that affect children.
- Capture what works regarding ART service delivery to children.
- Determine the capacity of facilities to implement the national and provincial antiretroviral treatment protocols with respect to children.
- In light of the findings, look at the convergence of practice and national policy and legislation with respect to health care for HIV-infected children and propose recommendations to support and enhance national and provincial guidelines.

This report presents the main cross-cutting issues that emerged from the initial consultative workshop with expert practitioners and stakeholders, which was held 21 January 2005 in Johannesburg. The purpose of the meeting was to introduce the study to site managers, familiarize the study investigators with the activities and context of each site, identify key issues in access to paediatric treatment, and obtain input and recommendations regarding the study design and instruments.<sup>1</sup>

In addition to consultative workshops with expert practitioners and stakeholders prior to fieldwork and post-data collection, the situational analysis will utilize a range of qualitative and quantitative methods to collect data, namely, antiretroviral (ARV) facility observations; semi-structured questionnaires administered to facility managers and health care workers; and structured questionnaires administered to caregivers of children on antiretroviral therapy. Eleven study sites in five provinces have been identified through snowball technique sampling.

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The study will provide information about current practices and perceptions relating to the treatment of infants and children with HIV/AIDS with a view to making recommendations regarding expansion of ARV access for children. Should the results of the study indicate the need for testing one or more programmatic interventions, the collaborators will consider planning, conducting, and evaluating an intervention study under separate protocol.

## **Key Findings From Consultation**

### **Initial paediatric ARV roll-out has resulted in a significant number of children on treatment.**

The sites represented from the five South African provinces at the consultation have made significant strides in providing ARV treatment for children during the initial roll-out of paediatric ARV services. Based on reports from Free State, Gauteng, and Eastern Cape public health services; Red Cross Hospital in Cape Town (Western Cape); the MSF program in Khayelitsha and Lusikisiki; and the McCord Hospital in Durban (KwaZulu Natal), more than 2100 children are receiving ARV treatment. Additional children are receiving HIV care other than ARV treatment. The majority of these children are younger than six years of age.

### **Gaps in referral to paediatric ARV treatment result in missing significant numbers of children in need.**

One of the major challenges of the paediatric ARV programme is to set up linkages to promote the appropriate referral of children to HIV care and ARV treatment. Referrals come from the in-patient wards, adult ARV programmes, community health clinics, non-governmental and other community based organizations, and prevention of mother-to-child HIV transmission (PMTCT) programmes. The relevant contributions of each of these sources varied among the sites represented at the meeting, but in general site managers expressed concerns that they were missing significant numbers of children in need, particularly children from poorer families. Several gaps in the referral system were identified. For example, the policy in the Western Cape is for all HIV-exposed infants to have a PCR test for HIV infection at 14 weeks, yet not all HIV-exposed children are tested or their results collected, some because their mothers have left the province after delivery. In general, much more of a “push” is needed to carry out PCR tests where they are available for young infants who are HIV-exposed.

Moreover, there is a problem with linking every HIV-identified child with HIV facilities, because ARV treatment is not generally available at community health clinics and mothers find transportation to the hospitals too difficult or costly. Participants also pointed to a lack of linkages between home-based care, groups working with orphans and vulnerable children, and other community organizations working on HIV care and support, on the one hand, and on the other hand, the public health system, particularly the tertiary system, where most paediatric ARV services are currently located. Efforts are needed to increase the staff capacity at the primary care level to treat children and to facilitate access by their clients.

### **Community and family issues are significant barriers to ARV treatment for children.**

Community and family attitudes and structures affect access and continuity of care for children at many levels. In some settings, a lack of awareness of the benefits of ARVs by people in the hospital and community negatively affects referrals to the paediatric ARV programme. A lack of clarity regarding who has guardianship and authority over children increases the reluctance of health care providers to test children for HIV. In Free State, the Program Manager noticed that the switching of caregivers contributes to children being stuck in the drug readiness programme. Some managers noted that while they have observed little stigma in the clinical setting, if stigma is present in the home or community and parents are reluctant to disclose their status to the family, then the prognosis for adherence and a favourable response to the ARV treatment by parents and children is poor.

## **In order to meet demand, approaches to paediatric HIV care must be expanded to include secondary and primary health facilities.**

Most paediatric care in South Africa is still at the tertiary level. Demands on the hospital for space and staff exceed availability. Moreover, lack of knowledge of the availability of services at tertiary facilities, long distances, high transportation costs, and lengthy waiting times are barriers to utilization of these services for many patients. Meeting participants felt very strongly about the need to expand approaches to paediatric HIV care to include secondary and primary health facilities. An example of this is the Enhancing Children's HIV Outcomes, or ECHO Project, of Baragwaneth Hospital in which children who are stable after five to six months of treatment are referred to primary care sites (currently all accredited treatment sites) for ongoing care.

The experience to date has revealed that expanding into community health clinics will require modified or new systems, particularly booking and health information systems, to track the chronic care needs of paediatric HIV cases. Some managers also noted the need for dedicated services or at least separate queues for children at primary treatment sites to improve access to paediatric care.

## **Hands on, tangible experience and on-site mentorship are needed to build the capacity and confidence of nurses to provide paediatric HIV care.**

Most of the programmes represented at the meeting are paediatrician-led programmes, with the exception of Free State, which has a 'nurse-driven' model. However, it was uniformly recognized that as the demand for paediatric care greatly exceeds the supply of paediatric HIV care in most settings, one of the biggest tasks is the need to reorient the organization of services from being driven by paediatricians, who are in short supply, to being led by nurses, who provide the bulk of care in community health clinic settings. The challenge is to adequately prepare nurses with the knowledge, skills, and confidence to provide paediatric HIV care. Theoretical training is not enough. There was a strong consensus among meeting participants that what is needed are hands-on, tangible experiences and on-site mentorship. For example, in Khayelitsha, they found that the physical setting—a series of cubicles among a common corridor and Medical Officer present to assist if asked—gave nurses confidence to move forward with HIV care for children. Another example of capacity building is contracting out staff from academic institutions, such as in East London (Cecilia Makawane), to the districts. There may also be a need to address the regulatory environment to make sure that the statutes and union regulations support nurses providing HIV care.

## **Currently there are diverse models of vertical paediatric services and integrated family care, depending on the availability of human resources and physical infrastructure.**

The sites have a variety of approaches to addressing the need to provide HIV care to both children and adults within the same family. For example, due to space constraints, the Red Cross Hospital in Cape Town offers separate, parallel services for children and their parents with interaction on group education and support. Similarly, children and adults at Baragwanath Hospital attend separate clinics for paediatric and adult care and also for TB and HIV. Free State has combined ARV care for both adults and children, and children are seen with their parents, but this is mainly an outcome of the way clinical services are organized rather than a model of family care. Cecilia Makawane (East London) only treats child-parent pairs, as they believe that adherence in the child will only be achieved if the mother (and father) are also getting care. The non-governmental McCord Hospital in Durban also has a family-oriented ARV program that gives priority for ARVs to parents identified during antenatal care PMTCT services. The ARK Project focuses on the caregivers of children in ARV programmes.

Services are more likely to be integrated and family care-oriented at the primary level, such as in the example of the ARV sites of the ARK Project in the Western Cape. The goal of HIV care systems should be to achieve a balance between integration at lower levels, to increase access and coverage, and vertical services, because children have special needs and providers require special training.

