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# The development of HIV-related mental health and psychosocial services for children and adolescents in Zambia: The case for learning by doing

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ABSTRACT

The success of antiretroviral therapy (ART) has sparked a global commitment to strengthen health systems for an improved response. The response, however, is largely biomedical. Far less attention and funding exist for mental health and psychosocial support services (PSS). While the evidence-base for these services is less developed, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) has responded to glaring needs through a "learn by doing" approach. This paper documents lessons learned as we responded to expressed needs for child-centered HIV support in Zambia.

We formed a multidisciplinary working group to improve support for children on ART. In collaboration with the Zambian Ministry of Health (MOH) and with support from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), we began, in 2008, by implementing a pediatric HIV counseling course focusing on disclosure, adherence, and stigma. Play therapy and adolescent-support programs followed. In 2013, with funding from the Conrad N. Hilton Foundation, EGPAF established HIV and developmental delay centers.

Through working with the Zambia MOH, we have forged a national response. This involved training pediatric HIV counselors, play therapy counselors, adult mentors and positive peer mentors, as well as clinicians and volunteers in HIV and early childhood development. We have learned that providing health workers with skills to dialog with HIV-affected children and families in honest and developmentally-sensitive ways yields results. Thousands of children have been reached and improved adherence and acceptance of one's status have been reported. Non-medical services have been developed by busy practitioners to meet glaring clinic gaps using a "learn by doing" approach. More resources are required to scale up these programs and for 'good practice' evidence to be gathered.



## 1. Introduction

> "Given the unprecedented scale of both the epidemic and the attempted response, one can only 'learn by doing' and doing is synonymous with knowing, with producing evidence" (Nguyen, 2009, p. 210).

The quote above demonstrates the rationale for our approach. The current state of affairs must be improved, particularly in relation to under-resourced HIV services for children and adolescents. Despite the massive investment in national HIV treatment scale-up, the percentage of children enrolled in care and treatment programs in Zambia has not kept pace with that of adults. Only 28% of the estimated children in need of ART receive treatment, compared with 58% of adults (UNICEF, 2010). Adults continue to outpace children in access to treatment, despite the latest international guidance calling for immediate treatment irrespective of immune status among children (WHO, 2010, 2013). Experienced health workers still struggle with *when* and *how* to talk to children and families living with HIV in an honest and developmentally-sensitive manner, which contributes to low enrolment and retention levels, as well as the need to "learn by doing".

While the transfer of biomedical expertise has been expanded through key partnerships between governments, large international non-governmental organizations and academia, the transfer of mental and psychosocial support has lagged behind (Rwemisisi, Wolff, Coutinho, Grosskurth, & Whitworth, 2008; Tumwesigye & Abate, 2008; van Dijk, Moss, & Sutcliffe, 2011; WHO, 2011). Tumwesigye argues that "a limited number of health care workers have adequate knowledge and skills to comfortably practice pediatric HIV care with respect to pre-test and post-test counseling, disclosure of HIV to children or helping care takers to disclose HIV status to children, provide

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on-going supportive counseling and address care and treatment adherence issues." These gaps, the authors believe, are the missing link to improved pediatric enrollment and retention.

In 2010, acknowledging the fact that children's access and treatment outcomes lagged behind adults', the World Health Organization (WHO) published revised guidelines on ART for HIV-positive children. While this document discussed the absolute importance of adherence to treatment, it noted that "the panel was not able to make strong recommendations for specific interventions [to address adherence] due to lack of evidence" (WHO, 2010 Guidelines, p. 78). The document, while representing a step forward in pediatric treatment, continued to focus on biomedical responses only. This is in sharp contrast to strongly worded guidance published by the American Academy of Pediatrics more than a decade *earlier*, recommending that parents and guardians be supported to disclose HIV status to a child, that repeated counseling would be needed, and that "Adolescents should know their HIV status. They should be fully informed to appreciate consequences for many aspects of their health, including sexual behavior" (AAP, Committee on Pediatrics, p. 165).

Recent qualitative studies are helping to explain the association between HIV status disclosure and adolescent treatment engagement (Midtbø, Shirima, Skovdal, & Daniel, 2012). Despite small sample sizes and a lack of a comparison group, adolescents are reporting that "disclosure contributed significantly to their adherence to ART…" (p. 268). Yet, when EGPAF began, it was found that parents were opting to "protect" and avoid disclosure for fear of their children's reactions. An experienced counselor explained that "parents used to tell children they were taking Panadol and that they had an illness which needs care. Parents expressed concerns about children telling others and then being labeled as sexually promiscuous: "The child may begin to think I played around."

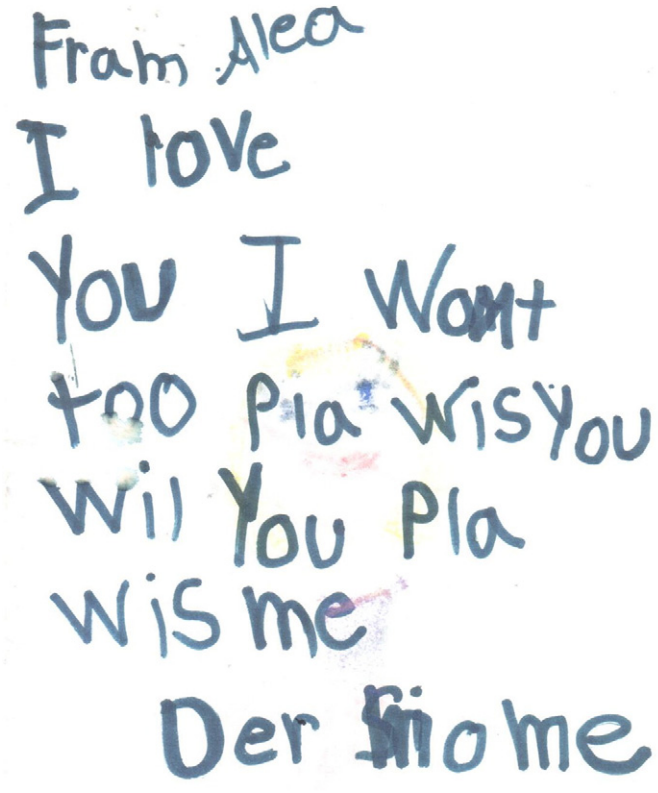


**Fig. 1.** A young child's simple yet profound request to play with her mother.

### *1.2. Responding through a "learn by doing" approach*

This paper documents efforts of the Elizabeth Glaser Pediatric AIDS Foundation in Zambia over the past five years to respond to these palpable concerns and barriers expressed by parents and counselors. We worked to strengthen Zambian mental health services by developing six psychosocial support programs within large-scale HIV care and treatment programs and, in the process, adopted a "learn by doing" approach. These efforts are in line with the idea of small wins, described by organizational theorist Karl Weick (1984). We advocate that these programs are not experiments, but incremental attempts to reduce severe service gaps. Still, scientific evidence rooted in clinical trials, case control studies, or rigorous longitudinal evaluations are needed to ensure that the optimal methods and mix of approaches are used efficiently and effectively.

Our programs were developed from expressed needs, clinical observation, and application of child development theories including Piaget and Inhelder (1969) and Erickson (1950), and best practices in pediatric nursing and medical care from implementation experiences. Our work is rooted in the humanitarian imperative of "First, do no harm."

Informing the development of the programs described below is a deep appreciation of the importance of play in children's psychosocial and cognitive development (See Fig. 1), the resource rich environment of an ordinary, devoted caregiver, and the construct of hope, as measured by agency in influencing children's wellbeing (Senefeld, Strasser, Campbell, & Perrin, 2011; Snyder, Pelham, Ware, Highberger, Rubinstein and Stahl, 1997).

In early 2008, EGPAF presented the *Psychosocial Care and Counseling Training Curriculum for HIV-infected Children and Adolescents* (2008) to the Zambian MOH for review. This curriculum was reviewed by the MOH Mental Health Unit and pediatric clinical care division and was officially endorsed on August 22, 2008 by the Acting Permanent Secretary (V. Mtonga, personal communication, August 22, 2008).

Also, in 2008, after four years of PEPFAR-supported ART scale-up and in recognition of the disparity between adult and pediatric enrollment, EGPAF applied for and received additional funding to improve the number of children enrolled in care and treatment programs. In the application, EGPAF proposed to expand community outreach activities to increase identification of children needing ARV treatment; to reduce loss to follow-up; and to strengthen psychosocial support by pediatric peer educators through competency-based training, refurbishing and equipping child-friendly counseling rooms with basic supplies and supportive supervision.

## 2. Program observations and development

With little evidence and few "promising practice" resources available, EGPAF formed a working group around a series of training programs and mental health/psychosocial support services for children on treatment. Applying this "learn by doing" approach along with continued support from and partnership with the Mental Health Unit of the MOH, we have been able to expand and develop our mental health services for HIV-infected and -affected families in Zambia.

Table 1 is a brief history of EGPAF Zambia's mental health and psychosocial interventions. It presents a description of each intervention employed, including timing, rationale, and training details. This table is followed by a description of each intervention.

The various programs highlighted above were developed sequentially; allowing activities to apply insights/lessons learned from previous projects. Some programs are suitable for all ages and some are targeted to either younger or older audiences. The target audience for each program and methodology are also provided in the table below.

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