



ELIZABETH GLASER
PEDIATRIC AIDS
FOUNDATION

Conrad N. Hilton
FOUNDATION

ZAMBIA Annual Report

Survive and Thrive Project



PY1 (APRIL 2012 - MARCH 2013)

"We all need to hope that our dreams can come true. I challenge you to make it happen because all our lives ... depend on it."

—Elizabeth Glaser (1947- 1994)

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
CBO	community-based organization
CDC	Centers for Disease Control and Prevention
CIDRZ	Centre for Infectious Disease Research in Zambia
EBF	exclusive breastfeeding
ECD	early childhood development
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
HEART	Help Expand Antiretroviral Therapy (Project HEART)
HIV	Human Immunodeficiency Virus
MCDMCH	Ministry of Community Development, Maternal Child Health
MOH	Ministry of Health
MP	member of Parliament
NGO	nongovernmental organization
PCR	Polymerase Chain Reaction
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PM&E	Participatory Monitoring and Evaluation
PMTCT	prevention of mother-to-child transmission
S&T	Survive and Thrive
SLT	speech and language therapy
TM&E	traditional monitoring and evaluation
UNICEF	United Nations International Children's Emergency Fund
UTH	University Teaching Hospital
ZANEC	Zambia National Education Coalition
ZNBC	Zambia National Broadcasting Corporation
ZNS	Zambia National Service

Foreword

Survive and Thrive began with a passion for children affected by HIV and AIDS and has grown into a dynamic, community-centered initiative to improve care and support for children with moderate-to-severe developmental challenges. Without the energy and enthusiasm of community volunteers, this work would not be possible. Working alongside various government ministries, nongovernmental organizations and community-based organizations, the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) has started to build a strong and sustainable foundation for the Survive and Thrive project. Flexibility has been essential during this critical start-up phase.

In the first half of 2012, EGPAF-Zambia navigated the reorganization of government ministries and the creation of new districts following the September 2011 Zambian presidential elections and change of government. The directives of many government ministries include policies and programs relevant to early childhood development (ECD), requiring wide consultation. To facilitate and support coordination across these ministries, EGPAF, in collaboration with the United Nations International Children Emergency Fund (UNICEF), participated in regional workshops, periodic ECD partners meetings and site visits to share knowledge, resources, experiences, and local data.

EGPAF also established a platform for influencing policy on ECD. Collaborating with Conrad N. Hilton Foundation partners and the Zambia National Education Coalition (ZANEC), EGPAF advocated for expanding and improving early childhood care, development, and education—especially for the most vulnerable and disadvantaged children. EGPAF also clarified the roles of the various ministries involved in ECD. Currently, six ministries are involved: the Ministry of Education, Science, Vocational Training, and Early Education; the Ministry of Local Government and Housing; the Ministry of Community Development and Mother and Child Health; the Ministry of Gender and Child Development; the Ministry of Health; and the Ministry of Youth and Sport.

In the second half of the year—in addition to sharing high-level coordination and information—our staff trained clinicians who run primary care clinics in the communities served by this project as well as lay volunteers and community leaders. Our staff has extensively mapped the community, raised awareness about the project, and became active members of technical working groups—even speaking over local radio to spread the word about early childhood initiatives.

I am honored to be part of a strong organization that balances evidence-based practice with community-centered approaches. EGPAF encourages both programmatic excellence and strong public policy and advocacy—and does so with the same tireless warrior spirit that Elizabeth Glaser herself exhibited. I am also proud of starting Survive and Thrive, which is the first project in Zambia to closely connect primary health care services and HIV care and support with ECD services.

I cannot thank our stakeholders enough.

SUSAN STRASSER

Zambia Country Director, Elizabeth Glaser Pediatric AIDS Foundation



ORGANIZATIONAL BACKGROUND

EGPAF is an internationally recognized leader in the fight against pediatric AIDS. Since its inception in 1988 as a U.S.-based 501(c)(3) nonprofit, EGPAF has been at the forefront of work to eliminate pediatric HIV infection through research, advocacy, capacity building, and delivery of comprehensive HIV services to women, children, and their families. Working in 16 countries worldwide, the organization takes a family-centered approach to integrated and comprehensive prevention, care, and treatment services for those living with HIV and AIDS. EGPAF is guided by the following mission and vision:

MISSION

The Elizabeth Glaser Pediatric AIDS Foundation seeks to prevent pediatric HIV infection and to eradicate pediatric AIDS through research, advocacy, and prevention and treatment programs.

VISION

By honoring Elizabeth Glaser's love for and commitment to her children and all children and families affected by HIV and AIDS—and by working with passion and dedication to provide global leadership on pediatric HIV and AIDS—the Elizabeth Glaser Pediatric AIDS Foundation will create a culture of hope, accelerate scientific discovery, and imagine a world in which children and families live free from HIV and AIDS.

EGPAF-ZAMBIA

EGPAF's work in Zambia began in 2001 with the establishment of 17 small, privately funded health clinics. Since then, EGPAF's programs in Zambia have rapidly expanded to national scale, supported primarily by the U.S. government in partnership with the Zambian Ministry of Health (MOH), nongovernmental organizations (NGOs), and community-based organizations (CBOs). From 2004 through 2012, EGPAF-Zambia has supported HIV care and treatment activities in the Lusaka, Southern, Eastern, and Western provinces.

EGPAF-Zambia has also supported the prevention of mother-to-child transmission (PMTCT) of HIV in the Lusaka, Eastern, and Western provinces, through Project HEART (Helping Expand Antiretroviral Therapy). By the end of Project HEART in 2011, EGPAF supported 45 percent of national PMTCT coverage and 58 percent of national infant antiretroviral prophylaxis coverage. Through a sub-award from EGPAF, the Centre for Infectious Disease Research in Zambia (CIDRZ) provided site-level HIV and AIDS services, which EGPAF has supported with technical assistance. This raised the number of children enrolled in antiretroviral treatment and pediatric counseling. EGPAF also focused on strengthening the organizational and technical capacity of CIDRZ as an independent, local nongovernmental organization.

EGPAF's current programmatic efforts in Zambia are diverse, but all of them advance its mission of eliminating pediatric HIV and AIDS. The primary focus of the five-year LiveFree project—funded through the Centers for Disease Control and Prevention (CDC)—is the expansion and management of the SmartCare electronic health record system and the strategic and systematic use of SmartCare data for the improvement of Zambia's HIV and AIDS programs. Through this project, EGPAF is supporting the expansion of SmartCare, along with building capacity for using data at the district, provincial, and national levels. EGPAF-Zambia also targeted four selected districts for intensive SmartCare scale-up and mapping of services under the Saving Mothers, Giving Life! initiative.

In addition, EGPAF has done considerable work to enhance the wellbeing of HIV-infected and HIV-affected children by improving the quality of counseling and pediatric psychosocial support provided in government-supported public clinics, NGOs, and CBOs. EGPAF has established a forum for facilitators of support groups for children living with HIV in order to develop and share best practices within MOH clinics, NGOs, CBOs, and faith-based organizations. One focus of this forum has been to tailor support group content to children according to age and developmental level.

EGPAF has funded and facilitated several national conferences to develop knowledge, share best practices, and inform policy among pediatric health professionals from all parts of Zambia. Conference topics have included pediatric palliative care, child counseling (with child development as a key component), play therapy, and quality improvement/quality assurance. EGPAF has also supported meetings of the Zambia Pediatric Clinicians Society, an important venue for sharing and highlighting national and international best practices in pediatric care and promoting shifts in policy.

As a sub-awardee to the Macha Research Trust, a Zambian NGO, EGPAF has been providing technical assistance, training and mentorship in PMTCT, and infant and young child feeding—integrated with HIV care and pediatric psychosocial support. EGPAF-Zambia is also implementing a UNICEF-funded project focusing on PMTCT interventions in select districts and a variety of smaller research projects. Additionally, EGPAF has supported national efforts to strengthen PMTCT service coverage, uptake, and quality—as well as the rollout and adherence to the revised national PMTCT guidelines. It has also continued to work closely with MOH staff on PMTCT and pediatric issues and has actively participated in several national technical working groups.

EGPAF has consistently received positive feedback on the activities of the Survive and Thrive project.

SURVIVE AND THRIVE

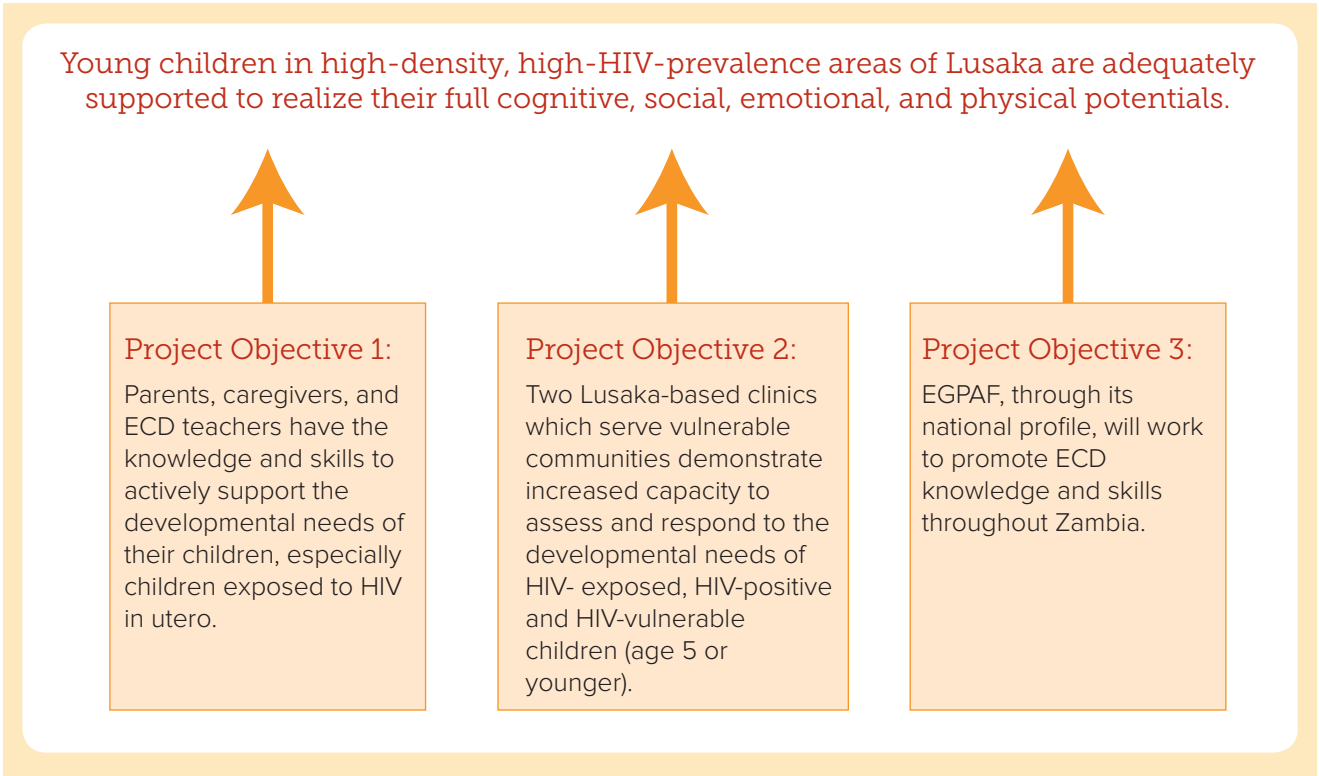
PROJECT OVERVIEW

Ninety-five thousand children in Zambia are living with HIV. Because of Zambia’s high HIV prevalence, countless children are affected by HIV or are vulnerable to HIV infection. As is the case globally, Zambian children affected by HIV are less likely to have access to basic resources such as education, healthcare, and proper nutrition. They are more likely to suffer illness, trauma, and abuse. And they are also more likely to become infected with HIV. Poverty, poor nutrition, lack of access to preschool education, and late or nonenrollment in school lead to a significant proportion of Zambian children experiencing slowed development. Many caregivers also have minimal knowledge of the techniques for or importance of promoting early childhood development.

Despite the global call for the development of comprehensive early learning centers and quality parenting programs for disadvantaged children, specifically those affected by HIV, few services exist for them. Although it is unknown how many Zambian children suffer from underdevelopment, data on malnutrition, HIV, education, and orphaned and vulnerable children show a great need for ECD services. While Zambia has a national strategy for supporting children affected by HIV and AIDS, few structured programs exist to meet the needs of children during the most critical period of development—age 5 and younger—in terms of language, cognitive, and socioemotional skills. Despite the many effects of the HIV epidemic in Zambia, family and community networks remain the most important setting for ECD.

PROJECT OBJECTIVES AND OUTCOMES

In line with the Conrad N. Hilton Foundation’s ECD strategy, Survive and Thrive aims to support children age 5 and younger in high-density, high-HIV-prevalence areas of Lusaka so that they can realize their full cognitive, social, emotional, and physical potentials. The project works to improve the knowledge and skills of parents and caregivers, as well as to facilitate high-quality, integrated, community-based services to ensure that children age 5 and younger have improved support for reaching key developmental milestones. Parents, as primary caregivers, are at the center of this initiative, which focuses on the Linda/Mount Makulu and Mandevu areas in Lusaka.



ACTIVITIES

OBJECTIVE ONE:

Parents, caregivers, and early childhood development teachers have the knowledge and skills to actively support the developmental needs of their children, especially children exposed to HIV in utero.

MAP THE COMMUNITY AND RECRUIT VOLUNTEERS

Activities began with mapping two communities chosen for Survive and Thrive. Consulting with community leaders, staff identified and recruited 42 community volunteers (20 in Linda/Mount Makulu and 22 in Mandevu). The mapping exercise also resulted in a directory of existing resources and social services around the two sites.

The mapping exercise included the identification of key support outside the community through relevant government ministries, including the Ministry of Health; the Ministry of Community Development, Mother and Child Health; the Ministry of Education, Science, Vocational Training, Early Education; and the Pediatric Center of Excellence (PCOE), which is located in central Lusaka and is the country's main referral center for specialist pediatric care. PCOE has an early childhood development (ECD) support program—with pediatricians, an occupational therapist, a behavior specialist, and a pediatric neurologist on staff.

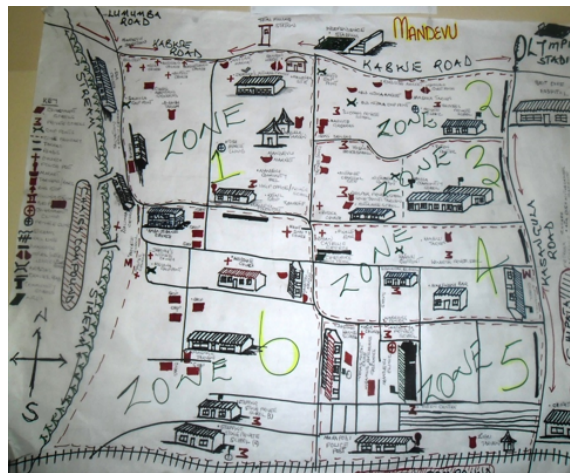


Fig. 1: The Mandevu, Lusaka, community map

TRAIN VOLUNTEERS

Volunteers were selected based on a number of criteria, including previous work with children and families as community volunteers, understanding of the local area, basic knowledge of HIV and AIDS, language skills, and trustworthiness. Parents of children under age 5 and HIV-positive caregivers, both male and female, were encouraged to apply as volunteers.

Volunteer training was conducted during two retreats and was aimed at enabling volunteers to understand the mission and goals of EGPAF, the objectives of Survive and Thrive, and the roles and responsibilities of volunteers in achieving success.

Part two of the training was conducted in Mandevu, Jan. 14-18, 2013. Part Two was conducted in Linda, Feb. 11-15, 2013. Sixty-three participants from Mandevu and Linda/Mount Makulu areas attended each session.

Trainers explained that Survive and Thrive was an innovative community-based service to assess and respond to the developmental needs of HIV-infected and HIV-affected children age 5 and younger, particularly those experiencing developmental delays.



Fig. 2: Community volunteers from Mandevu, Lusaka

Trainers and volunteers discussed the responsibilities of the various stakeholders in the Survive and Thrive project and the integral role of the volunteers. Project volunteers ensure continuity and sustainability of the project and serve as an important link between the community and Survive and Thrive. Some of the volunteer activities that were discussed during the trainings included

- identifying and referring children with developmental delays and other difficulties to relevant organizations and appropriate referral centers for further management and specialized help;
- following up and conducting home visits;
- informing community members and circulating information on child development, HIV care and treatment, and the Survive and Thrive project;
- assessing household care plans;
- training parents and caregivers;
- presenting nutritional talks to parents and caregivers;
- participating in income-generating activities;
- writing reports;
- participating in therapy sessions; and
- visiting clinics for children age 5 and younger.

Participants were trained to raise awareness and knowledge of Survive and Thrive and its services among community members and other stakeholders—generating public participation and support. Volunteers were encouraged to engage with trusted authorities and community members such as teachers, members of parliament, and local politicians—all of whom play an important role in educating families. The training included a practical session for volunteers to sensitize community members on the Survive and Thrive project.

The concept of child development was introduced, with discussion of the characteristics of physical, gross-motor, fine-motor, cognitive, and socioemotional development. This training helped participants better understand developmental delays and to identify children with developmental problems for referral to the Survive and Thrive units and other specialized intervention resources. Materials indicating the various developmental milestones by age were distributed to participants to use in identifying developmental delays. Trainers informed the volunteers that developmental delays are significant lags in one or more areas of emotional, mental, or physical growth.

Trainers and participants discussed some of the problems associated with developmental delays, including difficulties with language and speech, vision, motor skills, social and emotional skills, and cognitive skills. Participants were informed that a delay could occur in many or all of these areas. The causes of delays are numerous and include genetic and environmental causes. Early treatment is the best way to help the child make progress or catch up, which is why the Survive and Thrive project targets children age 5 and younger.

Participants learned about HIV and AIDS, especially in children. Various means of transmission were discussed including being born to an infected mother, blood transfusions unprotected sex, and sharing needles or syringes. Trainers also informed participants that HIV cannot reproduce outside the human body, and trainers punctured some of the myths surrounding the spread of HIV. They confirmed that HIV cannot be spread through the air or water, by insects, through saliva or tears, or through casual contact such as shaking hands or kissing. They emphasized to participants that because HIV has no cure, prevention is cardinal. The trainers emphasized the importance of voluntary counseling and testing to know one's HIV status. They also explained proper condom use and methods to prevent mother-to-child transmission of HIV.

The training also included a session on pediatric HIV, which is usually acquired through mother-to-child transmission. Volunteers learned that in many cases children are not suspected to be HIV-positive until they develop symptoms. These symptoms vary according to the age of the child and from one child to another—but they could include failure to thrive, failure to reach developmental milestones, frequent childhood illnesses, and opportunistic infections. The trainers explained that HIV-infected children are more likely to experience cognitive, motor, and language delays—thus, the imperative to diagnose infants early and enroll them in HIV care programs with antiretroviral prophylaxis, growth monitoring, and routine child health services.

Trainers also discussed the importance of maintaining measures to ensure child protection. They educated participants in indicators of physical, sexual, and emotional abuse.

ORIENT SUB-GRANTEES

The orientation workshop for sub-grantees took place in Lusaka, March 18-19, 2012, to help participants understand EGPAFs work and their roles and responsibilities with the Survive and Thrive project. The workshop also aimed to acquaint sub-grantees and volunteers with the accounting and reporting guidelines of EGPAF and explain how to monitor and evaluate the program. Trainers employed lectures, group work, cases studies, demonstrations, and role play to promote participation, interaction, and sharing. Because of the high number of children with developmental delays and other disabilities, a concerted effort from various stakeholders is necessary. EGPAF has decided to collaborate with community-based organizations (CBOs) to increase the effectiveness of its effort.

Facilitators provided participants with an overview of the Survive and Thrive project's main objectives and activities. They explained developmental theories and the important developmental role of parents, teachers, and caregivers. Facilitators defined the roles and responsibilities of the sub-grantees as follows:

- planning, coordinating, implementing, and managing ECD activities;
- sensitizing community members on the importance ECD;
- identifying volunteers to promote ECD in their communities;
- coordinating training sessions and other community meetings;
- providing support staff (including play workers and counselors) for the Survive and Thrive units;
- identifying and referring children with difficulties to relevant organizations for further management and specialized help;
- keeping up-to-date records of children examined and referred;
- following up on referred children to see if appropriate action has been taken; and
- preparing and submitting reports to EGPAF and other relevant stakeholders.

Facilitators defined the roles and responsibilities of government ministries as follows:

- providing policy guidance,
- coordinating ECD activities,
- providing technical assistance, and
- fostering an environment that supports development partners and complements government efforts.

SPEECH AND LANGUAGE THERAPY

The Survive and Thrive volunteer speech and language therapist introduced speech and language therapy (SLT) to the sub-grantees, explaining that language deterioration and neurodevelopment delay are common among infants and young children infected with HIV. This prioritizes periodic assessment of language development in infants and young children living with HIV. Observing progress in language skills, or lack thereof, is one means of monitoring disease progression and the efficacy of drug treatment.

SLT provides the following to the Survive and Thrive project:

- education and training on SLT assessment and the therapy needs of children age 5 and younger;
- individual assessments of children referred to Survive and Thrive units;
- advice and support to parents and caregivers;
- individual therapy;
- group sessions and activities; and
- support to volunteers, caregivers, and CBOs in identifying SLT needs of children.

FINANCIAL TRAINING

The workshop also included financial training to help participants and sub-grantees understand and differentiate between allowable and nonallowable costs. Facilitators emphasized the importance of ensuring that all costs incurred by sub-grantees are allowable. A cost is allowable if it is

- allowable under the donor's policies,
- allocable to donor projects,
- reasonable,
- properly documented,
- consistently treated (among various donors),
- incurred in accordance with the terms and conditions that were agreed to in the donor's award document, and
- incurred in accordance with the budget approved by the donor.

MONITORING AND EVALUATION

Facilitators then explained the concept of monitoring and evaluation as well as the differences between traditional and modern monitoring and evaluation. They discussed monitoring and evaluation indicators and deliverables of Survive and Thrive—as well as the roles and responsibilities of CBOs, volunteers, and government in collecting and recording information about the Survive and Thrive project.

NUTRITION AND COOKING

Facilitators explained the Integrated Management in Childhood Illnesses (IMCI) program. Similar to one of the requirements of Survive and Thrive, the IMCI program promotes the use of affordable, locally available, healthy foods for use in cooking demonstrations. This activity benefits CBOs undertaking the nutritional and cooking aspect of the Survive and Thrive project.



Fig. 3: Group work during sub-grantee orientation

OBJECTIVE TWO:

Two Lusaka-based clinics that serve vulnerable communities increase their capacity to assess and respond to the developmental needs of HIV-exposed, HIV-positive, and HIV-vulnerable children (age 5 or younger).

TRAIN CLINICIANS

Clinician training was conducted in Lusaka, March 4-8, 2013, with the aim of providing skills in development assessments, health development promotion of children age 5 and younger, and intervention techniques for health care workers chosen for collaboration on the Survive and Thrive project. Participants included nurses, clinical officers, laboratory technicians, psychosocial counselors, community health workers, and environmental health technicians. These were drawn from the Zambian National Service, the Neri Clinic, Save Our Souls Children's Village, Chilanga Hospice, the Chilanga District Community Medical Office, Lusaka District Health Office, and other clinics and health centers in Mandevu, Chaisa, Chazanga, Chipata, Mount Makulu, Makeni, Bwafwano, and Chilanga.

Through lectures, group work, cases studies, demonstrations, and role play, trainers promoted interaction and sharing among participants.

The workshop gave an overview of EGPAF’s activities and its partnership with the Conrad N. Hilton Foundation in implementing Survive and Thrive. The facilitators emphasized the importance of the project in assisting children with developmental delays and other disabilities in the Linda and Mandevu areas of Lusaka.



TRAINING SESSIONS

SESSION I – CHILD DEVELOPMENT AND EARLY LEARNING: What Every Family and Community Should Know

In this session, the differences between surviving and thriving were defined. To thrive, a child requires adequate food, clothing, and shelter; health care; love and attention; and play.

A child’s growth and development required active, nutritious feeding; drug adherence; play and stimulation; anticipatory guidance and safety; rule setting; and emotional support. Trainers explained the importance of nutrition for young children, pointing out that children need well-balanced diets appropriate for their ages. A balanced diet includes energy-giving foods, body-building foods, fatty foods, and protective foods. The importance and benefits of fatty foods for young children was emphasized, as these increase energy and growth and strengthen the immune system. Nutrition is directly linked to all aspects of a child’s growth and development. Trainers introduced the following nutritional plan:

AGE	MEALS PER DAY
0 – 6 months	Exclusive Breastfeeding (EBF) (plus adequate medicine if HIV-positive; no other food or water)
6 – 12 months	Three meals a day with regular breastfeeding
12- 24 months	Three meals plus two snacks and continued breastfeeding
2 – 5 years	Three meals and two snacks

“There is more to development than simple maturation and neurological factors. Stimulation, environmental factors, nutrition, opportunity, encouragement, and feedback/reinforcements all play a role in development.”

Ref: Sherr (2005). *Early Childhood Development – Young Children and HIV/AIDS sub-series. 33 Young Children and HIV/ AIDS; Mapping the Field. The Hague: Bernard Van Leer.*

SESSION II – PLAY WELL

This session was aimed at introducing the importance of play in child development. Children develop gross motor skills by running, hopping, throwing, moving to music, and balancing. They develop fine motor skills by drawing, cutting, pouring sand, and picking up objects. Children develop their cognitive skills by matching and sorting toys and other objects according to color and shape and by listening and following instructions. Through interaction with others, listening to stories, and acting out situations, children develop social skills. Trainers recognized play as a way to develop language in children as they listen to and sing songs.

Babies are natural copycats, mimicking facial expressions and behavior. Participants were urged to promote the use of natural abilities (for example, singing and dancing) by parents and caregivers in communicating and teaching their babies. Some of the games recommended include hide and seek, up and down, open and close, in and out, and big and little. Play is an important part of child development because through play children learn the three Cs: communicate, coordinate, and collaborate.

The session on play included the video “Learning Through Play” and a practicum for making developmental toys. Participants were taught to make toys for use in assessing child development and enhancing gross, fine motor, cognitive, and social skills. Participants made toys from locally available materials: boxes, strings, waste paper, bottles, jar lids, grains, stones, and seeds. This emphasized that families need not spend large sums to promote and stimulate child development through play.



Fig. 4: Toys made during the Play Well workshop

SESSION III - PRINCIPLES OF CHILD DEVELOPMENT: What Every Clinician Should Know

This session focused on development theories and the importance of parents, teachers, and caregivers. Development occurs in sequence, with children learning one skill or develop in one area before moving to the next. For instance, a baby learns to sit before she crawls; she crawls before she walks. Children go through stages of development with many changes, followed by periods of few noticeable changes. Understanding these stages is instrumental in determining and assessing a child’s development and determining whether or not a child has developmental challenges. Facilitators explained a number of development theories, including Piaget’s four stage model¹:

1. **Sensorimotor stage (birth to age 2)** The infant builds an understanding of himself or herself and reality (and how things work) through interactions with the environment. He or she is able to differentiate between him or herself and other objects. Learning takes place via assimilation (organizing information and absorbing it into existing schema) and accommodation (modifying schema to include an object when it cannot be assimilated)
2. **Preoperational stage (ages 2 to 4)** The child is not yet able to conceptualize abstractly and needs concrete physical situations. Objects are classified in simple ways, especially by important features.
3. **Concrete operations (ages 7 to 11)** As physical experience accumulates, accommodation increases. The child begins to think abstractly and conceptualize—creating logical structures that explain his or her physical experiences.
4. **Formal operations (ages 11 to 15)** Cognition reaches its final form. By this stage, the child no longer requires concrete objects to make rational judgments. He or she is capable of deductive and hypothetical reasoning. His or her ability for abstract thinking is similar to that of an adult.

Trainers also discussed other early childhood development parameters such as weight, height, and head size. These need to be measured at birth and periodically checked for physical abnormalities and developmental delays. Participants learned about developmental milestones, which are important in determining a baby’s growth and detecting abnormalities or delays in development. These were outlined according to the following charts, copies of which were provided to participants:

¹ <http://www.learning-theories.com/piagets-stage-theory-of-cognitive-development.html>

Developmental Milestones at a Glance²

AGE	GROSS MOTOR	FINE MOTOR	COGNITIVE LINGUISTIC AND COMMUNICATION	SOCIAL - EMOTIONAL
2 months	Lifts head 45 degrees <i>Lifts head</i>	Follows past midline <i>Follows to midline</i>	Laughs <i>Vocalizes</i>	Smiles spontaneously <i>Smiles responsively</i>
4 Months	Rolls over <i>Sits with head steady</i>	Follows to 180 degrees <i>Grasps rattle</i>	Turns to rattling sound <i>Laughs</i>	Regards own hand
6 months	Sits without support <i>Rolls over</i>	Looks for dropped yarn <i>Reaches</i>	Turns to voice <i>Turns to rattling sound</i>	Feeds self <i>Works for toy (out of reach)</i>
9 months	Pulls up to stand <i>Stands holding on</i>	Takes two cubes <i>Passes a cube (transfer)</i>	Says dada/mama (nonspecific) <i>Vocalizes single syllables</i>	Waves bye-bye <i>Feeds self</i>
1 year	Stands alone <i>Pulls up to stand</i>	Puts a block in a cup <i>Bangs two cubes held in hands</i>	Says one word <i>Imitates vocalizations and sounds Babbles*</i>	Waves bye-bye Imitates activities <i>Points protodeclaratively* Plays pat-a-cake</i>
15 months	Walks backwards <i>Stoops and recovers Walks well</i>	Scribbles <i>Puts blocks in a cup</i>	Says three words <i>Says one word*</i>	Drinks from cup <i>Waves bye-bye</i>
18 months	Walks up steps Runs <i>Walks backwards</i>	Dumps raisins, Makes a tower of cubes <i>Scribbles</i>	Points to at least one body part Says six words <i>Says three words</i>	Removes garment <i>Helps in the house</i>
2 years	Throws ball overhead Jumps up <i>Kicks ball forward Walks up steps</i>	Makes tower of six cubes <i>Makes tower of four cubes</i>	Names one picture Combines words <i>Points to two pictures</i>	Puts on clothing <i>Removes clothing</i>
2 ½ years	Throws ball overhead <i>Jumps up</i>	Imitates vertical line Makes tower of eight cubes <i>Makes tower of six cubes</i>	Knows two actions Speech is half understandable <i>Points to six body parts Names one picture</i>	Washes and dries hands <i>Puts on clothing</i>
3 years	Balances on each foot for one second Does broad jump <i>Throws ball overhead</i>	Wiggles thumb Imitates vertical line Makes tower of eight cubes <i>Makes tower of six cubes</i>	Speech is all understandable Names one color Knows adjectives <i>Names four pictures</i>	Names friend <i>Brushes teeth with help</i>
4 years	Hops <i>Balances on each foot for 2 seconds</i>	Draws a person with 3 parts <i>Makes a tower of eight cubes</i>	Defines five words Names four colors <i>Speech is all understandable</i>	Copies a cross <i>Copies a circle</i>

KEY
Black: 50 percent to 90 percent of children pass this item. **Red:** More than 90 percent of children pass this item.
 Absence of this milestone should trigger screening for autism.

²Source: See the Child Development theme in Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition.

Understanding these development parameters and milestones is essential for determining a child's physical (gross and fine motor), social/emotional, and cognitive development, because failure to reach the age-appropriate milestones or sustained developmental regression are warning signs of developmental delays or other underlying problems. Trainers identified investigation as an important task for health workers, parents, and caregivers because identifying developmental issues as early as possible is vital for early intervention and successful treatment.

SESSION IV – HIV IN CHILDREN

Trainers educated participants regarding HIV in children, explaining that most HIV-infected children acquire the virus from their mothers before or during birth or through breastfeeding. Risk of transmission increases if the mother has an advanced stage of HIV. In countries where safe alternatives to breastfeeding are readily available and affordable, breastfeeding is discouraged. In developing countries where these alternatives are not available, breastfeeding is encouraged—as its benefits in terms of decreased illness and death due to other infectious diseases greatly outweigh the potential risk of HIV transmission. Participants learned that studies have shown that the risk of transmitting HIV from an HIV-positive mother to her newborn infant is less than 1.5 percent in women on antiretroviral treatment, hence the requirement for expectant mothers to undergo voluntary counseling and testing. This is conducted during antenatal clinics, where expectant mothers are screened for HIV. Those found to be HIV-positive are put on antiretroviral treatment to reduce the chances of passing the virus to their babies.

Participants were informed that HIV infection was often difficult to diagnose in very young children because infected babies, especially in the first few months of life, often show no symptoms. Additionally, children born to infected mothers have HIV antibodies from their mothers' immune system that have crossed the placenta before birth and may persist for up to 18 months. This makes it difficult to detect HIV infection in newborns and infants through the antibody method. New techniques, such as the polymerase chain reaction, more accurately detects HIV infection in children 6 months of age and younger. Another accurate procedure involves testing cultured samples of an infant's blood for the presence of HIV. These techniques have made it possible for more HIV-infected infants to be identified before they are 2 months of age—95 percent can be tested by 3 months of age.

During the training, participants learned that the progression of HIV is faster in children than in adults. Researchers have observed that about 20 percent of HIV-positive children develop serious disease in the first year of life, and most of those children die by age 4. Many children infected with HIV do not gain weight or grow normally and are generally slower at reaching important milestones in motor skills and mental development—crawling, walking, and talking. As the disease progresses, many of them develop neurologic problems such as difficulty walking, poor school performance, seizures, and other symptoms of HIV encephalopathy, a degenerative brain disorder.

Participants also learned that children with HIV, just as adults with HIV, develop life-threatening opportunistic infections. Children with HIV suffer common childhood infections more frequently and more severely than uninfected children. Such infections can cause seizures, fever, pneumonia, recurrent colds, diarrhea, dehydration, and other health problems that often result in extended hospital stays and poor nutrition. These problems often lead to developmental delays and slower school progression—meaning that families affected by HIV require a multidisciplinary approach, integrating medical, social, mental health, and educational services.

SESSION V – HIV AND CHILD DEVELOPMENT

Trainers discussed the relationship between HIV and child development, pointing out that significant cognitive and motor deficits are more common among HIV-infected children. These deficits begin early in infancy. Significant delays are even seen in children with stable clinical conditions or from well-resourced populations, irrespective of other biological or environmental risk factors. Forty to sixty percent of HIV-infected children have some level of developmental impairment. According to the Pediatric HIV Care Toolkit released by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), the cognitive and motor deficits in HIV-infected children are attributable to the mismatch between control of HIV disease outside and inside the central nervous system.

Some of the problems associated with HIV in the central nervous system include delayed milestones; brisk reflexes in lower limbs; and microcephaly, a form of developmental disorder characterized by small head size, developmental delay, and intellectual disabilities.

Trainers also discussed encephalopathy, a degenerative brain disease caused by HIV Type 1. It manifests through a variety of cognitive, motor, and behavioral abnormalities.

Another problem associated with developmental delay is cerebral palsy. This group of disorders can affect brain and nervous system functions, like motor skills, learning, hearing, seeing, and thinking.

The presence of such complications in HIV-infected and HIV-affected children reinforce the need for a multidisciplinary approach, integrating medical, social, mental health, and educational services to addressing developmental delay.

SESSION VI – CHILD PROTECTION

Child protection is defined by UNICEF as preventing and responding to violence, exploitation, and abuse against children—including commercial sexual exploitation, trafficking, child labor, and harmful traditional practices such as female genital mutilation and child marriage. Trainers educated participants in signs and symptoms of physical, sexual, and emotional abuse, as well as how to handle a child who expresses concern about abuse, and referral issues.

SESSION VII – PRACTICAL FIELD WORK

During this part of the training, participants divided into smaller groups and visited the community to observe children with developmental delays—as well as the stigma and challenges associated with such children. Participants were provided with tips on how to approach households with such children. This session was led by S&T volunteers, who are also members of the facilitation team.

Upon returning, the participants discussed their experiences with the HIV-affected households. Facilitators provided feedback on how to best deal with specific issues. Families had confirmed that they were not aware that any interventions would be available for their children. They also confirmed that stigma associated with developmentally delayed children causes many families to confine their children.

SESSION VIII – MOVING FROM KNOWLEDGE TO ACTION

Participants were provided with practical skills for assessing developmental delays in children, specifically delays in growth, fine and gross motor skills, cognition, socioemotional adjustment, speech and hearing, head circumference, and reflexes. The participants were also introduced to the concept of a household care plan composed of the following components:

- Household register
- Primary caregiver status
- Child status (development and behavior)
- Caregiving environment

To assess development, the participants were trained to ask about milestones—when they were achieved and whether there were any regressions. They were also trained to look for warning signs to determine whether the child was slow in only one area or in many aspects of development. In assessing growth and development, participants were trained to use a Zambian Children's Clinic Card (also called the under-5 clinic card), and the household care plan.

Participants were trained to assess whether a child has normal or abnormal reflexes based on age and degree of reflex. They were also trained in measuring head circumference as a proxy measure to check brain growth in children younger than age 3.

Below are some of the factors that were identified as developmental warning signs that should be looked for when assessing a child. These warning signs could be used in determining whether or not the child should be referred to the Survive and Thrive team, the University Teaching Hospital/Pediatric Center for Excellence, or other resources.

SIGN	AGE
Not smiling at mother	8 weeks
Poor head control	6 months
Unable to sit supported	9 months
Not crawling	12 months
Unable to stand with help	12 months
Not babbling	12 months
Unable to stand unaided	15 months
Not walking independently	18 months
Unable to understand simple commands	2 years
Not using two or three words	2.5 years

SESSION IX – PROJECT DELIVERABLES: Monitoring & Evaluation

This session familiarized participants with monitoring and evaluation (M&E) and helped participants understand their roles and responsibilities collecting and recording information to measuring progress of the work and the impact of the project.

Participatory monitoring and evaluation is the process through which stakeholders at various levels to monitor and evaluate a particular project or program and share control over the content, the process, and the results of the M&E activity. Thereafter, the team engages in taking or identifying corrective actions. Participatory monitoring and evaluation (PM&E) focuses on the active engagement of the primary stakeholders. PM&E engages key project stakeholders—such as the community that the project seeks to reach—more actively in reflecting and assessing the progress and results of their project. This is opposed to traditional monitoring and evaluation (TM&E), which often involves outside experts measuring performance against preset indicators, using standardized procedures and tools.

Based on the outlined differences, participants stated their preference for the participatory approach towards monitoring and evaluation of the Survive and Thrive project. This means that participants would be involved in capturing and recording information. The roles and responsibilities of the health workers include performing in-depth development assessments for children age 5 or younger, identifying and referring children with development problems to relevant organizations for further management and specialized help, and keeping

up-to-date records of those children seen and referred. They were also tasked with following up on referred children to determine whether appropriate action has been taken. This includes information about children referred to the Survive and Thrive units as well as from other sources.



Fig. 5: Practical demonstration during the training for health workers

ESTABLISH TWO SURVIVE AND THRIVE UNITS

Preparatory work for the establishment of Survive and Thrive units at clinics has begun.

In the meantime, services are being provided to caregivers through home visits by service coordinators and volunteers. Negotiations and formal agreement have been conducted with the Ministry of Health and the District Community Medical Offices to build two mother and child health rooms with the Survive and Thrive units. With the Chilanga and Lusaka District Community Medical Offices, EGPAF-Zambia has secured two sites for construction of the Survive and Thrive units: Mandevu Health Centre and Mount Makulu Clinic. EGPAF has worked closely with the provincial engineer's office to submit architectural plans for the prefabricated structures and gain approval from the planning approval authority. EGPAF has identified contractors for the supply and installation of the prefabricated units at the two sites—and has conducted a site visit with contractor Afripanel of South Africa and agreed to a construction contract.



Fig. 6: A contractor and engineers from the Provincial Engineers Office inspect one of the proposed sites for a Survive and Thrive unit.

OBJECTIVE THREE:

EGPAF, through its national profile, will work to promote early childhood development knowledge and skills throughout Zambia.

LIASE WITH ZAMBIAN ORGANIZATIONS AND OTHERS WORKING IN ECD AND SPECIAL NEEDS

This was done through quarterly and annual meetings with partners and other stakeholders, including attendance at a UNICEF regional workshop on early childhood development and HIV with other Conrad N. Hilton Foundation partners. EGPAF coordinated with Save the Children Fund and Care International regarding essential package training and participated in stakeholder meetings with the Health and Education ministries in conjunction with local authorities and other ministries such as the MCDMCH.

EGPAF-Zambia also collaborated with other Conrad N. Hilton Foundation partners in Zambia through regularly scheduled informative meetings and site visits, which were used as avenues for fruitful sharing of knowledge, resources, and experiences. These events were also platforms for influencing policy on ECD. This helped Hilton partners find solutions to common challenges regarding ECD and pediatric HIV.

During this period, EGPAF also collaborated with and the Zambia National Education Coalition, advocating for expanding and improving early childhood care, development, and education, especially for the most vulnerable and disadvantaged children in Zambia.

The Survive and Thrive project launch included a provision of bicycles and was covered by ZNBC, a television channel that transmits countrywide. Site coordinators participated in a two-hour call-in radio show during which they explained the basics of ECD and Survive and Thrive. During the radio show, they fielded questions from callers, including some from the project areas expressing support and gratitude.

ACHIEVEMENTS

The Survive and Thrive project is managed by a team of well-qualified staff, assuring timely and effective implementation in all the project areas. It also operates with a pool of 42 trained volunteers who are currently sensitizing communities on the work of Survive and Thrive and circulating information on pediatric HIV and child development. More than 137 children with developmental problems have been identified and assessed in the first year of the project. Volunteers have also begun carrying out home visits and assessments and recording information for monitoring and evaluation reports.

To date, Survive and Thrive has trained 39 health workers from institutions in the project areas, Ministry of Health, and the Ministry of Community Development and Mother and Child Health. These health workers are able to perform in-depth development assessment. The pre- and post-test results from the healthcare worker trainings indicate an average increase of 11 percent in knowledge of early childhood development (ECD) and pediatric HIV essentials.

Orientation for the sub-grantees provided information on the work and objectives of the project to 70 participants, clarifying the roles and responsibilities of all the stakeholders. This ensures that all the players in the Survive and Thrive project work towards achieving a common goal.

Sharing information among Conrad N. Hilton Foundation partners helped determine solutions to issues common among the partner and has resulted in the increased use of the essential package. This has provided a platform to advocate for the expansion and improvement of early childhood care, development, and education—especially for the most disadvantaged children—and for greater clarity of the roles of various ministries in ECD.

CHALLENGES

Survive and Thrive faced constraints at the start-up phase because of the realignment of Zambian government ministries following the change in government in 2011. This resulted in the need for collaboration with numerous government ministries, which was time consuming. Currently, six ministries are involved in ECD: the Ministry of Education, Science, Vocational Training, and Early Education; the Ministry of Local Government and Housing; the Ministry of Community Development and Mother and Child Health; the Ministry of Gender and Child Development; the Ministry of Health; and the Ministry of Youth and Sport.

The classification of Chilanga as a separate district from Lusaka caused duplication of work, as EGPAF had to collaborate separately with the district health management teams in the two districts. Similarly, the architectural drawings for the two sites had to be submitted to two separate councils for approval.

Finally, disparity among partners in allowances given to volunteers is a challenge, in that some organizations working in the project communities may be able to offer allowances and other benefits to volunteers while others cannot.

CONCLUSION AND NEXT STEPS

Despite the challenges of the first project year, Survive and Thrive remains on track, and EGPAF will continue implementing the project as planned. The priority in the second year of the project will be the erection of the prefabricated units.

EGPAF will continue to develop collaborations with government officials in both districts as well as with other Conrad N. Hilton Foundation partners. EGPAF will also continue raising awareness about Survive and Thrive and ECD and contribute to influencing policy on ECD through various forums, including technical working groups, radio, television, and publications.

"Sometimes in life, there is that moment when it's possible to make a change for the better. This is one of those moments."

—*Elizabeth Glaser (1947- 1994)*



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