

# **Management System for Orphans and Vulnerable Children (MSOVC), a business information management system in response to the HIV and AIDS epidemic.**

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*"One of the great liabilities of history is that all too many people fail to remain awake through great periods of social change. Every society has its protectors of status quo and its fraternities of the indifferent who are notorious for sleeping through revolutions. Today, our very survival depends on our ability to stay awake, to adjust to new ideas, to remain vigilant and to face the challenge of change."*

*Rev. Dr. Martin Luther King, Jr.*

## **1. Background**

The "Arab Spring" is a historic marker in the evolution of democracy and human rights. The role of a disgruntled and "connected" youth in pursuit of social justice speaks volumes in terms of social change. In this regard, there is an increasing regard being given to the political impact of social media and related technology. How this impacts on South Africa and our own "disgruntled youth" is of significance.

Fueling this discontent are systemic problems that relate to our public health and education systems in which basic service delivery is seriously compromised. Added to which are levels of poverty and unemployment, producing a sense of "hopelessness" among our youth, the impact of which within the context of an HIV and AIDS epidemic, is devastating.

The challenge for government, business and civil society is to find innovative ways in order to tap into the entrepreneurial talents that exist. What is needed is an ethical and moral outrage that refuses to accept the status quo. Innovation and ICT offers a powerful platform from which to vent this zeal and engage in social entrepreneurship. The difference being that we don't need violence and destruction in order to promote change. South Africa has a different destiny to follow. While the movement from traditional CSI to "shared value" heralds an exciting opportunity to redefine the space between business and social enterprises, ICT and the transfer of

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<sup>1</sup>Robert Botha is the CEO of the James 1:27 Trust. Special recognition is given to Eldi van Loggerenberg who worked as a research assistant during an internship at the James 1:27 Trust as part of a gap-year between completing High School and enrolling to study medicine at the University of Cape Town. Her participation demonstrates the value of raising up a new generation of 'social reformers'. Recognition is also given to Automated Product Development, the Trust's tireless technology partner.

<sup>2</sup>The New Testament book of James 1:27, states: "Pure and lasting religion in the sight of God our Father means that we must care for orphans and widows in their troubles, and refuse to let the world corrupt us" (Bible 1998:1235).

technology to the social sector offers an historic opportunity for ordinary South Africans to share resources and take responsibility for the vulnerable and overlooked in our society .

In response, the paper will reflect on the James 1:27 Trust, as a case study in which social innovation and the migration of business information management systems, is demonstrated.

The James 1:27 Trust a social enterprise located at the Innovation Hub in Pretoria has developed the first phase of a management system for orphans and vulnerable children (MSOVC 1.0) in order to enable care-based organizations to scale present levels of care. It is estimated that levels of care need to double and redouble in order to even begin to match the extent of the problem.

South Africa with 5,6 million people living with HIV has the largest ARV roll-out in the world with 1.3 million people currently receiving treatment. HIV prevalence among pregnant women has levelled off just below 30%.<sup>3</sup> The harsh reality therefore, is that as a consequence of the epidemic, 4% of our child population are maternal orphans. Furthermore, research has confirmed that these children are 25% more likely to suffer abuse. While universal access to treatment therefore remains a top priority the new National Strategic Plan for HIV and AIDS, STIs and TB (2012-2016) has acknowledged the need to focus on prevention. In this regard, the Trust is pursuing a "prevention through development" approach.

Therefore, in order to scale levels of care, remove systemic blockages in service delivery, respond to inefficiencies and cover complex developmental processes, a need exists for innovation. The recognition of individual development plans in relation to family and community, highlight the need for a holistic approach to development that is both at a multiple sector level as well as within an integrated policy framework. The migration of business information and management systems into the social space, as promoted by the Trust, is therefore a timely value proposition. The main focus to date has been to create an innovative ICT platform in order to enable care-based organizations to scale existing levels of care and thereby promote holistic child development within integrated community development "best practice".

The Trust is developing what it terms "virtual adoption", which the Trust defines as a form of supplementary support in which virtual extended "families" or clusters are matched with households in which orphans and vulnerable children are living. This concept is located within a child rights framework, as guided by the UN Conventions and South African legislation, and ensures that all interventions are guided by one over-arching principle: that the interest of the child remain paramount. In this regard, privacy rights of the child are protected.

In order to manage the complexity of virtual adoption, the Trust is building the foundation of an ICT platform, which is referred to as a Management System for Orphans and Vulnerable Children (MSOVC). The system is an innovative migration of business management and intelligence systems into the civil society domain.

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<sup>3</sup> HIV prevalence among 15 to 29 year olds is 16.6%.

The Trust is intent on collaborating with relevant stakeholders in the identification of some kind of curriculum for holistic child development (HCD) that integrates all the developmental building blocks. That is bringing together the emotional, psychological, mental, physical and spiritual into an integrated developmental check list. The outcome being to have a kind of life cycle approach from which areas of risk and vulnerability emerge. Individual, family and community care plans can then be drafted within an integrated community development approach. The myriad of caring interventions needed become opportunities for social entrepreneurship and employment creation. The resource mobilisation within a "responsibility script" becomes areas for advocacy. From the father who must pay maintenance, to the neighbour who must report abuse, to the national government who must pay child support grants, to the local government municipal official who must provide a quota of water and electricity, to the school principal who must allow access, to the primary health care nurse who must immunise, to the local church elder to ensure pastoral care, to the resourced city church goer to pay for supplementary support etc.

The idea being to identify a "responsibility script" of who is responsible for what within HCD and children at risk (CAR). The "responsibility" must therefore start within the family, extended family community and then broader society. As the HCD gaps emerge within the context of poverty and the HIV and AIDS epidemic and the gaps in the HCD check list become more glaring, the question arises as to who will within the "responsibility script"<sup>4</sup> provide the supplementary interventions and care needed.

In response, the question of costs and budgets emerge. So it is in the tying together of HCD curriculum, identifying the gaps, sourcing a response from within a responsibility script, costing the interventions and then sourcing the resources both financial and human. Important high level outcomes include in addition to scaled care for children at risk, employment creation for women and a decrease in new infections.

## **2. The Context of the HIV and AIDS Pandemic**

The United Nations Security Council (UNSC) has suggested that the AIDS pandemic is a threat to world peace and international security. On 17 July 2000 the UNSC passed Resolution 1308, stating that the HIV and AIDS pandemic is exacerbated by conditions of violence and instability, which increases the risk of exposure to the disease. More recently (07.06.2011), the UNSC adopted a resolution which emphasizes the need for peacekeeping forces to address HIV prevention in their efforts, as it was found that many women in areas of conflict face the risk of contracting HIV, since sexual assault is still used as the "*weapon of choice*".<sup>5</sup>

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<sup>4</sup> The "responsibility script" should be comprehensive and include the responsibility of the father who should be paying maintenance, to the biological family, to neighbours and the local community, to child care forums, to ward committees, to municipal allocation of free quota of water and electricity, to national departments providing essential documentation, social security, health education etc. The innovative inclusion in this list is that of an extended virtual family who ensure supplementary support for the vulnerable family.

<sup>5</sup>UNAIDS press statement:  
<http://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2011/june/20110607apssecuritycouncil/>

Previously, UNAIDS also warned that more people are dying of AIDS than as a result of war or conflict. Against this background, children are particularly at risk, for forced recruitment as “boy soldiers” and girls into “sexual slavery” and horrific abuse.

In their latest report on the AIDS pandemic, UNAIDS estimates that 30 to 36 million people are living with HIV, with sub-Saharan Africa accounting for 67% of all people living with HIV and 72% of AIDS-related deaths. The report indicates that globally the pandemic is stabilizing and that the rate of new infections has fallen in several countries, including countries in sub-Saharan Africa. Despite these developments, the numbers of AIDS-related deaths, especially in the developing world, threaten advances made in achieving the Millennium Development Goals (MDG) – global benchmark in measuring development. The MDGs range from eradicating extreme poverty and hunger to achieving universal primary education; promoting gender equality and empowerment of women; reducing child mortality; improving maternal health; combating HIV and AIDS, malaria and other diseases; ensuring environmental sustainability and developing a global partnership for development. While combating HIV and AIDS is listed as an MDG, it has been found that the HIV and AIDS pandemic significantly impact the attainment of most of the other MDGs. As a result, UNAIDS is now calling for an AIDS plus Millennium Development Goals framework (UNAIDS 2009).

In reference to the 14 billion USD spent globally on AIDS last year, the CEO of UNAIDS, Michel Sidibé, has stated that although universal access to treatment remains a top priority, the present two-tiered system of global AIDS treatment – using outdated drugs for people in the developing world – needs to change. While UNAIDS estimates that approximately 3.2 million people are on treatment in Africa, only about 3% are on second-line treatment<sup>6</sup> and beyond. In this regard, UNAIDS is working with the World Trade Organization (WTO), World Health Organization (WHO) and the World Intellectual Property Organization (WIPO) to find ways of securing better access to treatment under the existing Agreement on Trade Related Aspects of Intellectual Property Rights (TRIPS Agreement); thus ensuring more affordable treatment (UNAIDS 2009).

Mr. Sidibé has also argued that, in order to “*break the trajectory of the epidemic*”, UNAIDS has to resume focus on HIV prevention – an area that has lacked substantive investment. Social movements with a focus on prevention are therefore of strategic importance. The church and other faith networks are therefore important stakeholders in this regard. In addition, UNAIDS is calling for the closer embedding of AIDS work in primary health services: maternal and child care, sexual and reproductive health programs and the tuberculosis community<sup>7</sup>. Tuberculosis remains one of the most common causes of illness and death among people living with HIV (UNAIDS 2009).

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<sup>6</sup>Once second line therapy has proved ineffective, the drug regime moves to third line therapy which is a more advanced combination of ARV drugs. <http://www.avert.org/treatment.htm>.

<sup>7</sup> “Embedding” means integrating HIV strategies into the sector.

In 2011 the South African government proposed an allocation of 25.7 billion ZAR for the department of Health, an increase of 15.3 % from the 21.7 billion ZAR allocated in 2010. In the 2010 national budget, R83 million was allocated as a response to the HIV and AIDS epidemic (a 33% increase from 2009 levels), intended to more than double the number of people on antiretroviral treatment to 2.1 million. According to UNAIDS, this allocation is the biggest domestic investment made by any developing country on the AIDS epidemic to date. Mr. Michel Sidibé has responded by stating that: "*South Africa can directly change the trajectory of the AIDS epidemic with such bold investments. This budget is pro-people and must serve as a model for increasing investments in health, education and social welfare even in times of economic crisis,*" (UNAIDS 2010:1)<sup>8</sup>.

As argued, however, allocating more money will not solve the HIV and AIDS crisis – the reason being that the HIV and AIDS epidemic is located in the context of a broader socio-economic challenge, relating to poverty and under-development. Intervention needs to be considered holistically, aligned to good practice and translated into the information society in order to scale. The issue of scaling interventions is perhaps the most pressing in the area of caring for orphans and children made vulnerable as consequence of the HIV and AIDS pandemic.

### **3. The Orphan Crisis**

Estimates indicate that there are more than 11 million children under the age of 15 in sub-Saharan Africa who have lost at least one parent to AIDS-related illnesses (UNICEF 2008:42). More than half of those orphaned are between the ages of 10 and 15, and of the total number of orphans in the world, 85% are in sub-Saharan Africa. To confirm this prediction, Save the Children UK, an international NGO working in the orphan and vulnerable children (OVC) field, have stated that "*Southern Africa is in the middle of a protracted and unprecedented disaster, and with HIV and AIDS at its center, the consequences for children are tragic*" (Save the Children 2005).

Furthermore, the UNICEF report (2008:42) indicates that children can no longer rely on the support of the traditional extended family system – "*...this coping mechanism has been over-stretched by poverty and by the sheer numbers of children to be cared for. Without the education and socialization that parents and guardians provide, children cannot acquire the skills and knowledge they need to become fully productive adult members of society.*"

A typical example for many households is an HIV positive father/adult partner, who works away from home, returning and infecting the mother who only discovers her status when going for prenatal check-ups (UNICEF 2008). Within this emotionally challenging environment the journey towards orphan-hood begins. Medical expenses start to erode the household income. The situation deteriorates as the breadwinner parent becomes too ill to work. The family is left to manage the additional expenses relating to home-based care, and in circumstances where the ill parent is the only breadwinner, the situation is complicated further. To compensate, the girl-child often discontinues schooling to reduce expenses and to assist with the home-based care

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<sup>8</sup> The reference is from a media statement made by on 19 February 2010 by UNAIDS.

of the sick parent. Household stress increases incrementally in the midst of anxiety, fear of death and destitution, as well as the trauma of stigmatization and discrimination.

The death of any child's parent is traumatic. When the death is as a result of AIDS-related illnesses the tragedy is even more devastating. Additionally, the second parent might also be infected, with the implication of developing AIDS and dying as a result. The pain of loss and grief is compounded by feelings of shame and isolation. Research indicates that levels of abuse and exploitation increase by up to 25%, compounding the risks of the children becoming infected themselves. The above hardships often exist within the context of stigmatization and discrimination as a result of perceptions towards the HIV and AIDS epidemic.

Once the parent dies, the household is forced to manage funeral costs; financial insecurity owing to the lack of the parents' income; risk of loss of shelter and home; displacement from family and friends; separation from siblings; often unwelcome moves to already overburdened homes, and inclusion in granny-headed homes with large numbers of other children. In some circumstances, the last baby born to the sick mother may also be HIV positive, thus increasing the burden of care of the young sick sibling. These traumatic circumstances negatively affect the normal process of bereavement. This in turn may stunt the emotional and psychological development of the child, contributing to incidences of dysfunctional behavior and subsequent dependency-related problems.

While the cost of school fees, books, stationery and school uniforms is a concern for most households, for orphans in AIDS-affected households, the problems become insurmountable, with access to education being compromised: *"Access to education for orphans becomes a critical issue; they are more likely to drop out, perform poorly, or not be enrolled at all. Children orphaned due to AIDS are also more likely to suffer from malnutrition, further robbing them of their potential. Much has been said of a 'lost' generation of parentless children growing up abandoned and bitter to become a budding security risk to the rest of society. But it is society that must be held accountable for how it treats its most vulnerable members. Without proper support and care, orphans are more likely to end up on the streets, be exploited as cheap labor, take drugs or sell their bodies - victims of society's neglect and policy failure."* (Save the Children 2005:8)

Some orphaned children are taken care of within their communities; in other cases their grandmothers are left responsible to take care of them. With meager resources; tired and already overburdened, these grandmothers are forced to bear unforeseen responsibilities and financial strain. Save the Children UK (2006:8) found that the *"...burden of care for orphaned and vulnerable children has been largely taken up by extended families at community level. These traditional support systems are under severe pressure and in danger of becoming overwhelmed."* (Save the Children 2006:8)

Alternatively, foster parents are identified and foster care grants awarded. Yet research has shown that foster parents experience much frustration with the welfare system – their position as foster parents has to be reviewed annually; grants are often only issued after long periods of time; foster parents have to wait in long

queues; grants are sometimes suspended without any notice. The implication of the above is that fostering children is not made easier by the welfare system (Mkhize 2006).

There are also circumstances when orphaned children cannot be cared for within their communities, by their grandmothers, by adult family members, or by foster mothers – they are left to take care of themselves. These children live in what is termed 'child-headed households'.

In a doctoral study on the social functioning of child-headed households, Mkhize (2006: 22) found that "*child-headed households are a deviation from the norm and a disaster,*" and that they "*create a situation where needs of children are unmet and their rights are eroded*". The study found that these households are at risk in view of the fact that the care-giving role of an adult is abdicated to children. "*The phenomenon of child-headed households presents a shift from the structural family, since a significant subsystem of a family – i.e. the parental subsystem – is non-existent*" (Mkhize 2006:22).

The study concludes that the extended family, as a result of being overwhelmed, is no longer the primary solution for orphaned children and that social workers have to create alternative options for the substitution of an adult in a child-headed household (Mkhize 2006). The findings indicate that given the extent of the orphan crisis, extended families cannot cope with the number of children that they have to absorb.

It appears that the local community<sup>9</sup> is the first line of defense, but as mentioned, is struggling to absorb the scale of the problem. Estimates vary, but it seems that only 15% of children at risk are receiving care from the abovementioned organizations (NIRSA 2009). Consequently, life for children at risk becomes progressively challenging, increasing the risks of HIV infection. Given the high levels of teenage pregnancy, the cycle of orphan-hood may continue – the difference being, however, that the subsequent generations might be even worse off. Orphaned young mothers leave babies orphaned. The cost to the individual, family, community and society is immense. How this will impact sub-Saharan African countries' ability to achieve their millennium development goals (MDGs) and New Partnership for Africa's Development goals (NEPAD), remains of great concern.

#### **4. Children's rights and responsibilities**

With regard to the provision of care for Orphans and vulnerable children, the United Nations Convention on the Rights of the Child (UNCRC) and the African Charter on the Rights and Welfare of the Child (ACRWC) provide a basic framework from which to work. Furthermore, the United Nations General Assembly has adopted guidelines

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<sup>9</sup> Corbett and Fikkert (2009) in "When Helping Hurts" present a useful map in which to navigate social change. Their underlying principle is not to start the development process by focusing on the needs of the poor but on rather on what the poor already have. They therefore define poverty in terms of relationships, and believe the causes of poverty to be individual, structural and multifaceted (Corbet and Fikkert 2009). In terms of practice, they advocate the principles of starting with people's assets, not needs. They look for resources, more than just financial, first from inside the community and then from outside. They also focus on participation, "not just a means to an end, but rather a legitimate end in its own right. This has to be done in a culturally appropriate manner (language, structure, etc.)" (Numan 2009). The over-arching principle is not to do things for people that they can do for themselves (Corbet and Fikkert 2009).

for the alternative care of children (UNGA 2009). The guidelines recommend “*efforts to keep children in, or return them to, the care of their family, or failing this, to find another appropriate and permanent solution, including adoption ...*” (UNGA Human Rights Council 2009). The main principles behind these guidelines is that the family is considered the natural environment for the growth, well-being and protection of children, and that all decisions should be made in the best interest of the children (UNGA Human Rights Council 2009).

In this regard, the First International Conference in Africa on Family-Based Care for Children, held in Nairobi, reaffirmed the above principles; in particular the right of children to a family – regarded as the best institution in which to raise children (ANPPCAN 2009:1)<sup>10</sup>. The Nairobi Conference recommended the need for institutions to replace the common practice of long term institutionalization of children with family-based care. They recognized the need for the establishment of community-based structures, such as child welfare committees. These would support the provision of basic services to children and their families – i.e. education, health and HIV and AIDS treatment, purposed to keep children in families. They supported calls for children to be consulted according to their evolving capacities and their input to be considered. It was felt that while institutional care may at times be necessary as a temporary measure for children under special circumstances, such care should be a measure of last resort. They noted the phenomenal and unregulated growth of institutions for child care in Africa.

In South Africa, many models of orphan and vulnerable children (OVC) care are in use, owing to the existence of many child care institutions. Some of those that have been identified as good practice include the Isibindi Model, SA Cares for Life Cluster Model; Save the Children Model and World Vision Model.

Thus, in addition to recognizing that children need (and have a right to) a family, medical care, an adequate standard of living, education, safety and recreation, the UN also recognizes the value of enabling spiritual development. Therefore, in addition to enabling physical, emotional, and cognitive development, spiritual development completes the foundation for holistic child development (HCD).

Finally, the Nairobi Conference, in addition to a focus on the holistic rights of a child, also highlighted the importance of the responsibilities of a child. The intent was that choice always remains at individual level with support needed for a child to exercise their rights within a qualified context of their personal level of responsibility.

If the above concerns are addressed in the policy development of childcare institutions in South Africa, the potential of HCD in addressing the orphan crisis, in the context of the HIV and AIDS giant, appears immense. In all forms of intervention relating to the OVC crisis, the importance of upholding the child’s best interests as the chief priority must be emphasized.

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<sup>10</sup> African Network for the Prevention and Protection against Child Abuse and Neglect (ANPPCAN) (<http://www.anppcan.org/node/>)



## **5. The role of social capital**

Given the scale of the HIV and AIDS epidemic, the degree of poverty in South Africa, and South Africa's peculiar history, the question that arises is: who in society is responsible for the children affected by HIV and AIDS? The answer is of critical importance, in that it identifies the source from which resources need to be made available and transferred. Therefore, without diminishing the responsibility of the state, in meeting its constitutional obligations in providing a social security net; common sense demands that resources are also needed from a broader stakeholder group. In this regard, capital that can be leveraged from stakeholder groups in business and civil society, in order to supply these resources, need to be secured. Concepts such as social capital are therefore of great value. Given the interconnected nature of our global society, the question arises as to whether social capital can be mobilized at international level. This is particularly relevant in the context of the opportunities characteristic within the information society.

It is suggested that social capital offers a unique opportunity to leverage benefit in mitigation of the negative impact of the HIV and AIDS epidemic. Firstly, the concept of social capital can be used to understand the negative consequences of the HIV and AIDS epidemic, particularly in terms of the depletion of the social capital of those affected by the epidemic. Secondly, this concept may offer a valuable source of leveraging resources for the benefit of those affected by the epidemic. It must be noted, however, that there is debate as to whether the conceptual framework of social capital is sufficiently refined to allow for scientific measurement (Halpern 2005).

While social capital can generally be regarded in terms of social networks, norms, values and sanctions, it also relates to different forms of capital. Social networks create a structure in which other forms of exchange take place: human; labor; intellectual; infrastructural.

The information society has opened up new possibilities in applying the concept of social capital. Advances in information, technology and communications provide access to social networks and structures allowing an exchange of resources. The ability to secure a regulatory environment mitigates against the inherent dangers of such an open society. Regulations in this context refer to internet law, internet crime, as well as a host of international telecommunication laws and protocols, as well as generally accepted norms and standards determining what is considered acceptable behavior and conduct for the virtual society.

South Africa's history is informative in illustrating the benefits of social capital for social transformation. For example, social networks and structures at national and international level, held together by common political and liberation objectives, were successfully used to mobilize a valuable source of solidarity, political and economic leverage and transfer of resources for the anti-apartheid movement – a powerful example of the value of social networks in the transfer of resources in solving a national problem and in pursuing the objectives of social justice.

Therefore, while there is consensus across the field that the scaling of care to children at risk is urgently needed, uncertainty remains as to how to actually achieve this objective. It would seem that there are two main challenges. The first relates to

finding new sources of funding to meet the needs of children at risk, and the second to the administration and management of the funds received by the sponsors and to the sponsored care of the children themselves. The concept of “virtual adoption” as promoted by the James Model, is an attempt to address the first challenge. The James 1:27 Trust’s development of a management system for orphans and vulnerable children (MSOVC) can be regarded as a response to the second challenge.

## **6. MSOVC and its Proof of Concept**

## **7. Some recommendations**

7.1 Holistic child development (HCD) within an orphans and vulnerable child context requires a multi-disciplinary collaboration in order to define an HCD curriculum. The curriculum setting out the developmental building blocks should then inform a “responsibility script” for the nation and society at large. The script should address the issue of who is responsible. Parties must then be held accountable to deliver on what is ethically, legally and politically expected. Advocacy can play a great role in this regard.

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