

Preventing Carer Burnout

Inter-Mission Care and Rehabilitation Society
(IMCARES)

UNAIDS BEST PRACTICE COLLECTION



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UNAIDS/07.34E / JC1384E (English original, December 2007)

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WHO Library Cataloguing-in-Publication Data

Preventing carer burnout.

(UNAIDS best practice collection)

"UNAIDS/07.34E / JC1384E".

1.Acquired immunodeficiency syndrome – psychology. 2.Caregivers. 3.Burnout, Professional. 4. Stress, Psychological. I.UNAIDS. II.Inter-Mission Care and Rehabilitation Society.

ISBN 978 92 9 173638 6

(NLM classification: WC 503.7)

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Summary

Burnout is not an event but a process in which every day stresses and anxieties that are not addressed gradually undermine the carer's mental and physical health, so that eventually care giving and personal relationships suffer. As a medical condition burnout has no clear definition, but as a psychological condition it has been well defined¹ and is increasingly recognized by people in the caring professions. Burnout has long been identified as a crucial issue in HIV care and support; yet there is relatively little known about what measures can be taken to prevent or mitigate it.

A UNAIDS study on caring for carers outlined the causes of stress in the following terms:

Much of the stress experienced by carers is in the nature of the work itself—the fact that they are dealing with an incurable condition that largely kills young people, causes terrible suffering and is heavily stigmatized. But stress may also be caused by organizational factors—the way a care programme is designed and managed. The most commonly reported causes of stress among carers working with AIDS programmes include:

- financial hardship;
- oppressive workloads;
- secrecy and fear of disclosure among people living with HIV;
- over-involvement with people living with HIV and their families;
- personal identification with the suffering of people with HIV;
- the unmet needs of children;
- lack of an effective voice in decisions that affect them and their work;
- inadequate support, supervision and recognition of their work;
- inadequate training, skills and preparation for the work;
- lack of clarity about what the caregiver is expected to do;
- lack of referral mechanisms; and
- lack of medication and health care materials.²

While there are no global estimates on the percentage of care provided by faith-based organizations, there is widespread recognition that in many countries faith-based organizations play a crucial role in providing care and support to people living with HIV and their families, particularly in remote and rural areas. In 2006, Cardinal Lozano Barragan, President of the Pontifical Council for Health Pastoral Care, estimated that the Catholic Church, in particular the Good Samaritan Foundation, administers 27% of the AIDS care provided globally.³ Furthermore, a 2006 report by African Religious Health Assets Programme and the World Health Organization on faith-based organizations' involvement in care in Lesotho and Zambia found that Christian hospitals and health centres provide about 40% of HIV care and

¹ Miller D (2000). *Dying to Care? Work, Stress, and Burnout in HIV/AIDS*. London, Routledge.

² UNAIDS (2000). *Caring for Carers: Managing Stress in Those Who Care for People with HIV and AIDS*. Case Study. Geneva, UNAIDS.

³ United States Embassy to the Holy See (2006). Embassy Hosts Conference to Mark World AIDS Day and the 25th Anniversary of the First Reporting of the HIV Virus, December 20, 2006. http://vatican.usembassy.gov/viewer/article.asp?article=/file2007_01/alia/a7010305.htm

treatment services in Lesotho and almost one third of the HIV treatment facilities in Zambia are run by faith-based organizations.⁴ Burnout in carers, particularly those working in faith-based organizations, is a crucial issue as efforts towards universal access to HIV prevention, treatment, care and support gather momentum.⁵

This report looks at one faith-based organization, the Inter-Mission Care and Rehabilitation Society (IMCARES) based in Mumbai, India, which through its faith and practical measures, has managed to prevent burnout among its staff members. It assesses whether the IMCARES model or certain aspects of it can be replicated by other Christian organizations, a broader array of faith-based organizations or more generally by civil society organizations. Two brief case studies from Rwanda and Thailand are also provided, highlighting the findings from the work of two other faith-based organizations:

- The Mother's Union, Diocese of Kigali, Rwanda, which focuses heavily on livelihood support for volunteers and genocide survivors, both principally women; and
- AIDS Care, Education and Training, Thailand, which describes lessons learnt in retaining volunteer carers in Bangkok and Central Thailand.

Both of these programmes are supported by Geneva Global.⁶

For the care providers at IMCARES, the term burnout is alien.

The reasons are:

- We have learnt to depend on God more than anything else.
- We have learnt that our call is not just about serving the poor and the needy, but also serving the servers. Being sensitive to their needs.
- We believe that "Whole Person Care for persons providing Whole Person Care" is very important.

Background to the report

This report is the result of a five-day on-site visit which enabled one-to-one interviews with members of the management and key project staff members of IMCARES using a semi-structured interview format; a focus discussion group with the members of the Inter-Mission Prevention of AIDS through Care and Training (IMPACT) Project team; and field visits to two of the Agape Community Care Centres run by IMCARES and following the Pavement Ministry team. In addition, a review of IMCARES' documentation was undertaken, including funding proposals, logframe, project evaluations and reports, staff evaluations, case studies, audio-videos, pamphlets and newsletters.

⁴ African Religious Health Assets Programme and the World Health Organization (2006). *Appreciating Assets: Mapping, Understanding, Translating and Engaging Religious Health Assets in Zambia and Lesotho*. <http://www.arhap.uct.ac.za/about.php>

⁵ In developed countries most people have an "assumption that religion should be segregated into a separate sphere of life, distinct from everyday reality" (P Jenkins, *The Next Christendom*, OUP, 2002); however, the opposite is true for the majority of people living in low- and middle-income countries, and this is reflected in the large-scale responses of faith-based organizations to HIV and IMCARES in particular.

⁶ Geneva Global. <http://www.genevaglobal.com/>

Chapter 1: Background to IMCARES' work in the HIV response

The Inter-Mission Care and Rehabilitation Society (IMCARES, sometimes referred to as Inter-Mission)⁷ is a registered charitable society based in Mumbai, Maharashtra State, India.⁸ IMCARES works in Mumbai (Bombay), the capital of Maharashtra State with an official population of about 18 million. However, it is estimated that some 20 million people live there, with an estimated 60% of its population living in slums or on the streets. The vision of IMCARES is “transforming lives of the poorest of the poor with the Agape⁹ love of God and compassion of Jesus Christ in fellowship of the church and local communities”.

IMCARES was founded by Pastor Peter Will in 1982. Peter Will was already running a home for poor and orphan children in Tamil Nadu in South India when he passed through Mumbai. He was moved by the plight of the dying destitute on the streets of Mumbai. He personally tried to help a number of people, giving them baths, taking them to hospitals, many times facing legal challenges and opposition, even from Christian leaders and churches. He was looking for people who would help him carry out the vision God had given him to reach out to the poorest of the poor. It was during this time that he met Pastor Sumitra Gaikwad, who was moved by Peter Will's vision inspired by his Christian faith and soon after Inter-Mission began its work with three people.

In 2007, IMCARES has 40 full-time staff members, 10 full-time community training course trainees (who are paid a stipend) and a variable number of Indian and foreign volunteers (between five and eight), who serve some 65 people living with HIV and reach between 6 000 and 7000 people per year through its medical clinics, which provide primary health care as well as referrals to hospitals for antiretroviral therapy and other medical treatment and to directly observed treatment short course (DOTS) programmes for tuberculosis. IMCARES' projects, which are described in more detail in Chapter 2, include two children's homes at the Agape Village in Pune; the Pavement Ministry (undertaking street work and joy clubs); four Agape Community Care Centres with day care centres and ladies development programmes; and the Inter-Mission Prevention of AIDS through Care and Training (IMPACT) Project, including providing community training courses and medical clinics.

IMCARES describes itself as an interdenominational, evangelical Christian social organization targeting the poorest and most needy groups in the city. The ministry seeks to be practical, simple, personal and holistic, providing social, physical, economic, emotional and spiritual care and support. IMCARES has pioneered holistic ministry on the pavements and in the slums of Mumbai over the past 25 years. Interestingly, the IMCARES staff members come from some 17 different Christian denominations in Mumbai.

⁷ 'Elim', 19 August Kranti Marg, Nana Chowk, Mumbai 400 007, India
Tel: +91 22 2380 81 34, 2380 62 37; Fax: +91 22 2380 32 78; agape@imcares.org, www.imcares.org

⁸ IMCARES is registered under Societies Act XXI of 1860, S. No. 634 of 1996 (Mumbai. M.S.), B.P.T. Act XXIX of 1950 S. No. F-18607 (Mumbai).

⁹ Agap is one of several Greek words translated into English as love. The word has been used in different ways by a variety of contemporary and ancient sources, including biblical authors. Many have thought that this word represents divine, unconditional, self-sacrificing, active, volitional and thoughtful love. The term agape was used by the early Christians to refer to the self-sacrificing love of God for humanity, which they were committed to reciprocating and practicing towards God and among one another.

1.1 IMCARES' approach

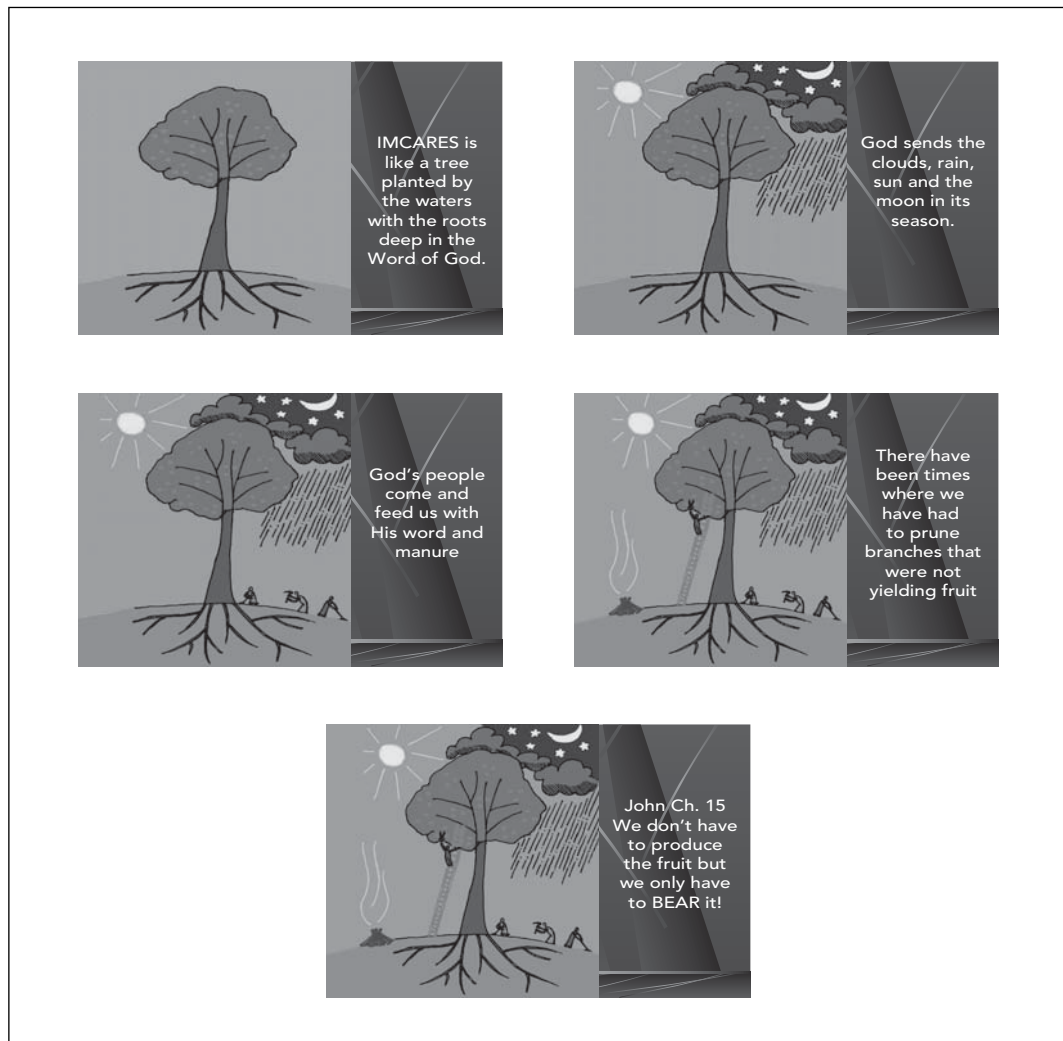
IMCARES operates in a society with extremes of wealth and poverty. Its mission is to offer care and hope to the poorest of the poor. Even in the slums, relative wealth also exists; some people are better off than others, and there are better and worse areas to live. A cursory look at Mumbai immediately shows that the needs of people are enormous. The sheer number of people living on the streets, under railway bridges, on any available space, many with obvious and serious health conditions, shows that in terms of public health, social security and development, the needs are seemingly unlimited.

The 2006 HIV prevalence estimate released by the National AIDS Control Organization, supported by UNAIDS and the World Health Organization, indicate that national adult HIV prevalence in India is approximately 0.36%, which corresponds to an estimated 2 million to 3.1 million people living with HIV in the country (see Annex 1: The AIDS epidemic in India). As such, the needs for HIV prevention, treatment, care and support and the concomitant needs of carers in the Indian context are vast.

It is in this environment that IMCARES works. Yet, rather than responding in terms of numbers of people reached (except to a limited extent as required by donors), IMCARES takes a different approach – put simply, quality over quantity. IMCARES' actions are not so much about saving lives but rather ensuring that people live and die with dignity, knowing and experiencing the love of God.

IMCARES accepts the situation in which it works, and it works with clients to accept their own situation, whether it is an HIV-positive diagnosis or illness or other condition. Furthermore, IMCARES accepts people as it finds them, whether they are poor, eunuchs or working as sex workers; caring for the person does not equal condoning the social conditions or ways in which some people live or earn a living. It is a practical, non-judgemental response to the realities of people's lives. Furthermore, with the exception of the Pavement Ministry, IMCARES does not “chase” clients but rather waits for people to come to the organization. It is an active principle that there is no discrimination on grounds of faith; IMCARES extends its care to people in need of any faith, or of none.

Explaining the underlying approach to the work of IMCARES



The director, Timothy Gaikwad, puts IMCARES' approach succinctly: "If we concentrate on the small things, then the big changes will happen by themselves. We have learnt that success and failures of a project is not in our hands. We only have to faithfully do what has been entrusted to us by God to 'simply bear fruits'."

On this basis, numbers do not come into the equation in the sense that providing services to an ever increasing number of clients or expanding the size of the organization are not the aims of IMCARES. So while staff members have performance targets, the emphasis is on living by example and responding to situations and circumstances as they present themselves. Funding is used to respond to needs rather than creating projects and programmes to fit funding opportunities offered by donors.

This flows into how IMCARES treats its staff. As described in this document, IMCARES spends a lot of time and energy investing in its staff as "we have realized that our staff is our greatest strength and 'Whole Person Care for persons providing Whole Person Care'". In practice this means that basic working conditions such as salaries and entitlements are in line with government laws and regulations, there is transparency about available

financial resources, staff members have the freedom and are encouraged to take initiative, they have the space to grow, they have ownership of projects and write project applications, there is practical training and, crucially for IMCARES staff members, prayer and devotion are at the core of daily life.

IMCARES believes that while many nongovernmental organizations start well, they are often beholden to or dominated by one leader. IMCARES is concentrating on developing new leaders with the opportunity for staff members to grow and the freedom to be innovative. Furthermore, in recognition of the nourishment that a person's local church provides, IMCARES never says "no" to a staff member's involvement in church activities. In fact, staff members are encouraged to grow within their church and to speak from the platform of their own church.

All of these measures help to ensure that carer burnout is not an issue. These measures create a supportive environment for staff. In effect, IMCARES has taken a preventative approach to carer burnout by treating staff members with respect and providing support so that staff members do not reach the point at which they are at risk of burnout.

"Before I came to IMCARES, through my church I was visiting people in hospitals, talking about Jesus. When I came to IMCARES I learnt to care for people with my own hands. This changed my whole outlook on life."

Indira, volunteer care provider

IMCARES also has a specific strategy to mobilize churches by demonstrating the importance of becoming involved with mission and social action, the Integral Mission approach. As a result of IMCARES ministry, churches in Mumbai are opening their doors to the poor. Many churches have adopted IMCARES models and started their own ministries in Mumbai and beyond, through the capacity building provided by IMCARES. Many of IMCARES' beneficiaries are now members of civil society organizations and churches.

As examples of the organic outcomes of IMCARES' approach, two medical clinics are now housed in churches in slum areas as a result of local pastors seeing the needs in their communities; having heard that IMCARES was providing community care, they offered IMCARES space within their churches to provide services. In these two centres, if you ask people in the community who is providing the services, people will say the church. IMCARES is not advertising its activities.

1.2 IMCARES as a family

One of the operational aspects that distinguishes IMCARES from many other organizations is the emphasis on family. While IMCARES has all the necessary organizational structures such as a board of trustees and an executive board as well as operational management teams that you would expect to find in any well constituted organization, it operates with a caring approach towards its staff members that is more akin to familial relations than those of employer/employee. As Timothy Gaikwad, the director, highlighted:

We believe that IMCARES has maintained a family culture since the last 24 years. As in a normal family, each one is encouraged to be approachable and open. Support, exhortation and discipline are encouraged. The board members are approachable and make them-

selves available as and when needed, at times even extending their hand in voluntary work. The staff has access to all the board members and vice-versa. Complete transparency is maintained.¹⁰

Staff members were quick to highlight the positive effects of this on their relations and work. For example, Shakuntala Nagre, an IMPACT Project officer, emphasized, “IMCARES cares for us as a family so we can remain happy. When we are happy we work well.”

IMCARES operating as a family is not a rigid, traditional-style organization. There is an atmosphere of openness and transparency. Managers and board members are approachable, regarding themselves as being servants of the staff members. Most board members live in Mumbai and are available to both management and staff members. While functional distinctions exist, these do not stand in the way of contact, support and dialogue.

1.3 Integrated approach to programming

HIV is being mainstreamed across the projects being implemented by IMCARES. All HIV-related work with the exception of the Pavement Ministry and the Children’s Homes emanates from the Community Care Centres. For example, if a husband is HIV-positive, his children may attend the pre-school or after school care centre and his wife may be integrated into the ladies’ development programme. The family as a unit is taken care of under the IMPACT Project; for example, food rations and referrals to antiretroviral therapy programmes are provided, and treatment for sexually transmitted and opportunistic infections such as skin infections are provided in the medical clinics, as are family planning and counselling.

1.4 Move towards professionalism

Originally IMCARES began with the work of one person, then two and then more. It now has over 40 staff members. Its growth both in the number of staff and projects as well as the changing environment in which it operates have meant that IMCARES has had to evolve.

Originally it operated on a loose charity model or organization with no hierarchy and specialization, growing and responding to needs as and when they arose. However, as it has grown as an organization, IMCARES has had to introduce organizational norms and structures; a move towards professionalism, away from a charity model to a charity-based development model, has taken place. The ultimate beneficiaries of this are clients though it has also improved the quality of and working conditions for staff members.

This process was not without its conflicts. There was much focused dialogue within IMCARES with the intention of coming together to decide on actions and then how to own them. Professionalism has also involved learning to keep a balance between personal and professional relationships.

¹⁰ Gaikwad T (2006). Ten Good Practices of Caring for Care Providers. XVI International AIDS Conference, Toronto, Canada.

1.5 Funding

A secure funding base means that IMCARES and its staff members do not suffer from many of the insecurities that other organizations face. This was done as part of the move to professionalize the organization. IMCARES also conducted an internal strategic review and it was during this time that salaries were compared with those of other organizations. The impact of this on operations should not be underestimated. Globally, civil society organizations consistently highlight funding as a core issue for organizational sustainability and in providing a secure working environment. At IMCARES, each member of staff knows the amount of funds available; this transparency provides certainty in terms of employment as well as the freedom to think about new projects or how to improve existing ones, and to address the outstanding needs of staff members. Furthermore, IMCARES has a reserve fund for emergencies of half a crore (i.e. five million Indian rupees equalling approximately US\$ 125 000), which means that in the event that the organization was dissolved, all staff members would receive their full financial entitlements.

Of all the IMCARES' projects, the IMPACT Project has the most secure funding base. TearFund UK provides 70% of the funding for this project, including staff salaries and the costs of the community training course. The training course is tied to the IMPACT Project but in fact is a source of staff training for all of IMCARES' projects and provides additional human resources to all projects.

IMCARES has to raise 30% of the funds for the IMPACT Project as well as funding for other projects. One of the roles of the director is to raise financial resources. In addition to TearFund UK, significant financial support comes from German faith-based organizations, including Inter-Mission e.V.; however, IMCARES is committed to raising funds locally. IMCARES has a variety of local donors, some of whom give regularly and some of whom provide untied grants, and others provide in-kind gifts for specific projects, for example, at one time a politician provided food rations for children on a bimonthly basis.

While the financial base is relatively secure, sometimes it can take a long time to mobilize resources. In these instances, IMCARES can on occasion move budgets around for specific projects; however, for bigger, more expensive items and projects often these have to wait until funds are received. Finally, IMCARES is committed to seeking funding for community-identified needs rather than developing projects to meet donor-led priorities. While all organizations should adhere to such principles, this is made easier when an organization has a relatively secure funding base.

1.6 Proselytising

One of the major concerns of some people is the potential for faith-based organizations to use their position of power for proselytising or "converting" clients. While most of IMCARES clients are not Christian, IMCARES is very clear that it does not proselytise or attempt to convert clients. However, IMCARES does approach its mission through its faith so prayer and Christian value-based teaching are evident in all of its projects and outreach work. So while members of the organization express their belief in God's love expressed through their Christian faith, and they seek to show this in their daily lives and work, clients can live their own faith, or none. Naturally, if a client expresses an interest in Christian teaching, IMCARES staff members will respond in their personal capacity.

1.7 The role of partnerships

IMCARES has working partnerships with the Church of Resurrected Jesus Christ, Dharavi; Immanuel Lutheran Church, Charkop; Bombay Baptist Church; Gateway Ministries International; and the Hume Congregation Church. Other partners include the Christian Organizations' Response in Networking to HIV/AIDS (CORINTH) network and government hospitals such as B.Y.L. Nayar Hospital, J.J. Hospital and Sion Hospital to which clients are referred for medical treatment and antiretroviral therapy. In addition, there are also active partnerships with Eduljee Framjee Trust's Nirmaya Niketan and the Jyothsi Hospices. Internationally, IMCARES is part of the MICAH¹¹ and VIVA¹² Networks. Church partnerships provide IMCARES with goodwill and strong prayer support and are a source of personnel. Participation in local, national and international networks provides IMCARES with an opportunity to learn about other organizations' best practices and to impart its lessons learnt to others. Active partnership with hospices and hospitals ensures a secure place for clients in case they need in-house care.

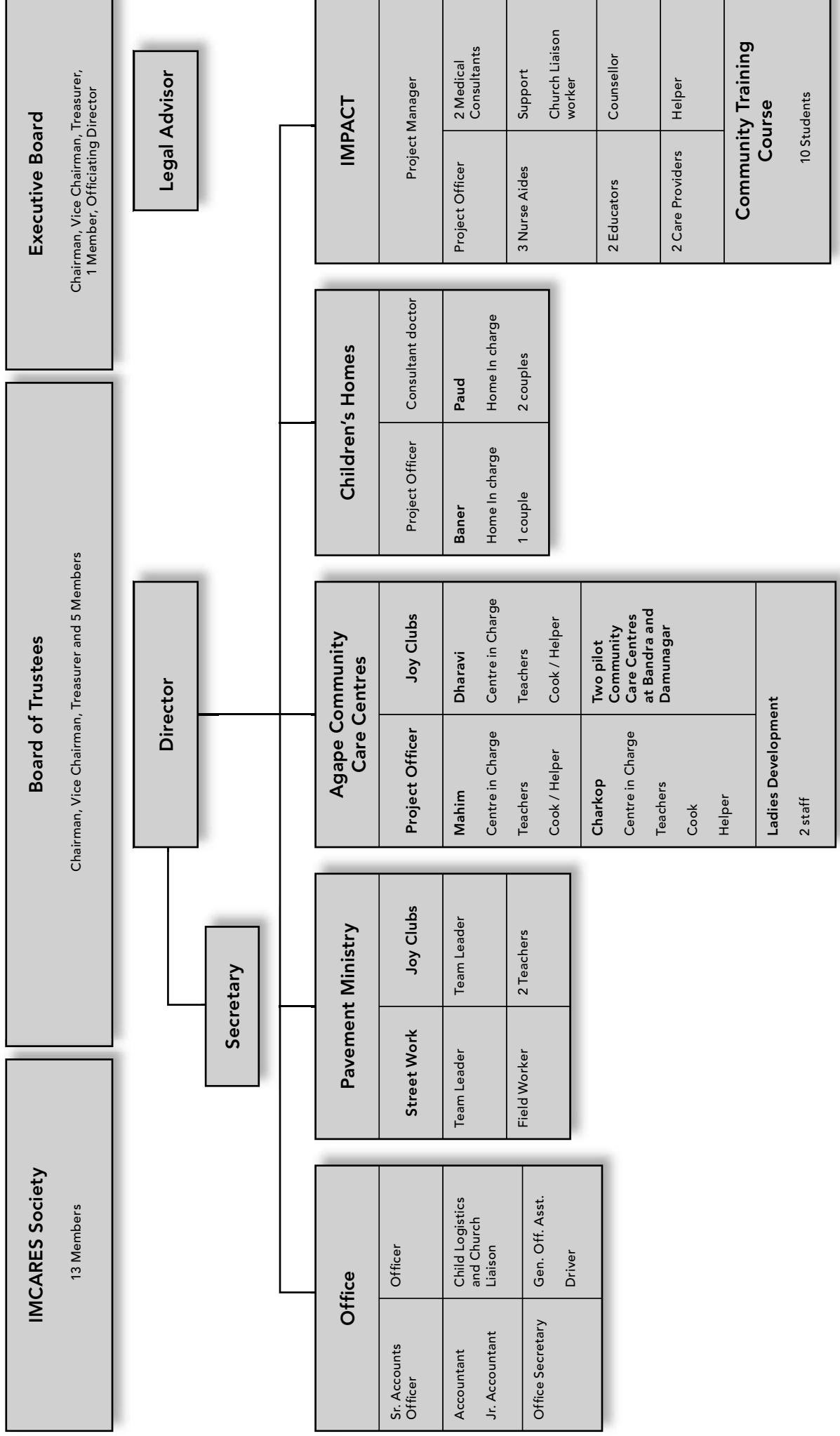
1.8 Mainstreaming HIV education into all projects

While the IMPACT Project specifically focuses on HIV, all IMCARES staff are being educated on HIV and how to discuss HIV-related issues with clients, and HIV mainstreaming is taking place across the organization. This is being achieved through a variety of measures. For example, over time staff members move between projects, which means that they are dealing with different groups of clients. As HIV is present at all levels of Mumbai society and particularly affects the poor, staff members are likely to come across HIV-positive people or people at risk of HIV infection in all projects. For example, people working in the Pavement Ministry counsel people on HIV prevention and encourage at-risk people to undergo HIV testing. People may be accompanied to voluntary counselling and testing centres for moral support. Furthermore, one ad hoc IMCARES baseline survey of HIV vulnerability in the slums (undertaken as part of a situational analysis before the 2006–2007 project proposal for TearFund UK was developed) showed that many, if not all of, IMCARES clients are at high risk of exposure to HIV; for example, the lack of sanitation means that women are vulnerable to attack and rape as they make their way to areas on the edge of the slums to relieve themselves. Thus HIV mainstreaming is crucial to IMCARES' mission.

¹¹ The Micah Network, formed in 1999, is a group of 300 Christian relief, development and justice organizations from 75 countries. The aim of the Micah Network is to create a dynamic process that facilitates collaborative action in: strengthening the capacity of participating agencies to make a biblically-shaped response to the needs of the poor and oppressed; speaking strongly and effectively regarding the nature of the mission of the Church to proclaim and demonstrate the love of Christ to a world in need; and prophetically calling upon and influencing the leaders and decision-makers of societies to "maintain the rights of the poor and oppressed and rescue the weak and needy". <http://www.micahnetwork.org/>

¹² Viva Network is a global movement of Christians with 81 network initiatives in 48 countries, helping 1.2 million children. <http://www.viva.org/>

IMCARES: Organizational Structure



Chapter 2: Projects reaching out to the poorest of the poor

IMCARES has four principal projects, namely children's homes, the Pavement Ministry, Agape Community Care Centres and the IMPACT Project. While these projects have distinct foci, IMCARES is mainstreaming HIV across all projects.

2.1 Children's homes – Agape Village

IMCARES runs two children's homes called the Agape Village situated in Paud about 180 kilometres from Mumbai. Three families live here. Two families care for younger children and girls while one family cares for boys. The Agape Village offers medical and psychological care, hope and a future for the children who may be the children of sex workers from Mumbai and Pune or from earthquake-affected areas or other orphaned or vulnerable children. The Agape Village currently has two children living with HIV and six children whose parents are HIV-positive.

In 1989, some children were “rescued” from sex work districts; now IMCARES works in collaboration with secular organizations working with sex workers and does not undertake “raid and rescue” but waits for individual sex workers to approach IMCARES about taking custody of their children. In the event that IMCARES takes custody of a child, the legal authority is provided by the mother and IMCARES encourages mothers to maintain contact with their children through visits to the Agape Village and taking holidays there.

In the Agape Village, the children are brought up in a family-style system as opposed to the more traditional regime of an orphanage. Three committed couples provide these children with parental love and guidance in a family atmosphere. The children attend local schools, studying with local children from the village, which promotes their social integration rather than exclusion. The children work with the home parents to take care of the kitchen garden, and they help in the daily household chores. Activities such as vacation bible schools, summer camps, outstation exposure visits, computer classes and other skills development activities are organized for the children. Special attention is given to children who are challenged in their studies or are physically sick. Children are encouraged to have dreams for their lives, though providing for higher education is in itself creating new financial challenges for IMCARES.

The Agape Village address both the psychosocial and physical needs of the children who, in the words of one of the IMCARES staff members, “are both physically and socially orphaned”. When the children's homes are full, as is often the case, children in need are referred to one of the homes supported by other agencies in the area.

2.2 Pavement ministry

The IMCARES Pavement Ministry reaches out to the poor and dying on the streets of Mumbai. Most of these people are an “invisible” population in the sense that while they are visible, they are uncared for, merely surviving on the streets. Many of these people have no birth certificate, which means that they have no voting rights and hence no one to represent them. Survival entails rag-picking or begging, and if they are too sick and tired to

find for themselves, they may live on leftover food from restaurants and individuals, at times scavenging through dustbins to find something to eat. At night, they sleep on the streets and are often exposed to the danger of being injured by speeding vehicles.

This population, especially women, is highly vulnerable to sexual abuse, which increases their risk of contracting sexually transmitted infections, including HIV. An internal IMCARES study revealed that in one South Mumbai area there has been more than a 65% increase in tuberculosis and AIDS cases in the last two years.

A lack of sanitation and not knowing about or practising basic personal hygiene make street people vulnerable to many infections. Other common factors – including poor nutrition, a lack of access to clean drinking water, untreated wounds and non-adherence to medications for infections (due to a lack of supervision) – exacerbate their ill health. Many vulnerable people are abandoned by their family or peer group and left to die in misery. It is not uncommon for unhealed wounds to be covered in maggots and become putrid. Officials from local authorities move these people on in order to make their area look “clean”. They are unwanted and lie uncared for in their own excreta. These are the people that the IMCARES Pavement Ministry team reaches out to. The Pavement Ministry is comprised of street work and joy clubs.

Street work

IMCARES teams carry out daily rounds and identify people in need. They reach out to them; provide a hand of friendship; dress their wounds; and give them baths, clothes and food. Furthermore, when the team identifies someone who needs further medical assistance, they advocate on the person’s behalf to secure admission to hospitals and health care programmes such as voluntary HIV counselling and testing, and tuberculosis diagnosis and treatment through DOTS programmes. For many of these clients, the care and support provided comes too late and they die; however, other clients, through systematic follow-up, counselling and advice, are reabsorbed into society and are enabled to live with dignity. The Pavement Ministry is at the heart of IMCARES’ mission.

Joy clubs

Children living along the pavements in Mumbai are exposed to crime, alcohol, gambling and abuse, and are often lured into a vicious cycle of crime and destitution. IMCARES conducts joy clubs for 225 street children in different areas of Mumbai. Held on the streets where the children live, joy clubs aim to educate and challenge these children to grow up to be responsible citizens; they provide instruction on the Bible, in basic hygiene or other topics as may be helpful to the children. A wide range of methods such as games, poems, songs, dance and drama ensure that the children are engaged in the programme. The children are also given a healthy snack each day. The IMCARES teams keep regular contact with the parents of these children and motivate them to send these children to school.

2.3 Agape Community Care Centres

From all parts of India, unskilled day labourers work on constructions sites and roads or as rag pickers or doing other manual jobs, living in the sprawling slums spread across Mumbai. It is very common for their children to be left on their own while their parents are out working. These children are often neglected and grow up amidst the insecurities, abuse and negative influences of slum life.

IMCARES has three Agape Community Care Centres in the slums of Charkop, Dharavi and Mahim with two pilot centres in Bandra Pumpapur and Damunagar. The Agape Community Care Centres provide a range of services that aim to alleviate the suffering of the poor and to empower them, transforming the whole community. The services provided by the Community Care Centres include day care centres, a ladies' development programme (i.e. sewing classes) and medical clinics, including HIV programmes.

Day care centres

IMCARES conducts day care centres in Mahim, Dharavi and Charkop, catering to more than 450 children daily. Children attend pre-school classes, receiving a basic education, a healthy meal as well as a piece of fruit and a glass of milk. As parents are encouraged to send their children to local schools, the day care centres also provide study classes where the school-going children can do their homework after school and study in a quiet place under supervision. All children receive regular medical check-ups and medication as and when necessary. The day care centres aim to bring about a positive transformation in these communities by investing in the next generation through values-based education.

Ladies' development programme

IMCARES also conducts ladies' development programmes at its day care centres. Women are enrolled in classes where they learn tailoring skills from instructors. Some of these women go on to take the government-certified tailoring exams, which enable them to have greater economic independence through increased access to credit in order to set up a small business. Furthermore, financial independence means that these women are less dependent on the income of their husbands, which is often squandered on alcohol and gambling, and in the event that the husband, the primary financial provider dies, these women can support themselves and their children. To date, no such training programmes are provided for men, though IMCARES would consider sponsoring short-term training for men.

Mothers of children in day care attend the classes, as do teenagers and pre-adolescents with the majority of the participants being between 11 and 15 years of age. Up to 90 girls and women are reached every year through this programme, with a maximum of 30 persons at each of the Community Care Centres in Charkop, Dharavi and Mahim.

The programme also conducts periodic sessions on a wide range of topics to increase the well-being and empowerment of these women. The ladies' development programme is also a place where women come for social support, prayer and values-based counselling.

2.4 The Inter-Mission prevention of AIDS through care and training (IMPACT) project

IMCARES' response to HIV began in 1990, when Pavement Ministry workers found seven-month old Reshma in a garbage bin near a red-light district of Mumbai. Her mother, a sex worker, had abandoned her during a police raid. Reshma was HIV-positive. Initially, she was taken into the home of IMCARES' director and eventually placed in the IMCARES Agape Village in Paud, Pune. At that time little was known about the care of HIV-positive children.

Reshma's life

Reshma has grown up to be a beautiful 19-year-old girl living with HIV, still healthy and able to study. IMCARES cites her example as a testimony to the success of love and care in keeping HIV-positive children alive and healthy, as well as to what God can do if His people are obedient to His call on their lives.

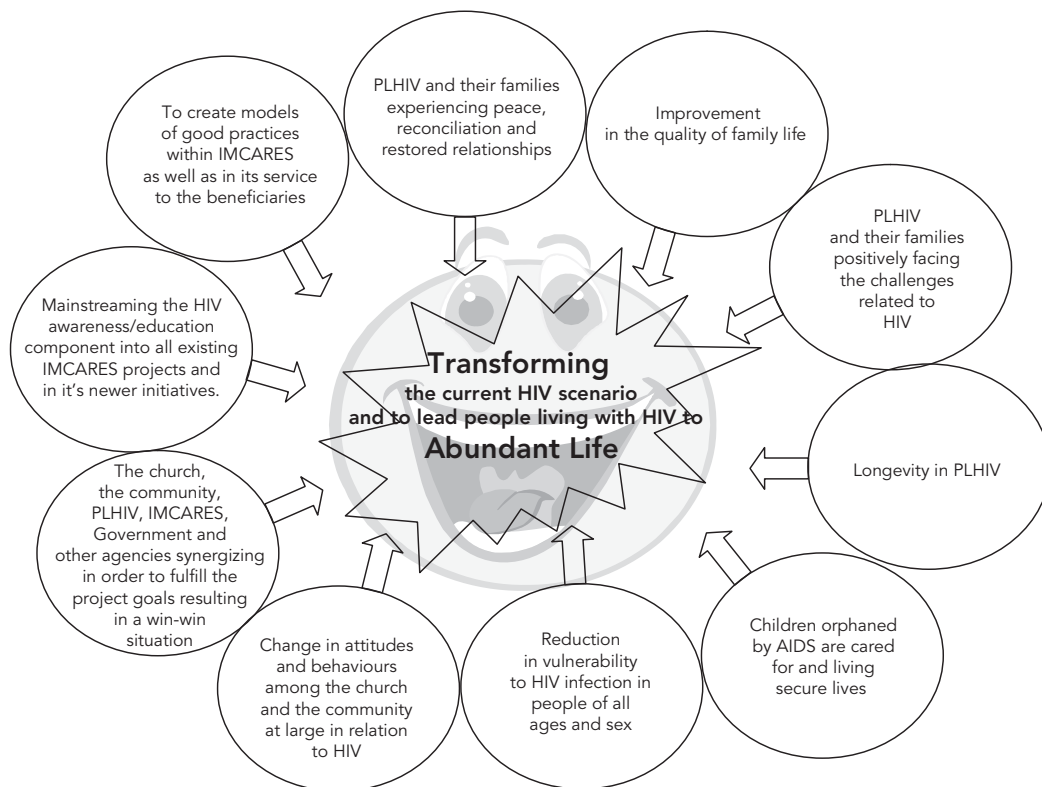
About 13 years ago, Reshma's case brought national attention to the situation of children living with HIV, in particular the importance of nurturing and caring for these children in a loving and supportive family situation. As Reshma was one of the first and longest surviving HIV-positive children in the country, thriving due to love, care and good nutrition without taking antiretroviral therapy, a delegation from the national Parliament visited IMCARES, interviews were conducted to verify the case and a film was made about her life.

This event brought to light the need to respond to HIV. The PACE Project, later renamed the Inter-Mission Prevention of AIDS through Care and Training Project, or IMPACT, was launched in November 1992 through the initiative of World Concern and TearFund UK in partnership with two local organizations, Action for Christian Thoughtfulness (ACT) and Inter-Mission. The result was two separate but complementary HIV programmes providing a Christian response to HIV in Mumbai. Subsequently, IMCARES has evolved its understanding and capacity to address HIV (See Annex 2).

IMPACT Project medical clinics operate from the Community Care Centres in three slums, providing HIV education, pre- and post-test counselling as well as bereavement counselling, medical care and support and nutritional support to 65 people living with HIV and their families. The community training course (discussed below) is an integral component of both the IMPACT Project and IMCARES' overall strategy. IMCARES is finding that more and more of the people on the street it has worked with are HIV-positive: three people in 2004, five in 2005 and twelve in 2006.

The IMPACT Project has been evolving with the HIV epidemic and the city of Mumbai's response. For example, previously, the IMPACT Project offered voluntary HIV counselling and testing, but as the government scaled up access to antiretroviral therapy programmes, several developments have led to these services being discontinued. Firstly, it is now a requirement for access to the government's free treatment programme that people are tested by government-accredited facilities. If IMCARES had continued offering counselling and testing, it would have resulted in duplication of services as HIV testing would have had to be repeated by government-accredited facilities at an added cost. Furthermore, the cost of government-provided voluntary counselling and testing is now heavily subsidized. Previously, an HIV test cost 150 rupees (US\$ 3.80) but now costs only 10 rupees (US\$ 0.25) at government-accredited facilities. In response to this development, IMCARES has ceased to provide the service and now provides people with referrals to the government-accredited facilities. A member of IMCARES staff will accompany a person for a test if he or she needs psychological support; if the 10-rupee charge and other associated costs are too great a financial burden for a person, the IMPACT Project may cover them up to 500 rupees (US\$ 12) for a CD4 test and up to 500 rupees for travel and incidentals, totalling up to 1000 rupees.

IMCARES' approach to supporting people living with HIV



People living with HIV and their families receive home-based care, dietary supplements and dry rations (for three months, though this period can be extended) through the IMPACT Project. IMCARES encourages long term self-sufficiency through training and work. For example, if a woman is not working, training is offered through the ladies' development programme to ensure financial independence, particularly in the event that her husband becomes too ill to work.

"In hospital, the patients came to you. Here, you go to the patients, you care for them. You are not just giving drugs. Some patients say that they have been to other doctors with no effect. When we come to you, we get better."

Prema, IMPACT Project nurse's aide

"I like working here because I am able to meet the needs of patients. When I am working with these people, I am strengthening them. Before, I didn't know much about HIV, now I have increased my knowledge."

Indira, volunteer care provider

"In hospitals, I used to work on patients who were undergoing operations. Here I can work WITH patients. Here I have learnt to serve different types of people. Early on I was afraid of working with HIV-positive people. I have learnt how to protect myself and I can give hope to people. I can encourage people and help them get back on their feet. This makes me happy. I used to be afraid of eunuchs. Now I can sit and be with them. This is serving God."

Nita, IMPACT Project nurse's aide

The IMPACT Project does not discourage people living with HIV from seeking support from other organizations whether religious or secular, or from the government. This is an acknowledgement that people are in precarious economic situations and that the IMPACT Project cannot provide for all the needs of a person. However, the IMPACT Project does try to keep up to date on which services a person is receiving from other organizations. For example, when a new client is registered with the IMPACT Project, a staff member will telephone other organizations in the vicinity to see which organizations are providing which services to the person.

The IMPACT Project also holds periodic (generally monthly) support group meetings for people living with HIV. An advocacy programme helps HIV-positive people to access other services such as antiretroviral therapy through government programmes or DOTS programmes for the treatment of tuberculosis. The IMPACT Project recognizes the importance of and promotes behavioural change and a responsible lifestyle that can prevent further HIV transmission. It aims to transform the community's response to people living with HIV from stigmatization to acceptance.

To date, IMCARES has not had to turn anyone away from its services, though some people have been referred to other organizations. Referrals to other services such as those provided by Médecins Sans Frontières and to the government's antiretroviral therapy and DOTS programmes are based on what people need. As one senior IMCARES staff member noted, a "web" of services for people living with HIV is now available in Mumbai, though information on what is available and where and how to access services is lacking.

However, IMCARES does provide services that the government and other organizations do not. For example, while people living with HIV can now register with government programmes for antiretroviral therapy and homoeopathic and traditional Indian medicines, the government does not provide any services or support for depression. The IMPACT Project provides counselling and support when people are discouraged, ill or depressed as well as nutritional counselling. Furthermore, the IMPACT Project counsels HIV-positive clients with the aims of clients accepting their diagnosis, understanding the need to disclose their HIV-positive status to family members to prevent further HIV transmission and understanding that they can still live, work and be part of their family. Counselling is also provided to other family members to work towards acceptance by the whole family of their common situation.

Community training course volunteers:

Since 1995, the IMPACT Project has trained over 100 church volunteers in HIV prevention and care skills through its community training course. Originally the community training course involved taking volunteers from different churches for six months of training, after which they would return to their own churches. However, people perceived that the community training course was in fact a job, as volunteers have no status in India (volunteers are often looked down upon for not being paid in a country where poverty is so generally widespread). As a result the course was restructured into a longer certificate course, providing full-time on-the-job HIV training for one year, with participants receiving a stipend, though they are not officially members of staff.

The aim of the community training course programme is to expose volunteers to the needs in their communities and to build their confidence so that they can respond to these needs by using the skills that they learn. Many of the volunteers take secular jobs or become church volunteers. One of the purposes of the training is for people to begin new projects or to integrate the IMCARES approach into other organizations and churches. The idea is that the philosophy of IMCARES will enter into the life and the work of churches in Mumbai so scale-up will be effected through replication of small-scale programmes with more churches actively responding to HIV – “new trees growing and bearing fruit”.

The curriculum for the community training course includes:

- one month of theory on social issues, inter-mission and biblical training;
- eleven months of hands-on training alongside staff members in community centres with one day per week of lectures at IMCARES headquarters;
- personal development, including dance drama and use of audio-visual equipment (i.e. making videos of the dance drama, which the course volunteers perform); and
- a basic computer-skills course.

While the community training course training programme, supported by TearFund UK, was developed for the IMPACT Project, placements for the hands-on training take place across all of IMCARES’ projects, supporting the whole organization. Most people following the course have known or met people living with HIV prior to their induction into the programme. Probably as a result, stigmatization of people living with HIV is not a significant issue among community training course volunteers.

Chapter 3: Burnout prevention – implementing strategies to prevent carer burnout

This chapter looks at an array of preventive measures that IMCARES has undertaken to minimize the risk of carer burnout. These include:

- investing in staff members;
- ensuring that staff members’ working conditions are adequate;
- ensuring that the operations of IMCARES are conducive to supporting and enabling staff members to fulfil their roles; and
- specific measures aimed at stress management.

3.1 Investing in staff members

This sub-section looks at the steps taken by IMCARES to build the capacities of its staff members. While investing in its clients, IMCARES has also recognized that investing in its staff members provides a number of benefits, including maximizing positive outcomes for its clients, and is an essential component in preventing carer burnout. Investments in staff members are made in a variety of ways, including through prayer and devotion, the recruitment process, training, providing opportunities for personal growth and networking, fostering the IMCARES family and creating a relaxing physical and supportive workplace environment.

Prayer and devotion

Crucially, all staff members come from their church to IMCARES, which means that all staff members have a strong Christian faith. Time and again when asking staff members about their motivation for working with IMCARES, phrases such as “serving the poorest of the poor”, “I am here because this is God’s work”, “God has chosen me to do this work” are mentioned. This motivation, combined with an overarching emphasis on prayer, underpins IMCARES’ work and how it operates on a day-to-day basis, and it is central to carer burnout prevention.

“I wanted to serve people and God. I came to IMCARES because its work is rooted in the word of God. We pray every day so we are strengthened. This is why we can do effective work.”

Mahendra, educator

“I grew up in an orphanage and saw how people served others through mission. I had a desire from that time to serve people. It was my desire to talk of God’s love to others. Through my work I am able to express the glory of God. I used to work in a factory where I could earn lots of money but I still had the desire to serve God.”

Yakub, IMPACT Project educator

Community prayer and reflection play a central role in the life of IMCARES. For example, in addition to private prayer, each day whether at the headquarters or at the community centres, all staff members spend approximately half an hour from 9 a.m. reflecting on and discussing the day's devotion from *Our Daily Bread*,¹³ which offers encouragement and hope focusing on the life-changing principles of God's Word. The text is translated from English into Hindi by one of IMCARES' staff members. Furthermore, this time allows people to rest and refresh themselves after the arduous trip to work, to talk and discuss matters.

"Daily devotions help us to grow."

Shrutika, accounts assistant

Insights from the daily devotion can be particularly useful in providing staff members with information on their role as carers. For example, a devotional reading on coping with caring, in addition to Biblical references, provided the following:¹⁴

A survey titled "Care giving in the United States" estimates that more than 44 million Americans are unpaid caregivers, and a majority of them currently work or have worked while providing care. The survey also found that God, family and friends were most often cited as sources of strength by people who are caring for others.

Three fourths of the respondents said they relied on prayer to deal with the demands of care giving. "Prayer is the best way to refresh yourself," said one person. "I find a quiet place and pray and cry and get relief. Then I can go back into the room calm."

Through prayer, we can step into the calming presence of the Lord and find strength to go on. As we bring our heartaches and needs to God, He meets us where we are and gives us peace. He is an ever-present help who cares for us in every situation.

Care giving is a high calling and a difficult task. But there is strength from the Lord to help us as we care for those who need us.

Prayer is not confined to the hourly devotion. Each Wednesday is set aside so that all IMPACT Project staff members (and all other staff members on alternate weeks) come to IMCARES headquarters; no project work is done during this time. Half of this day is devoted to prayer while the afternoon is given over to training and other activities such as writing reports or hospital visits. The rationale for this day off is to maintain contact with all members of staff and reaffirm and strengthen the family nature of IMCARES. Similarly, staff members also refer to each other as "brother" and "sister". Prayer also plays a role in being with clients. For example, staff members will pray with clients and clients often ask staff members to pray with them.

¹³ RBC Ministries <http://www.rbc.org/>

¹⁴ Our Daily Bread <http://www.rbc.org>.

Preeti Damodar Balaji

Preeti lives in Dharavi, a slum, with her husband and three children. After the 2005 floods, rashes appeared on her body. She was told by a government doctor that she was going to die; however, her HIV-positive diagnosis was not given to her. She told this news to her brother. Someone who the brother knew was involved with IMCARES and asked her to come to pray.

Her husband who was a migrant labourer has begun the community training course programme. A change has taken place. He takes time to take her to the hospital and is more involved in the family life, taking an interest in their three children. He is nominally a Christian and now regularly attends church.

“To me they are like a family that God has sent to me. They give comfort, take care and treat me as if I am not HIV-positive,” says Preeti about IMCARES.

Recruitment process

IMCARES as a Christian organization confines its workforce to Christians. Recruiting people to work for IMCARES takes a variety of forms. As part of IMCARES’ strategy for encouraging churches to respond to HIV and the social conditions prevalent in their communities, IMCARES has screened its videos in churches in Mumbai and encourages its staff members to speak from the pulpit in their own churches about the work of IMCARES. This word of mouth process, it is hoped, may spark an interest in some people in the congregation to work with IMCARES. IMCARES is now finding that churches are more open to discussing HIV than in the early days of the epidemic when many slammed their doors on people wanting to talk about HIV. Churches are slowly recognizing that they too have AIDS. IMCARES is fostering the notion that “me and you = IMPACT Project plus Church” can respond to HIV.

IMCARES also uses more direct methods for recruiting staff members such as advertising, particularly when there are distinct positions to be filled. However, the process is not simply an application and interview; the recruitment process is about finding people who have a desire to do something and who are willing to “go the extra mile”, to give something of themselves. IMCARES encourages prospective staff members to think and pray about whether working with IMCARES is what they really want. IMCARES takes a lot of time when taking on new staff members, believing that working with IMCARES is more of a calling than a job. This is one reason why there is no burnout among staff members as the people who finally do choose to work with IMCARES have made an informed, faith-based choice. IMCARES also recognizes that each staff member is an individual with his or her own needs, weaknesses and strengths, and encourages staff members to extend themselves.

"Here I am, serving the poorest of the poor and work with my own hands. If a patient is not able to walk, I carry him. I am giving practical care to people."

Ishwar, volunteer care provider

"I am only working here because it is a Christian organization. I am doing the work of God."

Sunita, IMPACT Project nurse's aide

"IMCARES is based on the word of God and that is the one reason I like to work here. I used to work in a hospital and I was not interested. I wanted to serve people and the love of God came into me."

Nita, IMPACT Project nurse's aide

Disclosure of HIV status, and stigma and discrimination are generally not a problem at IMCARES as staff members are carers and come with a calling, many of whom have worked with or known people living with HIV prior to working with IMCARES.

It is a minimum requirement that all IMCARES staff members have completed Year 10 at school (i.e. the school leaving certificate). However, as with many of IMCARES' methods, there are always pragmatic exceptions to the rule. While a person cannot be a staff member without this minimum education level, IMCARES has found creative ways to engage committed people while they complete their studies.

In the event that someone begins working for IMCARES, depending on their experience, he or she will be trained and placed on probation for a period, normally between six months and one year after which he or she becomes a fixed staff member. However, recruitment also emphasizes willingness and ability to learn on-the-job, rather than a formal professional training background as a major criteria for hiring. Many staff members do not have professional qualifications but rather have come from the communities in which IMCARES works and have learnt primarily through experience. Currently about 50% of IMCARES' staff members come from the communities that they are serving with at least one person from the local community working in each Community Care Centre.

The structure and organization of the staffing is designed to facilitate on-the-job training and support. It includes a system of rotation between locations for training and to facilitate team building, as well as new staff members receiving on-site guidance through monitoring visits by experienced supervisory staff. In addition, as an example of IMCARES' work, several current staff members were former residents of the Agape Village children's homes, gained on-the-job training through IMCARES or attended training programmes that equipped them for health or social work.

"When I was small, I lived on the streets. IMCARES took me in and provided well for me. I completed my studies and nursing training. I asked myself, "What can I do now?" I prayed to God. Someone provided for me, so I would like to serve needy people."

Gauri, IMPACT Project nurse's aide

Training

IMCARES views its staff members as its most valuable resource. Ongoing training provides staff members with the skills and knowledge to be able to fulfil their roles as carers and to cope with the environments in which they work.

In recognition that people give their hearts and souls to the project, IMCARES provides training not only on work-related issues such as HIV and computer skills but also on other issues that have a direct impact on the lives of staff members such as saving money, health insurance entitlements and how the health insurance scheme operates. Furthermore, IMCARES provides much of its staff training through hands-on experience. In recognition that the central requirement of staff is a willingness to serve, IMCARES operates on the basis that if staff members have this core motivation, then experience is the best teacher. As one person involved in IMCARES for many years stated, “I teach from experience, personal examples and experience”. Another staff member described training as “It’s like watering an earthen pot; water goes on and gets sucked in”.

However, as IMCARES has become a more professional organization with norms and structures, training has been provided on organizational development, HIV, home-based care, project management and values-based living as well as occupational health and safety for nurses. Funding partners, including TearFund UK and Inter-Mission Germany, also provide regular training support. Much of this training, which is provided to a limited number of managers through seminars, workshops and conferences in English, is then translated into Hindi and imparted to the staff using the training of trainers methodology.

The IMPACT Project care providers also receive periodic training on HIV-related issues. For example, nurses treating HIV-positive clients are trained in universal precautions as well as in the relative risks of infection through needle stick injuries and exposure to tuberculosis infection in the clinic setting. Interestingly, in the IMPACT Project focus groups discussions, there were requests for more information and training on antiretroviral therapies, particularly the new drugs, so that they can inform clients. Clients are quite well informed and staff members felt that they needed increased knowledge so as to be able to both inform and discuss with clients new antiretroviral therapies and other drugs that are becoming available. This is not just to be of service to clients but also to maintain their respect as, if the client is more informed than the care staff, this will undermine their position. These needs expressed by the care providers reflect the increasingly fast-moving changes in treatment and access to therapies taking place globally. The democratization of information is fundamentally changing the relationship of care provider and client.

An important resource for IMCARES’ management was the Myers-Briggs Type Indicator¹⁵ training to assess staff behaviours and personalities, and match strengths and interests to areas of work. This was an intensive, three-week training in three units of one week with the addition of a mentor for six months. In addition to the course materials being translated into Hindi and IMCARES’ staff members being trained, the Myers-Briggs training provided a useful resource for learning about staff members’ strengths and weaknesses. For example, one staff member with creative talents, who had been underperforming as a street play trainer and in developing information, education and communications materials, was as a result of the assessment moved to clerical work and has since performed extremely well while continuing to be involved in creative work.

¹⁵ http://www.personalitypathways.com/type_inventory.html

IMCARES also encourages its staff members to undertake training outside of the organization. Staff members can bring ideas of what types of training they need to IMCARES and the organization will search to see what training is available. Alternatively, a staff member may have identified a specific course that he or she wants to undertake. For example, one staff member had identified a three-day course, “Dare to be different”, on children’s sexuality, specifically peer pressure and abstinence, and was intending to bring this to the attention of management for support. Many staff members pay for the cost of training themselves or may be directly subsidized by IMCARES. In addition, IMCARES rewards staff for undertaking training through the salary review process; for example, a staff member undergoing training may receive a double salary increase in recognition of his or her increased skills, which benefit clients.

Volunteers working with IMCARES may also train staff. Previously a German volunteer trained the entire staff on basic computer skills, including MS-DOS.

Sanjay Waghmare

Sanjay Waghmare has now worked with IMCARES for 17 years. After leaving school without completing his school leaving certificate (i.e. Year 10), he worked as a lift worker and cleaner in schools. During this period, in his church he prayed for a life mission. His church gave him the address of IMCARES, which he approached, and he was taken on as a staff member in a low-level position. IMCARES encouraged him to complete his schooling, which he did through night classes after work. After he was married, he and his wife became home parents at a children’s home, and he subsequently worked in the Pavement Ministry. Now he is the project officer for the Children’s Home Project and has been supported by IMCARES to undertake a six-month social work training and a week-long home-based care training in New Delhi. He is about to participate in the VIVA network¹ conference on Invisible Children in Bangkok, Thailand.

“Jesus wants me to be a 100% disciple. The Lord speaks to our hearts as we walk and meditate on our work. The Lord does not make me responsible for the whole world, which is outside of my capacity. For those things that I can do he will make me responsible,” says Sanjay.

Opportunities for personal growth

At IMCARES there is a freedom to innovate and express ideas and every staff member has a chance to grow in experience and to improve their skills. Staff capacities, even skills such as singing, preaching and hospitality, are identified, strengthened and used to the maximum. IMCARES promotes building leaders, recognizing that leadership is not a position but a choice made by each person.

Networking

IMCARES encourages its members to network. IMCARES has found that many organizations are afraid of networking, fearing that their staff will move to another organization. IMCARES believes that even if staff members do move to other organizations, they will take the philosophy of IMCARES with them. As such, IMCARES does not view staff moving to another organization as a loss but rather as an opportunity for a new tree to be planted, which will ultimately bear fruit. IMCARES fosters non-competitive openness between organizations, particularly through the CORINTH Network (discussed below) and promotes the sharing of ideas, projects and plans, asking for input. IMCARES sees networking

as an important way to exchange information and ideas, and strengthening contacts between organizations can only benefit clients.

In 1992, three organizations, Inter-Mission, ACT and The Salvation Army, came together and felt the need to network on HIV. As a result, the Christian Organizations' Response in Networking to HIV/AIDS (CORINTH) was formed. CORINTH is not an organization but a functional network, facilitated by IMCARES.

However, over the years, essentially only the managers and leadership of the different organizations were networking, not the staff. In response and as part of IMCARES' internal review process, in October 2005, CORINTH in partnership with Christian AIDS/HIV National Alliance (CANA)¹⁶ held the first one-day meeting of care providers in which 89 people representing 15 Christian organizations (including people from Chennai, Tamil Nadu), working with HIV-positive people participated. This forum allowed carers to discuss good practices and the challenges that they faced. The meeting undertook a mapping exercise, which showed that the members of the network covered 205 areas across Mumbai, nearly the whole city. The day ended with an exhortation, worship and prayer.

One of the principal benefits of this meeting was that all of the care providers were encouraged to know that they were not alone but could see that there were other people facing similar challenges to their own and that there was much to learn from each other. As a result, one of the outcomes of this meeting was a call for a longer meeting in 2006. Even though this created logistical difficulties, a three-day retreat was held in November 2006 with more than 80 participants from Mumbai and Thane.

The "Fellowship of Care Providers", which was established through these meetings, will certainly continue as it is recognized that the greatest strength of any HIV project are the field staff, who need opportunities to refresh themselves and interact as a peer group. Staff members feel good when they can meet like-minded people struggling with similar challenges, and it provides a forum for exchanging information and creating a dialogue on successes. The flow of information also facilitates referrals within the CORINTH Network as people refer clients to the IMPACT Project when they know that it is working with people living with HIV and they understand which services are being provided and in which settings. The CORINTH Network also enables some stress situations to be dealt with through the sharing of experience, successes and failures by field staff.

Fostering the IMCARES family

IMCARES spends a lot of time, energy and thought ensuring that its staff members have the sense that they are part of a family, as well as allowing time out from the harsh conditions and emotionally draining situations in which they work. For example:

- **Wednesdays are kept as open days:** On this day the staff members gather together in the IMCARES office or at times in different locations to spend time in fellowship and to encourage each other. It provides an opportunity to discuss matters apart from work. IMCARES mandates that the open day is an essential activity for its staff.

¹⁶ Christian AIDS/HIV National Alliance <http://www.cana-india.org/>

- **Staff retreats:** IMCARES undertakes annual staff retreats to which the spouses and children of staff are invited. While not all staff members take the opportunity, financial constraints are not an obstacle to participation. Depending on the financial situation of the family, IMCARES may subsidize or pay the costs of a staff member and his or her family.
- **Family visits:** IMCARES places an emphasis on visiting staff members in their homes in the event of hardship or illness. This is partly in recognition that families are making financial and other sacrifices if a member comes to work for IMCARES but also to strengthen solidarity between staff members.
- **Christmas celebrations:** IMCARES invites all staff members and their families, including those from the Agape Village children's homes in Pune, to Christmas celebrations held in Mumbai, providing the possibility of accommodation for those who require it.

Creating a relaxing physical and supportive workplace environment

At IMCARES headquarters, efforts to create a relaxing environment for the staff include the installation of an aquarium and table tennis, landscaping the garden, refurbishing the training hall, and installing air conditioning.

At the time of writing (2007), IMCARES is in the process of rewriting a child protection policy and intends to develop a policy on HIV in the workplace. These moves to formalize workplace policies add another level of security and accountability for staff members.

3.2 Staff Members' working conditions

This sub-section outlines the steps taken to create a secure working environment, which is crucial to ensuring that staff members are not ill at ease about their ongoing employment and ability to support their families, both of which can create stress affecting their ability to perform and contribute to carer burnout. The working conditions that IMCARES has instituted create a stable and predictable working environment for staff members. Job security and clearly defined entitlements such as salaries, health insurance, holidays and maternal leave, as well as the availability of special measures in case of emergencies, ensure that staff members have a sense of security, that they feel that their work is appreciated and valued, and that they know that they will be supported in case of personal or family emergencies.

Job security

One of the measures that IMCARES has instituted that creates security for staff is that once new staff members have completed their probation period they become fixed staff with full entitlements. This means that people are hired as staff, not tied to a specific project. Often organizations employ staff on a contract system tied to specific projects. If, for whatever reason, funding for the project ceases then staff can find themselves unemployed. The fact that IMCARES' staff members are employed by the organization rather than on a project basis means that the employment of staff is secure. While this has financial implications for the organization, it does create a secure working environment. Staff members do not have to think about whether they will have a job next week or next month.

As IMCARES explains:

“Each staff member working in IMCARES has a job security. We believe that if staff members feel insecure in their own future, they cannot invest security in those who have lost all hope. Our pay packages are competitive compared to other mission organizations. All the rules and regulations, remunerations and facilities are designed in line with the labour laws set by the Government of India”.¹⁷

Entitlements

Staff entitlements are in line with statutory entitlements, neither low nor lavish. All staff members are encouraged to ask the accounts department if they have questions about entitlements, health insurance or other work conditions-related issues. Staff entitlements include:

Salaries:

- Salaries range between 3 500 and 14 000 rupees per month. The salary scale was revised in 2006 after IMCARES convinced Inter-Mission Germany and TearFund UK to cover the staff costs for the IMPACT Project. Salaries are now competitive with other faith-based organizations but below those offered by nongovernmental organizations and government agencies.
- The staffing grade system was developed by IMCARES and payments are in line with the government’s minimum wage levels.
- The salary structure is performance-based. Staff members set their own targets, and performance against these targets is assessed during the appraisal process with pay rises made accordingly.
- IMCARES may contribute to the costs of staff training or in some instances staff members pay the entire amount. However, staff members undergoing training are entitled to a double pay rise.
- In addition, IMCARES has an Employee Provident Fund, offers gratuity payments when leaving IMCARES and contributes to a pension fund (for staff members 59 years of age and over).

Health insurance:

The cost of health insurance is 2000 rupees (US\$ 50.70) per person per year, half of which is paid by IMCARES and half by each staff member. However, the health insurance only covers people if they are hospitalized for more than 24 hours, something which staff members were not aware of until one staff member became ill. The staff members have now all been made aware of this. Furthermore, coverage was increased from 15 000 rupees (US\$ 380) to 1 lakh rupees (i.e. 100 000 rupees) due to the rising cost of health care. This level of coverage is viewed as adequate due to the relatively young age of IMCARES’ staff. However, pre-existing conditions are excluded, including conditions that develop during the period of coverage (i.e. a chronic illness is covered during the first episode, but if it recurs during subsequent years, it is deemed to be a pre-existing condition).

¹⁷ Gaikwad T (2006). Ten Good Practices of Caring for Care Providers. XVI International AIDS Conference, Toronto, Canada.

Holidays:

All members of staff are entitled to the statutory holiday entitlements, which includes 23 days holiday per year and six days institutional leave as well as 10 days sick leave.

Parental leave:

Women are entitled to 90 days of maternity leave. This is the one area where management identified that discrimination takes place in the workplace, as currently fathers receive no paternity leave.

Special measures

While IMCARES provides entitlements in accordance with statutory entitlements, the organization has been extremely flexible when unforeseen circumstances arise. In effect, there are the statutory entitlements but parallel to these, there have been an array of ad hoc measures to respond to exigencies that various staff members have faced. Some examples of special accommodation measures are:

- A senior staff member was diagnosed with tuberculosis in the spine in December 2006. She received one month paid leave and worked from home for three months. In addition, board members called and she received home visits from IMCARES staff members and friends.
- In one case, the potential for burnout was recognized in one staff member. She was told to take off 10–15 days and spend time at home to rest and revitalize.
- Two staff members lost everything in the 2005 Mumbai floods. IMCARES provided funds for these two staff members. One staff member received 35 000 rupees.

(US\$ 887.70) to purchase items such as clothing, a radio, school books, etc. This staff member was a habitual borrower from other staff members so rather than providing cash, IMCARES accompanied the person to go shopping. An accord was made with IMCARES so that money is paid into a fund and the debt is slowly repaid. The other staff member was provided with a 25 000-rupee cash loan to buy necessary essentials. Normally such loans are only available for staff members when they are married or for housing purposes.

"IMCARES is a family. People help each other, share their problems and pray with each other. In 2005, there were the floods in Mumbai and my home was inundated. IMCARES helped a lot. IMCARES inquired about my situation and helped financially."

Shakuntala Nagre, IMPACT Project officer

"During the 2005 floods, my wife and children were saved but my house was flooded. IMCARES helped in every way. IMCARES helped to restart the family."

Yakub, IMPACT Project educator

In relation to assisting the two staff members affected by floods, questions could be raised about whether this was an appropriate use of the organization's time and resources. However, IMCARES believed that this was a special effort, responding to exceptional circumstances and in the longer term meant that members of staff were in a position to fulfil

their mission, rather than being focused on their family's situation. It was an expression of the caring, family nature of IMCARES.

Furthermore, IMCARES responds to family problems, providing extra leave when there is no provision. In the event of such needs arising, the director talks with the board, explaining the situation, and seeks approval for extraordinary measures. IMCARES has also responded to financial burdens placed on parents. Schools now require that school fees are paid in full at the beginning of the year. IMCARES has responded to this change by advancing the money to its staff, which is repaid during the course of the year. IMCARES believes that putting its staff at ease will reduce stress and ultimately ensure that clients receive better care.

Whether all organizations are in a position to be so flexible in their financial and staffing arrangements would depend on the financial situation in which any given organization finds itself. Clearly, for IMCARES such measures are sustainable while the number of staff members is not too large and the funding base is relatively stable.

"While working here I have direct contact with leadership, including the director. Our director is invaluable. Increased help when I was ill: for example, I was given more sick time than statutorily available. He also visited me and prayed with me."

Rajratnam Imlapur, counsellor

Another faith-based initiative working in Africa

Mothers Union, Diocese of Kigali, Rwanda

The Mother's Union, Diocese of Kigali, Rwanda, targets genocide victims where 70% of the women are widows, and as such are the most vulnerable group and who must bear the responsibilities of caring for households. The Mother's Union is providing care to care providers at two levels:

- the widows; and
- trained volunteer staff, mainly comprising widows.

Peninah Kayitesi, the Mother's Union coordinator, describes the group's guiding principles as, "Through the Diocese of Kigali, we had a vision to heal people in a holistic way, addressing their spiritual, mental and material needs. Women comprise the majority of survivors and are usually in the most vulnerable position and yet, they are instrumental in building up households, the society at large and also the church. We have a vision to build a new Rwanda and strengthen the church, by empowering women, starting from their household."

The Mother's Union cares for these important community care providers in a variety of creative and contextually appropriate ways.

- The Mother's Union runs a day care centre for the children and young people for whom these women care.
- Through the Mother's Union, women have access to income generation activities, which provides them and their children with financial support and/or security.



- The Mother's Union's also provides agricultural education outreach to improve agricultural knowledge and practices. For example, previously entire communities would plant identical crops, taking their cues from each other. As such, women missed market opportunities. Furthermore, women lacked education on seasonal planting and food storage, lowering their ability to provide for their households.
- The Mother's Union has come to understand literacy as an important means of caring for care providers. Kayitesi observes that illiteracy keeps the poor in poverty because they are ignorant of the value of their work. She contends, "People don't know how to count; they sell their produce for too little; they don't know how to value their work. Middlemen take their money. Many people do not know how to pay taxes and they are cheated." Providing literacy skills leads to measurable progress as it enables women to cope within their society and care for their small business. Furthermore, the Mother's Union highlights the often overlooked role of literacy in spiritual anchoring and cultivating a sense of hope, crucial for providing holistic care for caregivers. The endeavour has required partnership with locally based organizations and continuing moral support from the Church.
- The Mother's Union invests deeply in the spiritual life of both volunteers and programme participants. Regular, frequent meetings for prayer, biblical teaching and counselling are held. Strong bonds are formed among the women, who love and support each other and have committed to supporting each other through prayer. Strong bonds are also formed among women as they work together to generate income through sewing, knitting, basket-weaving and animal husbandry.
- The Mother's Union follows up with their trained volunteers regularly. Volunteer staff meet with community-based volunteers and members every three months to resolve problems and identify any needs for further technical assistance. Programme leaders also visit groups periodically for both follow-up and additional training. Such visits encourage volunteers as they feel supported and connected to the Mother's Union network.

3.3 IMCARES Operations

This sub-section outlines IMCARES' operational methods, which are designed to create security and transparency for its staff, reducing uncertainty and stress and the resulting risk of carer burnout. For example, the fact that development and ownership of projects rests with staff highlights the confidence placed in them by management, strengthening their feelings of self-worth and confidence. IMCARES is also transparent with its staff members, particularly about budgets and funding, which again creates confidence among staff, reducing uncertainty and stress. The daily diaries, which staff members are required to complete, ensure that self-monitoring by staff and monitoring by supervisors is part of the support mechanisms that have been created to identify issues and potential problems before they lead to poor performance or burnout.

Ownership of projects

The care providers take ownership of their projects. They are involved in every part of the design of the logical framework, budgeting, reporting and evaluations. They choose what they are supposed to do. This in itself reduces a lot of the stress as the targets they set are

realistic and SMART.¹⁸ Management personnel are encouraged to give a spring board effect to the project, giving directions and corrections wherever necessary but always making sure that the care provider at the field level feels in control rather than imposing a top-down approach, which tends to pressure staff. Regular self-appraisals by staff members are carried out and actions taken to ensure that projects are implemented in line with the original vision.

“IMCARES has different projects and staff get experience of working with all projects. When I joined IMCARES, I was working with the Pavement Ministry in the morning and with people living with HIV in the afternoon. When there were special programmes such as Bible classes or summer camps for children. We can work with sick, community people – different types of people.”

Rajratnam Imlapur, counsellor

Operational transparency

IMCARES operates on the basis of transparency with staff, donors and clients.

In terms of the staff, IMCARES is open as to what financial resources are available and encourages its staff to propose innovations and new projects responding to the needs that they identify in the communities in which they serve. This can lead to discussions and disagreements regarding priorities. However, if there are disagreements, these are discussed openly and in some instances the needs identified by staff may prevail.

Clients are also sometimes asked about their needs and services are adjusted accordingly. For example, IMCARES normally provides people living with HIV with a food ration of wheat flour and rice. However, one client said that he did not eat wheat so the food ration was adjusted to provide extra rice.

The people living with HIV support group normally meet at the Community Care Centres and are involved in activities. At one support group meeting, people living with HIV expressed the wish to live outside the slums. IMCARES, without raising expectations, responded that it would look at the possibilities and assess the financial implications.

IMCARES also seeks to be transparent with donors, whether small or large. If funding is provided for a specific project, this is noted in reports. If there is a dispute with donors over how money was spent, IMCARES is open as to why money was spent in a certain way and makes clear that its first priority is to respond to community-identified needs rather than donor priorities.

Diaries

Each staff member is required to fill a daily diary, which becomes the property of IMCARES. Each day staff members are expected to write four to five lines on each of the following: reflections on the daily devotion, what work he or she did today and what the person is taking away with him or her. These are housed in the library for anyone to view and are used for monitoring and evaluation purposes. Members of staff are aware that if they have not completed their daily entry then they have, in effect, not worked that day.

¹⁸ Specific, Measurable, Achievable, Relevant and Time-bound (SMART) is a mnemonic used in project management at the project objective-setting stage. It is a way of evaluating whether the objectives that are being set are appropriate for the individual project.

The diaries provide both staff and supervisors with a means of reviewing how they are doing both in work and morale (for example, ongoing low staff morale and discouragement is revealed by the diary entries). Furthermore, the diaries serve as part of IMCARES' institutional memory. For example, if a staff member needs to know which activities a certain staff person did in a specific location, if they know the approximate date they can find the entry in the diary filed in the library.

Another faith-based initiative working in Asia

AIDS Care, Education and Training, Thailand

AIDS Care, Education and Training (ACET) seeks to mobilize the Christian church in Thailand to reach out to people living with HIV and their families, trains volunteers for community care and organizes support groups for people living with HIV and their families. ACET started its home-based care programme in Bangkok and now includes the surrounding provinces in Central Thailand. Since 1998, ACET has had 147 volunteers from 83 churches in Bangkok and Central Thailand who have made home visits once or twice a week to over 320 people living with HIV and their families.

As of September 2005, ACET had retained all of its volunteers. Several practices have been identified as promoting this outcome, including:

- ACET bringing together its volunteers two or three times annually to share with each other and to provide them with training on relevant issues such as antiretroviral therapies and healthcare. Volunteers are permitted and encouraged to bring their families to these retreats. The inclusion of families shows volunteers that they are valued as whole people, embedded in relationships and their communities, and is crucial for maintaining motivation among volunteers.
- throughout the year, ACET's staff conduct informal meetings with volunteers to provide them guidance or counselling. Two ACET staff members go to Singburi three to four times each month to oversee the work there and recently, a full-time coordinator, who lives in Singburi, was appointed. Proximity of the leadership to volunteers allows for accountability and ongoing support – the key to retaining staff.
- finally, churches involved in ACET provide group Bible studies with prayer and sharing for volunteers and supportive community members.

The nature of care is also changing. As the Thai Government has started to provide antiretroviral therapy free of charge to HIV-positive people, the health of many clients has improved greatly. Many clients have been able to return to work and provide for themselves and their families. This in itself is good. With more people out working, home visits are less often necessary than previously when people were ill at home. However, people living with HIV often have an initial reaction when commencing antiretroviral therapy and members of hospital staff have expressed their appreciation of the follow-up provided by ACET through home visits to encourage adherence to therapy.

3.4 Stress management

This sub-section outlines a number of measures that have been undertaken by IMCARES to reduce stress in the workplace. In order to reduce stress and thereby prevent carer burnout among IMPACT Project staff members, IMCARES has introduced an array of practical efforts to reduce stress such as keeping Wednesdays as an open day, setting achievable work-related targets, making provisions for shared responsibility and case sharing, ensuring clearly defined working hours, maintaining faith as central to IMCARES staff members' work,

and providing practical care for care providers when they are ill or in need. Furthermore, the IMCARES director is also supported in his work through a variety of mechanisms that aim to minimize and alleviate stress. Finally, IMCARES' board members also play a pivotal support role for both staff members and management.

Practical efforts to reduce stress

IMCARES has spent time and effort creating working conditions that reduce some of the more strenuous aspects of care providers' work. For example, during the summer months, home visits in the slum communities are curtailed due to the extreme heat.

Wednesday as an open day

As has been outlined previously, Wednesday is an open day for IMPACT Project staff with no programmes; instead relaxation, prayer and reflection, discussing family and work matters, and fulfilling administrative tasks or undertaking training or similar communal activities are undertaken.

Setting targets

IMCARES also assesses work loads with the input of staff so that targets are realistic and attainable. For example, a calculation is made about the time that each home visit takes, including average walking/travel time between homes and rest time between visits, and the eight-hour working day is divided by this time. This provides the maximum number of visits per day, which sets a limit on how many people can receive home visits. The only way to increase the number of home visits is by increasing the number of available staff. In effect, IMCARES is ensuring that staff are not overtaxed or stressed by unrealistic work demands.

Shared responsibility and case sharing

While each staff member has his or her own project areas, case sharing takes place in the event of emergencies. For example, the Charkop slum is a considerable distance from the hospital. If a client from Charkop becomes ill and needs to be hospitalized, instead of Charkop staff visiting the client with all the travel involved, IMCARES staff members in closer proximity to the hospital in combination with family members will undertake visiting duties.

Clearly defined working hours

Nurses and care workers in the medical clinics not only have clearly defined working hours, there is also a half-hour period at the end of the day in which any issues between staff members that have arisen during the day can be solved. This debriefing time means that when staff members finish work, they do not take work home with them and that their home time is spent with their family rather than mulling over real or perceived hurts.

"This is 9-5.30 work. After that I can go home and am with my family. There are no nightshifts. It is a five-day working week. I have job satisfaction".

Shakuntala Nagre, IMPACT Project officer

Faith is central to IMCARES staff members' work

Everything extends from people's faith and calling. While there are at times disagreement and debates, in the end everything is said for the good of people served. When decisions are made, the staff members come together for a cause, which takes away the stress.

Practical care for the care providers

This is also part of IMCARES' work. For example, if a staff member is sick, whoever is closest will visit. Further, staff members know each other's families through annual retreats, Christmas gatherings and other events. As a result, the staff members are also a source of counselling and support for each other. Wednesday meetings and eating together at lunch provide opportunities for sharing, and management ensures that it is available at all times to provide assistance to staff when needed. Furthermore, while IMCARES believes that people are responsible for their behaviour and must face the consequences of their action, it also lets staff members know that there is a way out for every situation.

Who cares for the director?

The director leads IMCARES by example with his Christian faith and family at the centre of his life. As Timothy Gaikwad states, "If I cannot care for my family then I cannot care for anyone else." His wife, Sonali, echoes this with a slightly different emphasis, "I point out to Timothy that if you do not care for yourself then you cannot care for others properly."

This dichotomy highlights the gap that can arise between knowing something and acting on it. The director's position entails a lot of responsibility, including ensuring the livelihoods of some 65 personnel, including Indian and overseas volunteers, as well as serving the clients, the reason for IMCARES' existence. While the funding base is relatively secure, the director is responsible for ensuring that donors' needs are met, new resources are raised, competing priorities are resolved, the day-to-day operations of IMCARES continue and IMCARES continues to grow in fulfilling its mission. In addition, the director has undertaken to be available to staff members as and when they need him.

However, despite such pressures, IMCARES as a family has developed a number of mechanisms by which the director has the ongoing support of both staff and the board. While he is available for the staff, the board is available to support him. The director feels that he can pick up the telephone at any time of the day or night and board members will listen. In this sense, the board is a major source of support through its members making themselves available and their demonstrated willingness to be involved in work.

In IMCARES we believe that each one of us is a care provider to the other. The Director is also a care provider to the staff. The Board of IMCARES cares for the Director. The Board of IMCARES regularly empowers, encourages and advises him on various issues.¹⁹

The staff is also a source of support for the director. His position involves frequent travel – over 22 000 km annually. Mobile phones allow staff to keep in contact and they use them to keep in touch with the director when he is travelling, offering support and words of encouragement. Furthermore, staff members also pray for the director and, as with all IMCARES members, home visits are also extended to him.

¹⁹ Gaikwad T (2006). Ten Good Practices of Caring for Care Providers. XVI International AIDS Conference, Toronto, Canada.

The director and his family live above IMCARES' offices, which can be difficult and in itself creates its own dynamics. As Timothy Gaikwad says, "The pay packet is not the rationale for involvement. Inspiration is the motivation for my work with IMCARES. I get down and dirty my hands and use my skills. My media skills complement my work and I still do photography for relaxation."

Role of board members

The board plays an important supportive role in IMCARES work. In addition to being a source of support to the director, board members sometimes attend staff meetings, offering encouragement and expressions of appreciation for staff and the director, which helps reduce stress. The board cares for ordinary people.

Chapter 4: Lessons learnt from IMCARES' measures to prevent carer burnout

The lessons learnt have been divided into those that are specifically faith-based and those that may be undertaken by any organization. While this is an artificial distinction, it is aimed to assist the reader to assess which interventions are most likely to suit his or her organization. In addition, IMCARES and how it operates is only one example of how a faith-based organization has responded to the needs of its clients and staff in the particular settings in which it operates. Readers are encouraged to assess their own organizational settings and to adapt measures to meet the demands and circumstances of their own operations. It should be stressed that there is no one answer to responding to carer burnout. Instead flexibility, transparency and dialogue are needed in responding to the physical, psychological and spiritual needs of care providers.

It needs to be stressed that the funding base for IMCARES is largely secure, which has an enormous impact on both day-to-day operations and long-term planning and responses. The IMPACT Project receives 70% of its budget from TearFund UK, leaving IMCARES to raise 30%. This 30% and the overall funding for IMCARES are provided by Inter-Mission Germany and other partners such as Rushmere Christian Fellowship, Faith Missions Trust and a few Indian donors. This relatively secure financial base means that the management and staff of IMCARES know that funding is both available and relatively secure. Furthermore, the “wind-up” costs (i.e. pensions and other entitlements of the organization) are also covered. In effect, one of the major causes of stress – whether an organization has funds to continue – is not an ongoing issue for IMCARES. This financial stability should not be underestimated in creating a secure work environment for staff, most of whom have families and other commitments.

4.1 Faith-based lessons

Take time for prayer, Biblical reflection and devotion

Central to the success of IMCARES is that its staff members are grounded in their local church and come to IMCARES as committed Christians. All staff members are Christians; yet, as has been highlighted, IMCARES is a multi-denominational organization with staff members coming from 17 different churches. Faith is central to people's motivation and work. IMCARES provides a loving and caring environment in which care of the spirit is nurtured as much as the physical care of its staff and clients. In this respect, daily devotions, which entail both morning and evening prayers, for IMPACT Project staff members play a central role in the life of the organization. Prayer and reflection have equal weight in terms of the time available during the working day.

Church as a source of nourishment for the staff

IMCARES has learnt that a Christian organization cannot compensate for the nourishment and fellowship a care provider receives from his or her local church. Staff members are encouraged to be involved in their own church activities and IMCARES never turns down leave applications for church retreats or family camps.

4.2 Practical measures

Taking care of staff

IMCARES spends a lot of time on staff recruitment to ensure that new staff members are people with a faith-based mission. Thereafter IMCARES treats them as family, creating working conditions that assist staff members in fulfilling their mission. For example, job descriptions and tasks are clear, pay rates have been reformed and increased for some of the lower paid staff, training and achievements are rewarded by double pay increases, staff members undergo self-appraisals, and problems inside and outside of work are discussed with individual members of staff.

Setting achievable targets

The IMPACT Project has set achievable targets for its staff. These targets were set through an assessment of what can be achieved in a day, with input from workers, and are relatively fixed. For example:

- Home-based care targets were made including the time for travel to and from people's homes.
- As the needs of community work are endless, nurses are asked how many patients they can see. Once the limit is reached, only emergency cases are seen, with other clients being asked to come to the next clinic session.
- Doctor's consultations finish at 5pm, which allows the nurses half an hour to complete tasks, and reporting duties are kept to a minimum.

Most importantly, these targets are adhered to. People are not overtaxed, and by setting targets with the input of staff, joint ownership is achieved.

Fostering interpersonal relationships

One of the strengths of IMCARES is the family bond that is created between staff and the support provided to people. As one staff member described it, "It is like a fire net being held by people. If a person needs to jump, he or she can, knowing that he or she will be caught." Furthermore, IMCARES actively fosters interpersonal relationships through an annual picnic, Christmas festivities (which now go over several days and are attended by people from the Agape Village children's homes) and the communal Wednesdays held at headquarters. All IMCARES staff members attend on the first and third Wednesday of the month and IMPACT Project staff members attend every Wednesday, as their work is seen as more stressful.

"IMCARES shares in all aspects of our lives. If we do anything wrong, we are corrected. I can learn from my mistakes."

Sunanda, care provider

"There is a family atmosphere. We have a family relationship with both the staff and with the patients."

Sunita, IMPACT Project nurse's aide

Ensuring a safe work environment

An array of common-sense, practical measures have been introduced to protect the safety of staff. For example:

- Home-based care and community outreach involves sending two people together for company and protection, as the settings are potentially dangerous.
- During summer (March to May), home-based visits are curtailed due to the extreme heat.
- While nurses rotate between the clinics, they remain at any given clinic for a reasonable period of time so that their daily life becomes regular and they do not have the constant turmoil of changing clinics.
- Staff members, particularly the nurses, have been promised access to post-exposure prophylaxis in the event of exposure through needle stick injury. However, more importantly, the medical doctors have explained to the staff that working with tuberculosis and HIV-positive clients is never without risk, though the relative risk of HIV infection through occupational exposure is minimal. Universal blood precautions are adhered to.
- Vaccination for a number of infections has been provided at no cost. Vaccination has cost implications for IMCARES. As a result, hepatitis A and B, tetanus, encephalitis and typhoid vaccinations have been provided on a staggered basis over the past few years or when urgently required (for example, typhoid vaccine was given during the Mumbai floods).

Creating a time for sharing

At the end of each day, staff members have the opportunity to discuss disagreements and to sort out any problems. As one nurse said, “When I go home, I leave the work behind.” This debriefing allows issues to be discussed before they are allowed to fester and create disharmony.

Not promising clients more than can be delivered

Staff members are encouraged not to promise clients more than can be delivered. This has two rationales: firstly, to avoid raising the expectations of clients and then not being able to meet them, and, secondly, to avoid placing staff in the position of disappointing clients, which can result in feeling that they have let the client down. Staff members are encouraged to “walk with the client” with the philosophy, “if God wants to provide, the necessary things will come”. Furthermore, people living with HIV are treated as whole people with families and other cares and responsibilities, not just as people living with a virus.

When staff members work they are not just givers but also receivers

Many of IMCARES’ staff members have previously worked in government hospitals or secular nongovernmental organizations. In both instances, staff members spoke of something missing in terms of the lack of time they had to develop relationships with patients. Staff members talk about their work with IMCARES as filling this void, providing satisfaction and feelings of being blessed. For example, home-based care and community outreach allow the time for relationships to be built between staff and clients. Many of the

staff members do not see themselves just as service providers but feel that they are received into the families with love, which provides strength to the staff. The positive feedback from clients greatly supports carers in their mission.

"As a nurse, my contact with patients was limited to giving drugs. With IMCARES I can sit and pray with people. Initially I was scared of working with eunuchs but after I had worked with them I can sit and talk and meet them. One day, one eunuch said, "You are my family." This made me feel good. The kind of relationships which get built are important. We receive the same types of comments from patients."

Premlata, IMPACT Project nurse's aide

"In hospital I was only doing physical work, what the doctor ordered me to do. Here I can touch people, I can touch their lives, and I can advise them. In hospital there was no time to touch on people's personal problems."

Shakuntala Nagre, IMPACT Project care and support officer

Transparency with staff about available funding

As noted above, IMCARES, in particular the IMPACT Project, has a relatively reliable and sustainable funding base. In addition, management is open with the staff about what funds are available, which means that staff members are aware of the financial health of the organization and what funds are available for which projects. This is particularly important in developing new, community-based projects and ensuring ownership of these.

Projects are in response to community-identified needs

Unlike many organizations, the inspiration for projects comes from the field workers and clients rather than being imposed by management or in responding to the priorities of donors. Clients are encouraged to express their desires and needs, and field staff can bring forward proposals for new projects or programmes based on observed needs. IMCARES as an organization has a philosophy of responding to clients' needs rather than chasing the "donor dollar". Donors are presented with proposals that reflect needs in the community and are encouraged/invited to fund these. Furthermore, IMCARES will not solely undertake or tailor a project just to meet the needs of donors. As such, ownership of projects rests with communities, and their design and implementation is in response to community-identified needs.

The benefits of integrating services under one roof

The Community Care Centres provide a range of services such as clinics, day care centres for children and training classes for women. Staff members are encouraged to move around the centre and can be with children if they have experienced highly emotional experiences (for example, being with a dying person in a hospital or at home). Having the children on site is in itself a healing process, taking staff members away from the darker side of their work.

Envoi

Critics could argue that IMCARES and its IMPACT Project are small scale and labour intensive, underpinned by a secure funding base and that moving towards universal access to HIV prevention, treatment, care and support services requires large-scale, public health approaches. However, an alternative view is that long-term HIV care and support may be addressed effectively by a web of small scale, dedicated projects that respond to community-identified needs, investing in both the clients and carer providers ensuring a sustainable, functioning support network. In the case of IMCARES, this work is underpinned by prayer and devotion. While it may be costly and time consuming, placing people in the centre of the AIDS response, both as carers and clients, may be the only effective response both in terms of quality of care and ensuring that carers do not suffer burnout.

This study focuses on the experience and practice of one faith-based organization but UNAIDS recognizes that throughout the world, since the start of the epidemic, many different faith communities and faith-based organizations have played a major and literally vital role in the AIDS response. Their responses have been all the more remarkable and valuable because understanding HIV transmission necessarily involves addressing the reality of sexual and other behaviours that may be regarded as unacceptable or wrong within the context of faith-based values. Leaders of faith-based communities have shown courage in addressing such issues, vision in guiding their communities and care in their teachings in the response to AIDS. Working with broader communities, extending supportive outreach to those infected and affected, supplementing official action, or being often the only providers of care and support, all members of faith communities play their part. Without their work, the burden of suffering imposed by HIV would be many times greater. Their contributions, whether large- or small-scale, will remain an essential part of the long-term task of sustaining an effective response to the epidemic.

Annex 1: The AIDS epidemic in India

Estimates of HIV prevalence in India have been controversial for a number of years. The new 2006 estimates released by the National AIDS Control Organization, in India, supported by UNAIDS and the World Health Organization on 6 July 2007,²⁰ indicate that national adult HIV prevalence in India is approximately 0.36%, which corresponds to an estimated 2 million to 3.1 million people living with HIV in the country. The revised estimates have been possible largely due to three main factors:

- a new population-based survey that included an important HIV component;
- expanded sentinel surveillance that included groups at higher risk of exposure to HIV; and
- revised methodologies to make the best use of the new data.

As part of its continuing effort to know its epidemic better, the Indian Government has greatly expanded and improved its surveillance system in recent years and increased the population groups covered. In 2006, the government created 400 new sentinel surveillance sites and facilitated National Family Health Survey-3, a population-based survey.

Launching the third phase of the national programme, Dr. Anbumani Ramadoss, Union Minister for Health and Family Welfare said, “Revision of estimates based on more data and improved methodology marks a significant improvement in systems and capabilities to monitor the spread of HIV, a sign of the progress we have made in understanding the epidemic better. This is welcome progress. Unfortunately, the new figures still point towards a serious epidemic with the potential to trigger off if the prevention efforts identified in the NACP III are not scaled up rapidly and implemented in the desired manner. We must remember that India has nearly 30 lakh [three million] people living with HIV. These are people facing stigma, discrimination and irrational prejudice every day of their lives and need all our support and understanding.”

Resulting from a more robust and enhanced methodology, the revised estimates will be used to improve planning for prevention, care and treatment efforts. “While it is good news that the total number of HIV infections is lower than previously thought, we cannot be complacent. The steady and slow spread of the HIV infection is a worrying factor. The better understanding of India’s epidemic has certainly enabled us to have more focused HIV prevention and treatment strategies and more effective deployment of resources,” said Mr. Naresh Dayal, Secretary Health and Chair of the National AIDS Control Board.

The new methods developed for the revised estimates has also been used to “back calculate” the prevalence for years since 2002 based on the new set of assumptions and measures. These figures allow a fair comparison of year-on-year trends in HIV prevalence. They show an epidemic that is stable over time with marginal decline in 2006.

²⁰ UNAIDS (2007). There are now 2.5 million people in India living with HIV, according to new estimates. Press Release 6, July 2007. http://data.unaids.org/pub/PressRelease/2007/070706_indiapressrelease_en.pdf

HIV prevalence shows signs of slight decline among the general population

While overall, the HIV epidemic has shown a stable trend in recent years, there is variation between states and population groups. The good news is that in Tamil Nadu and other southern states with high HIV burdens where effective interventions have been in place for several years, HIV prevalence has begun to decline or stabilize.

New pockets of high HIV prevalence identified

HIV continues to emerge in new areas. The 2006 surveillance data have identified selected pockets of high prevalence in the northern states. There are 29 districts with high prevalence, particularly in the states of West Bengal, Orissa, Rajasthan and Bihar.

The Indian National AIDS Control Organization web site²¹ has not been updated for a considerable period of time. The last figures on AIDS cases in India (reported to the National AIDS Control Organization) reflect figures received up to 31 August 2006. In the case of Maharashtra States, the cumulative number is 14 325. Hence, the web site does not provide any addition information on the situation in Maharashtra State and the City of Mumbai to that released in the UNAIDS press release on 6 July 2007.

HIV prevalence continues to be high among vulnerable populations

The 2006 surveillance figures show an increase in HIV infection among several key populations at higher risk of HIV infection, such as injecting drug users and men who have sex with men. HIV prevalence among injecting drug users has been found to be significantly high in the cities of Chandigarh, Chennai, Delhi and Mumbai. In addition, the states of Kerala, Orissa, Punjab, Uttar Pradesh and West Bengal also show high prevalence among injecting drug users.

While data do suggest that HIV prevalence is declining among sex workers in the southern states, overall prevalence among this group continues to be high, necessitating a scaling up of focused prevention efforts among these groups.

Transgender people²²

IMCARES works with a number of hijras communities in Mumbai. Many hijras (sometimes referred to as eunuchs) are recruited from Mumbai's slums as teenage boys by mafia-type gangs. After undergoing an initiation ceremony (which can include various forms of castration undertaken in non-sterile environments and usually carrying a high risk of infection and even death), they are sent to the temples of southern India. After several years, these hijras usually return to work in Mumbai, both in the red light districts and to perform at weddings and other "life events". Surveys have found that HIV prevalence among hijras is high. While healthy, hijras can lead privileged lives; however, when dying of HIV they have no support network. The saying among the hijras in Mumbai with whom IMCARES works is "To live the life of a eunuch is to live like a prince, but when you die, you are abandoned like a dog".

²¹ National AIDS Control Organization <http://www.nacoonline.org/>

²² Known as *hijra* in India. Other terms include eunuchs or transvestites.

Stigma and discrimination

In India, as elsewhere, HIV is perceived as a disease of “others”—of people living on the margins of society whose lifestyles are considered perverted or sinful. Discrimination, stigmatization and denial are the outcomes of such a perspective, affecting families, communities, workplaces, schools and health care settings. People living with HIV continue to be burdened by poor care and inadequate services, while those with the power to help do little to make the situation better. In India, the social reactions to people living with HIV have been overwhelmingly negative. For example, in one study 36% of people felt it would be better if HIV-positive people killed themselves and the same percentage believed that HIV-positive people deserved their fate. Also, 34% said they would not associate with people living with HIV and one fifth stated that AIDS was a punishment from God.²³

People in marginalized groups such as female sex workers, hijras (transgender people) and men who have sex with men are often stigmatized on the grounds of both their real or perceived HIV-positive status and their lifestyles.²⁴ Stigma and misconceptions, coupled with complicated social norms and conservative attitudes toward sex, make it difficult for politicians and policy-makers to get beyond taboos when responding to the epidemic. For example, prostitution is illegal yet widespread. And, contrary to the belief of many Indians, homosexuality, even among married men, is quite common even though it is also illegal. According to studies by the Naz Foundation, a New Delhi-based nongovernmental organization, sex between men is widespread in all South Asian countries.²⁵ Those involved often do not consider that some common instances of sex between men are homosexual acts. In a society where dating and sexual relations before prearranged marriages are generally not allowed, such acts include teenage males’ sexual experimentation with other boys before marriage and sexual encounters between truck drivers and their young assistants.

Towards universal access

In 2006, treatment coverage tripled, with 55 000 patients on antiretroviral therapy. Prevention efforts were also scaled up. However, people at high risk, especially men who have sex with men and injecting drug users, remain insufficiently covered.

²³ UNAIDS (2001). India: HIV and AIDS-related discrimination, stigmatization and denial.

²⁴ Human Rights Watch (2002). AIDS in India: Money Won’t Solve Crisis, Rising Violence Against AIDS-affected People. *Human Rights News*. 13 November 2002. <http://hrw.org/press/2002/11/india111302.htm>

²⁵ National Institute of Allergy and Infectious Diseases, National Institutes of Health (1997). Studies Shed New Light on HIV Epidemic in India. *NIH News*. 16 December 1997. <http://www3.niaid.nih.gov/news/newsreleases/1997/hivindia.htm>

Annex 2: Inter-Mission prevention of AIDS through care and training (IMPACT) (formerly PACE) Project: history and process

Phase 1 (1992-1995): Set up of the PACE project

The start-up phase included research, development of a strategy, recruitment of personnel, establishment of structures and development of activities. There was an emphasis on HIV awareness and education in the target slum communities and outreach to churches. Medical clinics were established as the entry points for HIV prevention and care in communities. Staff and community training programmes were developed along with information, education and communication materials.

Phase 2 (1995-97): Development and consolidation

The project made significant progress in HIV prevention, training of counsellors and creating awareness of HIV among churches, leading to the greater involvement of a number of churches. Home-based care and social support for people living with HIV and their families living in slum communities were developed, as were strategic group initiatives targeting women, young people and eunuchs. Training programmes were strengthened and expanded, and the project's work was extended to the Dharavi slum.

Phase 3 (1997-2001): Training and awareness-raising

Coverage in the target communities of Mahim, Charkop and Matunga with HIV awareness and education was extensive, and significant impact was observed in certain areas of the Dharavi slum. Existing activities were further strengthened and consolidated while new initiatives were undertaken, including:

- community training course – earlier community and volunteer training was formalized and further developed;
- surveys of the rates of sexually transmitted infections were undertaken and treatment provided, including the establishment of a skin and specialist medical clinic in the Charkop slum;
- new information, education and communication materials, including the film, “Mein Jeena Chahata Hoon” (A Reason to Live) was produced, providing HIV awareness to hundreds of thousands of people in Mumbai and across Maharashtra and other parts of India; and
- the establishment and coordination of the citywide Christian Organizations' Response in Networking to HIV/AIDS (CORINTH) network.

Preparation for Phase 4 (July 2001-March 2002): Redesign and strategic review

Restructuring the HIV project (renamed the Inter-Mission Prevention of AIDS through Care and Training or IMPACT), emphasizing HIV awareness-raising at all levels through a variety of means, including use of mass media. The project was developed based on the findings and recommendations of a strategic review process and the 1999 external evaluation.

Phase 4 (April 2002- 2007): Implementation – new strategic plan focusing on children

Increased emphasis on at-risk and highly vulnerable children (i.e. an emphasis on investing in the next generation). Increased awareness-raising using a variety of approaches such as mass media and providing training to churches to mobilize the HIV response.

Phase 5 (2008-2012): New project – mainstreaming HIV

This phase involves mainstreaming HIV into all projects and the development of new activities, including HIV education, protecting children's rights, provision of care and stigma reduction.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) brings together ten UN agencies in a common effort to fight the epidemic: the Office of the United Nations High Commissioner for Refugees (UNHCR), the United Nations Children's Fund (UNICEF), the World Food Programme (WFP), the United Nations Development Programme (UNDP), the United Nations Population Fund (UNFPA), the United Nations Office on Drugs and Crime (UNODC), the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO), and the World Bank.

UNAIDS, as a cosponsored programme, unites the responses to the epidemic of its ten cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to AIDS on all fronts. UNAIDS works with a broad range of partners – governmental and nongovernmental, business, scientific and lay – to share knowledge, skills and best practices across boundaries.

Produced with environment-friendly materials

■ UNAIDS BEST PRACTICE COLLECTION

The UNAIDS Best Practice Collection

- is a series of information materials from UNAIDS that promote learning, share experience and empower people and partners (people living with HIV, affected communities, civil society, governments, the private sector and international organizations) engaged in an expanded response to the AIDS epidemic and its impact;
- provides a voice to those working to combat the epidemic and mitigate its effects;
- provides information about what has worked in specific settings, for the benefit of others facing similar challenges;
- fills a gap in key policy and programmatic areas by providing technical and strategic guidance as well as state-of-the-art knowledge on prevention, care and impact-alleviation in multiple settings;
- aims at stimulating new initiatives in the interest of scaling up the country-level response to the AIDS epidemic; and
- is a UNAIDS interagency effort in partnership with other organizations and parties.

Find out more about the Best Practice Collection and other UNAIDS publications from www.unaids.org. Readers are encouraged to send their comments and suggestions to the UNAIDS Secretariat in care of the Best Practice Manager, UNAIDS, 20 avenue Appia, 1211 Geneva 27, Switzerland.

Burnout is not a single event but a process in which everyday stresses and anxieties that are not addressed gradually undermine carers' mental and physical health, so that eventually caregiving and personal relationships suffer. Burnout is the final stage in the stress process when everything falls apart. As a medical condition, burnout has no clear definition, but as a psychological condition it has been well defined and is increasingly recognized by people in the caring professions. Burnout has long been identified as a crucial issue in HIV care and support; yet there is relatively little known about what measures can be taken to prevent or mitigate it.

This document looks at how carer burnout can be avoided. It focuses on the approach used by a faith-based organization, IMCARES, Mumbai, India, to care for their staff and volunteers employed in their programmes and as carers in the community. Their strategy and practice may provide useful lessons in caring for carers for both secular and faith-based organizations working with people living with and affected by HIV.

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