‘LOSS, HOPE, AND FAITH THROUGH A COMMUNITY CAPACITY DEVELOPMENT APPROACH TO HIV/AIDS - THE FOUNDATION TO AN EXPANDED RESPONSE’

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INTRODUCTION

Many here are conversant with health related community development approaches. My comments are drawn from 17 years of experience in health and community development work in both implementation and design, mostly in economically developing countries of the south, yet in the last decade, in some areas of North America, Australia, and Eastern Europe. So the thoughts that I will present may appear very conceptual, with global derivation and relevance yet I want to assure you this in no way diminishes my understanding of the need for application of the concepts into other cultural contexts. The next speaker will give this more attention. Actions undertaken in different parts of the country would appear different from each other, and from those in other countries. Yet there can be a conceptual congruency, and mutual strengthening of direction, approaches, ways of working and strategies.

First, can I ask you to look beyond the images that you will see into some concepts that relate to community development across cultures and nations; second, can you look beyond action that is implied to the strategic questions and processes that lead to capacity development for actions; and third beyond apparent answers to recognition of issues and further questions that inform the approach.

HIV/AIDS AND COMMUNITY CAPACITY DEVELOPMENT

I could begin with figures which illustrate the global, statistical impact of HIV. I prefer however to share two images.

The first is a newspaper article from a Zambian weekly called '*The Monitor*' which I read three weeks ago whilst in the country to visit the Salvation Army Hospital at Chikankata.

I read that in the capital city of Lusaka, population 2,000,000, there are over 300,000 deaths each year. The headline was '*Lusaka running out of burial space'*. The question being raised was about the capacity of the city council to adjust in terms of making more space available. A subsidiary focus was the economic difficulty faced by families in arranging for funerals.

Whilst it is known in Lusaka that most of the deaths are due to AIDS, HIV is not even mentioned in the newspaper article.

The second image is a conversation that happened between our joint facilitation team from Zambia, Australia, the United States and China during an evaluation visit

to the province of Yunnan. There was a discussion about the pattern of response to AIDS and HIV in the Chikankata community over a 10 year period.

The Zambian with us was the Director of the Chikankata Health Services. His name is Elvis. He notes an increasing community fatigue in Zambia, characterised by people chatting in the villages rather than having serious focussed conversation. There are fewer people gathered for purposeful conversation because many have died. Apart from that others will not bother to talk together. This is what can be meant by loss of community memory - loss of valuing the past, celebrating the present, and storing up hope in the future can happen because of accelerating continuing impact of loss which is felt to be negative. Instead of acknowledging this loss there is actually denial of it, and it is projected into discussion of a more superficial nature. As I said the headline was *'Lusaka running out of burial space'* . People coming in for a short time can only hear the words of immediate need felt by the community such as crops and poverty whereas the real concern is larger.

What is really needed is to stop and simply be there - start again with the communities by listening to them. Elvis commented that listening is not practised much now.

He said: '*Communities are reaching out but drawing on the past. But the response should not be stuck in the past. They may ask about reaching for the future. Yet until you have celebrated the present the future won't be there'.*

We do not have to recapture the symbolism of the past but we have to recapture the values or beliefs which represent the space that is needed for people to grow - this space becomes a place characterised by core beliefs that connect us together - for example: care, respect, and capacity for change.

The origin of conflict and stress in communities that links to paralysis and loss of community memory comes back to the question of 'Who are we as a community?' Lack of recognition of who we are is evidenced by naming our problem in terms of the problems of others, or blame, or punishment, or the expectations of solutions outside ourselves. Alongside this can be chronic denial of loss. There is an indivisible connection between acknowledgement of loss and a journey into sustained hope.

Learning about community capacity for response to crisis has not only come from developing countries. We need to acknowledge that relationally contexted cultures have much to teach those of us who are working with health in western cultures which in the last few decades have been dominantly individualistic. There are also some western countries that have been centres of excellence regarding capacity for reflection and clarification of learning pathways. Many here are better placed that I to note the influences that have led to this. The 'Ottawa Charter for Health Promotion'[(1)] of 1986 affirmed the need for community action in health. Australia built this principle into the first national HIV/AIDS plan and retains it as the foundation of the 4th plan now being formed.

The 'Jakarta Declaration'[(2)] of 1997, drew on the principle of community involvement articulated in Ottawa, with the notion of 'community capacity'. '*Health promotion is*

*carried out **by** and **with** people not **on** or **to** people. It improves both the ability of individuals to take action and the capacity of groups, organizations or communities to influence the determinants of health.'* This promotes the view that public health effectiveness is dependent on a much clearer understanding of the inherent and the developmental capacity within circles of relationship, for participation and mutual learning in response. This is in contrast to the view that people outside the health professional world need to be provided for, are essentially victims in their own situation, and by implication, are inherently unequal partners at best, and usually are not considered to be realistically able to be in partnership at all. From the Jakarta Declaration '*The challenge for the coming years will be to unlock the potential for health promotion inherent in many sectors of society, among local communities and within families....specifically this reflects the creation of new partnerships for health on equal ground between the different sectors at all levels of governments and societies'.*

For most health professionals, especially doctors and nurses, it is difficult to design programmes from the perspective of being within a learning process - it is a legacy of medical and nursing school training that we tend to view ourselves as experts, or to accept other people's view of us as experts. Priests and pastors can equally suffer from this problem.

Is this appropriate for the issue of HIV and for many other health issues that require good community involvement?

When working with the reality of impact of HIV/AIDS in persons, families and neighbourhoods, the conclusion is inescapable that more is needed than the usual public health approach, as it is commonly understood. Community voices must be heard. Interventionist approaches, often the product of poorly understood public health philosophy, are not the answer in any part of the world, They are part of an answer but when they are dominant, they dilute the community voice, and diminish the idea that there is capacity in people for care and for change and for hope. They spread confusion through expectation of provision and external support that can never be sustained.

Understanding of community health and of health related community development is based on the viewpoint that a community has capacity to move into its own future, supported by health institutions and people with professional qualifications, but not supervised by them. Again the Jakarta Declaration is informative – '*Both traditional communication and the new information media support this process. Social, cultural and spiritual resources need to be harnessed in innovative ways'.*

Community has its own life and process. We can be interventionist or we can be participatory, and we will understand more of the life and a process of the community through a participatory/facilitation approach. The product of such participation is partnership, mutual learning, and integration of care with prevention.

With this approach, the conclusion is that HIV/AIDS is a window into the problems of life but it is also an opportunity for exploring these problems in the context of true partnership and community development.

This assumes an understanding of community as a group of people with positive belonging, in mutually accountable relationship. A community development process is one in which we should contribute as a facilitator of change, but we do not own responsibility for change, or the development of people with a problem of HIV, nor do we own their future and yet we can be intimately involved. We function as outsiders working by invitation from the 'inside', and we learn with others.

STRATEGIC QUESTIONS AND PROCESSES FOR COMMUNITY CAPACITY DEVELOPMENT

We learn by questioning and listening more than by doing. The necessary questions need to be even more searching than those we confront every day about allocation of time, people, and money, to health programs.

I will explore some key strategic questions often used in response to HIV/AIDS in home and community based work.

1. *Why be concerned?*

   From the point of view of health systems, mission hospitals, doctors, nurses and other health professionals, some real challenges include staying in front of the epidemic, or at the very least, tracing its progression; linking care with prevention; helping to transfer learnings about community capacity and development from 'south' to 'north'. And there is distraction that is negative, focussed on preoccupation with technology, and access to drugs rather than giving scope for human capacity for care, for change, for better relationship and for development.

   For a community member, there is premature loss of life - loss of family members, loss of income providers, and confusion about the future.[1]

   There is deep concern about the accelerating loss In high prevalence communities that is not explicitly recognized.

   Without a concerns analysis it is difficult to work together with a local community on a vision in the future.

   Note that concerns analysis is different from needs assessment. A concerns analysis releases expression of passion, and opening of vision about the broader dimensions, present and future, which is an appropriate and conducive environment for authentic participation.

2. *What is a vision of capacity development?*

   A core element of vision is care - not by provision but by participation within the situation of suffering, which is often the living environment; *community*, defined

[1] A family in Lima, Peru went through this experience recently - an HIV positive man infected his wife and indirectly one of his two children. He was rejected from the home by the grandmother after his wife died. Through home care and neighbourhood relationship building reconciliation with his sister became possible. He is now at home - however his journey has been painful and confusing.

by belonging, positive relationship; and shared confidentiality; *change* that happens not by imposition but by facilitation, in attitudes, behaviour and environment; *leadership* that happens through support, servanthood and inspirational presence rather than imposition; and *hope* that is characterized by concrete positive opportunities available now as well as more diffuse but equally necessary ideas about future, solidarity, ongoing community memory and relationship with God.

3. *What ways of working help achieve the vision?*
Vision is not reached only through actions - success has its foundation within a context of participation, of teamwork, of facilitation of capacity of local people who are struggling to live every day with the impact of HIV and other issues. Leaders need to find passion for this process - they need to live it out, lead by influence and service compared with power and implicit desire for self-service.

There is a great difference between participation and observation. On the one hand it is possible to be sympathetic and to do things for people even as an observer but this is insufficient for sustainable hope to develop. HIV/AIDS is an issue that leaves problems with people - problems that accumulate if unattended and problems that do not go away from homes simply because a person has attended a clinic or a hospital or because they have received a home visit from an outreach team. People have to live with the epidemic - and we need to be inside that experience, which is an ongoing conversation about loss, hope, and therefore of desire for valid future. This is inextricably linked to a mysterious yearning for connectedness for a future that is unseen as well as seen. It is speaking therefore of the experience of faith - reaching out for something beyond what human beings can touch and articulate, something bigger than we are. Faith is about innate desire to touch the essence of creativity and creation, and of relationship that can always be better than what we feel it is at the moment, and that recognises people in a spiritual situation, where God is, and where hope is glimpsed. Such faith is not naive - it is realistically grounded in honesty, and recognition of loss and pain.

4. *What constitutes meaningful action?*
Our exploration of ways of working tells us something about the environment for action - in brief, people need presence in the home; *there is a need for participation in neighbourhoods; and there is a need for adequate support by health and other institutions.*

Home care is indivisibly linked to neighbourhood based prevention, but it depends for this effect on a relational approach[2]. Home care is more effective with a viewpoint that a person with HIV is an agent for change at least potentially; and a team approach that can include people from local communities. Teams need to work in a multi-disciplinary fluid integrated way by spontaneously responding to a local situation with information, pastoral care,

[2] In Philadelphia, USA, a pre- and post-natal home based care approach with low income women is to be linked to family and neighbourhood counselling. The goal is to facilitate important family and community counselling for self care, mutual care, and change of risk behaviours.

counselling, clinical care, equipping and training of local people, and always having a mind for the non-verbal but palpable neighbourhood interest in relationships that exist - people watch but may not comment.[3]

It is this understanding that can be an *entry point into the neighbourhood* - through a question of curiosity from a neighbour following a home visit it is possible to put the question back to the whole neighbourhood to explore why there is interest.

Neighbourhood building processes are often the missing link in strategic understanding and practice of integration. I refer to integration not only of structures but of capacities of people. This view shifts a culture of expectation and demand for services on the part of so called consumers, and on the part of expertise-based providers because this idea of integration affirms the necessity and opportunity of participation by people in their own health.

What is the real concern of the whole neighbourhood? Is it the individual who appears to be the subject of a home visit or is it inner anxiety that is felt by many people in the neighbourhood?[4]

Very often it is the latter - people project their anxiety on to a 'target' but a skilled counselling approach by a team is needed to help the community acknowledge its own concerns, speak the truth to one another about relative risk and safety, and form agreement on issues that are intimate to the group and that are discussed confidentially within the group, for which all community members can act in the interest of one another. They will do this because they know that the future is at stake. Integrated care and change hinges on the recognition of the power of issue-centered confidentiality - this is part of the continuum that stretches from person to person interaction that is based on personal intimacy and confidentiality, to family conversations that can still focus dominantly on personal confidentiality but can shift to issue based confidentiality. This is certainly the situation reached in community conversation and has counselling elements. For effectiveness of forward movement regarding decisions for change that are owned by a local neighbourhood community, there can be no deliberate shaming of persons - but there can be collective recognition of issues of concern to all, and capacity to act by all. This is centered around issues that are common to all rather than persons who dominate the conversation with their own anxiety, or who are

[3] In a spontaneous village role play in China, a family depicted the normalcy of community knowledge and shared responsibility for behaviour change by showing how they would include a married HIV positive son, yet would expect him to change behaviour - and they should enlist neighbourhood support, the agreement of the son being implicit.

[4] In Dhaka, Bangladesh, six former commercial sex workers have recently relocated from a brothel to a 'normal' neighbourhood. They are generating income by craft work. They are now respected. The neighbours want them to work within the neighbourhood on HIV issues. Initially however they were nervous about the new residents but now they are beginning to think about the implications of HIV for themselves.

felt by people in the group to be needing to be revealed because they are the source of the community problem[5].

There are many examples of local neighbourhood groups functioning as healthy community in this way - in parts of Africa cultural practices have been named by communities, and are being changed whilst respecting the underlying cultural beliefs that has led to the practice. Similar processes are now being observed in India, and in neighbourhood communities in Latin America and the Caribbean.

Hospitals, clinics and churches have a part to play - separate programmes of community work and hospital work are not the answer - there needs to be a fluid continuum of involvement of people within an institution outside that place, and people outside the institution involved inside the place of speciality activity.

> There is a dynamic continuum between the locations of work, (that is the home, neighbourhood and institution or building); the ways of working (characterized by participation and teamwork); and the activities that happen which at least need to include team approaches to home care expressed through presence, linked to facilitation of ongoing community conversation and a community counselling approach.

5. What results can be expected?

In *local communities*, we can look for and find better *capacity for caring* - this can improve the quality of life of people affected and infected with HIV. There is better *capacity for change*, characterized by decisions made about corporate behaviours. This often links to specific reconciliation and to prevention. There is better *community capacity to cope with the present impact* shown by community decisions about income generation, about family welfare, about plans made before death that carry the explicit view for the families and the communities of *continuity into the future*, despite the fact that community members are dying in increasing numbers.

There is an increasing community capacity for *hope*, when there is participatory presence inside the neighbourhood - sustained care and facilitation of change can lead to continuity, and sustainability of action and positive emotion and mutually supportive relationship.

In the *implementing teams* that work from hospitals and clinics, there can be increased maturity of understanding of the community development approach. A key indicator will be the capacity of the implementing team to keep generating itself; to keep incorporating new team members. Are hospital managers, administrators and chief medical officers competent and willing to

[5] In Ahmednagar, India, anxiety was expressed by neighbours and community leaders about a person with AIDS among them. Yet as they were counselled to explore the root of their concern, it was the shared occupation (truck driver) of most of the men in that village, and a genuine recognition of their own risks for HIV infection through their own behaviours

have a dynamic team formation of this kind? Are governments, churches and non-government organizations willing to let go and engage with the wider community?

Within organizations, leaders and policy, there can also be a positive development - characterized by willingness to listen to the local community voice. When an organization is self critical of its function to the point of seeing that it is there primarily to support local community capacity development, then we can afford to say to ourselves that we have a desirable organizational result, and it may be possible to see that we are fulfilling our healing mission, to be present with others in their living space; often difficult, fragile, yet always within what I sense to be the healing grace of God.

6. *How do we know that success is happening?*
These results are indicators of capacity development. In the *local community*, there are also some generic indicators - at least three are the formation of community action groups such as care and prevention teams; the development of a process of motivation and action for community to community transfer by these action groups; and indicators of change named by local communities.[6]

The indicators that show community capacity are mainly qualitative, and relational in nature. When people tell stories that are frequently similar that relate to care and change, and these stories are sustained over time and are accompanied by new stories, then we can reliably know that community is involved and that capacity for positive care and change is developing given that these stories reveal acknowledgment, movement through denial, and serious attention to implementation of agreements reached.

Qualitative indicators of capacity can be supported by quantitative measures - numbers of people living reasonably well at home, without stigma; numbers of families working together to care, and to be agents of change in the local community; numbers of communities willing to take action for the future, and to share their learnings with other communities.

SOME OTHER QUESTIONS AND STRATEGIES RELATING TO AN EXPANDED RESPONSE

Despite the key strategic questions crucial to a planning process such as those above, there are **questions** that remain which need continuous exploration.

1. *How are community voices, feelings, emotions felt and heard? How can 'community voices' form an environment for measurement of the forward impact of the epidemic, and of other health issues?*

2. *How can leaders in a local community and in organizations listen and learn? How can they move from observation into participation in suffering?*

[6] In Mumbai, India, an HIV/AIDS support group has been active for five years. Recently some members have sensed that they need to link to their families. This requires respect. They have some changes to make as do the families - they say that when it is again possible to visit homes, they will have hope for the future.

3. *What influences local capacity development? For example when a hospital team designs its approach by consultation with community, what difference does this make? When working with a local community on desirable outcomes, to what extent does this influence the action that community undertakes? What are some listening and learning processes that need to be explored?*

4. *Regarding the role and approach of systems and organizations, of churches, hospitals and hospital leaders, how can a culture of expertise be reshaped by willingness to engage in learning processes? Rather than continuing to cling to the view that institutions, including churches are the centres of expertise and moral authority that counts most of all, how can the function of organizations be more facilitative?*

Within these reflections on vision and direction for a community capacity development approach, some key **strategy analyses** will occupy us for many years.

1. *Central to these is the linkage of care to prevention* - when we participate with persons, instead of only providing for them we see their capacity increase for self respect and healthy choice making within and between accountable communities. Participation is not the same as decentralization. Often the relational link of care to prevention is not seen because of structural preoccupation. We need to pay attention to the function of participation.

2. The link of care to prevention can only be understood when a non-Western understanding of a *wider confidentiality* is opened up - with recognition that people in local neighbourhoods live in an environment of shared confidentiality, referring to the inevitable diffusion of information that helps shift secrets to shared knowledge, shared understanding and shared safe intimacy, which is a confidential environment. Recognition of this community capacity is an entry point to disciplined community counselling, which can rapidly accelerate commitment toward prevention processes by local communities, as well as to care for each other.

3. *Home care and community counselling proximity* - when home care is done through a visitation process by a team, either systematically (house to house) or by specific invitation, its effect is greatly increased when community counselling processes are happening in some neighbourhoods. These facilitated community conversations may appear not to be linked to the home care visits but if both activities are happening in the same neighbourhood there is a synergism that is expressed through expanded care and change processes.

4. *Community to community transfer* - initiated and implemented by local neighbourhood people, working in teams, with a concern for other neighbourhoods, and willingness to respond to their requests. One neighbourhood can be an example to another. The function of the 'health system' or organization is to facilitate the belief that this is possible and

exploration of ways of doing this effectively. The people of the health organizations are often external and they often include people like ourselves. Yet we need to function not only as facilitators but as learners because we too work with communities in other places.

5. *Fifth, there is the challenge of transfer of learnings*. What can we learn from the community development approach to HIV that is applicable to drugs and alcohol, to nutrition, to disability prevention, other health issues to hospital attitudes and practices, and to a growing understanding of the role of non-government organizations, churches and government in the wider community? What difference does this learning make to our thinking about the future with respect to size, scope, disciplines and function of a hospital or a clinic? In high prevalence areas of the world, how are we coping and managing change brought about by the HIV/AIDS epidemic? As morbidity and mortality increase, how can we strategically listen, learn and plan so that ten years from now, we will be participants with community in an ongoing coping, learning and change process? How can we truly share in suffering to the point that people perceive that it is happening and that it is genuine? How can we learn to value experience based approaches to design and evaluation instead of being dominated by an expertise based culture of support.

This view could have some surprising implications, one of which is that hospitals may need to be smaller yet more efficient, and community participation approaches can be correspondingly more intense, widespread, and relational. Another is that we will more clearly see that hope emerges through honest recognition of loss; and by movement from denial to truth telling, from burden bearing to burden sharing, from fear to hope, and from provision to participation, we will have grown in faith in ways that are mysteriously hard and perplexing, yet graciously and relationally enriching.

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