‘ENHANCING COMMUNITY AND NATIONAL RESPONSES TO HIV/AIDS THROUGH LOCAL RECONCILIATION APPROACHES’

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Twenty years of implementation of home care relating to HIV/AIDS, in the context of family, friends and neighbourhood, have led to the realisation that local conflict and reconciliation within and between local communities are highly significant factors influencing the scaling out of integrated care and prevention.

An example from Narva, Estonia:

A young man of 18 years is living in a house with his grandmother in the city of Narva in Estonia. The country of Russia is just across the border – his mother lives in the adjoining city on the other side of the river. At the time of the dissolution of the 'Soviet Union' in the early 1990s, many thousands of Russians did not go back across the river to Russia to their 'homeland'. For one or another reason they were not able to go. They stayed in Estonia, but they are stateless. They do not have citizenship. They are marginalised in many ways.

In the context of AIDS and associated risk factors such as injecting drug use, the experience of personal stigma within local neighbourhoods grows, as is the case of the young man, and the sense of corporate stigma for the marginalized 'Russians' living in Estonia, is significantly negative. This is a well established realization within the country, and the emergence of HIV in this city in particular, in Estonia, has been a window into self examination by national policymakers concerned with responses to HIV.

The young man had become infected through sharing needles. He was diagnosed at the local hospital, but was refused further treatment. He met a Salvation Army officer at a bus-stop, who heard his story, and who referred him to the National Reference Hospital in Tallinn. After some weeks, he found his way there, was treated well, and is now taking antiretroviral drugs. He has behavioural problems and is in constant conflict with authorities, his grandmother and his mother, whom he occasionally visits. His father lives somewhere in Narva, but there is no active link.

Local conflict links to other cofactors, which help expand the quality and quantity of response. These cofactors are characterized by relationship, intimacy and conflict resolution.

1. **Care has a dynamic link to prevention**, particularly when the care process is a practice of presence, accompaniment, support, and solidarity that is relational. This takes into account the effect on family, friends, and neighbourhood.

Example of Kituthuni, Kenya:

A local church group fostered positive relationships with local community members by home visits and by community conversations.

Over 12 months at least ten local neighbourhoods, within walking distance determined their own response to HIV through home care, community determined behaviour change, youth response and referral for treatment.

Now, two years later, over 55 neighbourhoods are responding. They each have their own plan. They are connected yet autonomous. They are watching each other in a positive way - if one neighbourhood stops caring and preventing, or if there are conflicts, then at least one other neighbourhood will engage to help them make progress again. Each neighbourhood is committed to action, self measurement and transfer. Each can share a story of needing to overcome local family and neighbourhood conflicts, so that shared acknowledgement can happen and shared action can result.

Such a response is indivisible from the necessity of local reconciliation.

The link between care of persons especially in homes, and motivated, sustained, shared response by others who watch and feel is well documented. This is a core foundation for expansion of local response that is characterised by care, support, prevention and transfer of inspiration and action from community to community.

There are many other pathways for the link of care with persons in homes to prevention outcomes in those who watch and surround that person. Equally there are many pathways for the establishment of stigma.

The critical approach that activates a positive destigmatizing care and prevention relationship is the connection of the experience of persons in the home environment to acknowledgement of pain, anxiety and loss in surrounding community members – through an intentional facilitation of

community conversation, that is counselling in nature in the same geographic area in which the home care process is taking place.

Some key strengths distilled through learning through local exposure, and which are consistently found in local communities under stress, and which can be embedded within the behaviour or organizations include:

- Care is not just treatment. It is participatory identification with pain, loss and hope.
- Development of community response means the facilitation of positive belonging . The experience is not easy or comfortable, but transparent, conflict resolving, and satisfying because it is associated with learning and growth.
- Capacity for change is not something induced from outside. It is brought out by a nurturing, counselling presence.
- Hope is about faith for the future that cannot be seen as well as to concrete action in the present.

Grounded in these belief that infected and affected people have the capacity to respond, it should not be surprising to discover that expansion of home care and community change is mediated, amongst other elements, by spiritual intimacy and comfort. This is an intrinsic element for many in the reconciliation process.

A transition is often experienced from stigma of persons in home settings expressed by community members, to shared responsibility for care, support and change for the whole community. The transition does not need to take very long. It requires the presence of authentic care expressed through action, including counselling that is group based that helps people in their neighbourhood relationships reflect on their own situations and redirect their anxiety from projection on those with HIV, to their own family and behavioural context.

This transition is mediated through shared confidentiality. 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.

Example from Narva, Estonia:

During some home visits in the city of Narva in February 2005, a young married couple, both of whom are HIV positive, spoke of their secret joy – their newborn baby appears to be HIV negative.

Initially they said that no-one else knows of their situation. They also said that they know of other people who are HIV+ who have a child.

When asked how it is that they know of this other couple, they said that they know quite a few people who have been at risk from drug use, and who are HIV+. They said they would be willing to share their story with other people and to help others seek testing. They acknowledged this should happen because the people they know with HIV are holding their secret and they are lonely, and in conflict with each other very often.

They reflected on their own experience and explained how much better they feel now that they can share their thoughts, confidentially. They want to help others do that because they think it will bring about better safety, prevention, and will bring people much relief.

The care-prevention linkage is crucial to expansion of response. Shared concerns are interwoven with shared hope. People begin to come together across perceived boundaries to talk, share concern, and respond. This is a reconciliation process.

2. The dynamic link between the home, the neighbourhood and institutional support.

Organizations are usually insulated from the reality of home and neighbourhood life. However, local reconciliation requires engagement in all three environments.

A strategic context for shared response is generated when staff from any support institution take on the mindset that community response needs to be supported above all else, rather than being pre-occupied with delivery of services as the primary contribution to the HIV/AIDS situation.

The principle could be applied to other areas of reconciliation. Advocacy alone is insufficient. Organizational response alone does not touch the places where values, viewpoints, and relationships are formed.

Organizations need to explore a relational approach – one of listening, reflecting, experiential learning, being prepared to go out of the building and into the living situation. SALT team methodology fosters linkage of people in policy and organizations to the local response. The word SALT describes the approach:

S : Support and stimulation
A : Appreciation
L : Learning
T : Transfer

It is a method that is very low cost yet that has high returns in terms of stimulation for the visitors and growth of dignity for those visited. It is the precursor to the 'facilitation team'. It is a learning tool where the learning is based in local experience and action.

This does not happen easily. It happens most often and most effectively where there are people of commitment who are prepared to break their schedules, to add to the load, to explore the unfamiliar. It is usually activated by people who are respectful of relationship and the intimacy of others.

3. Religious response – a cofactor in reconciliation and stigma

(1) *Perceptions and realities*

Religious groups, in general, have a reputation for responding to the issue of HIV in negative terms. Factors that have influenced this perception

have included judgmental comment from religious leaders; debate about condoms; and an obstructive stance towards policy development, particularly regarding drug use, commercial sex, and harm reduction approaches. Engagement by the religious sector that implies dilution of moral standards has been discouraged, and so some people with HIV have experienced rejection by religious people, congregations or institutions.

Such experiences have been widely shared, yet is this the whole story? Have religious organizations been stigmatised before they are given a chance to respond? Why has it taken so long (20 years) for the role of religion to be affirmed in contributing to responses? What have been the assumptions on the part of governments, WHO (GPA), UN co-sponsors, and UNAIDS (since 1996)?

Consider some other experiences of assertive engagement which has reduced stigma dramatically. Home care systematically linked to a multi-disciplinary community development approach, including counselling for care, support and neighbourhood behavioural change; income generating approaches linked to skills and vocational development; advocacy by religious leaders to other leaders within the religious sector; interfaith collaboration; pastoral support not only in local communities but in organizations and in civil society.

Efforts have been made to analyse the effect of accumulating loss on the hope of persons with HIV, their families and communities. This has been linked to faith, to views about the future and to stigma reduction.

There has been characterization of a relationally based community development approach that affirms a wider confidentiality determined by the community that is a safe haven for expansion of response for inclusion. This is in contrast to community fear, lack of inclusion, and stigma. The fact that religious communities are usually interwoven into the wider community is a major asset and strength for scaling up, for sustaining

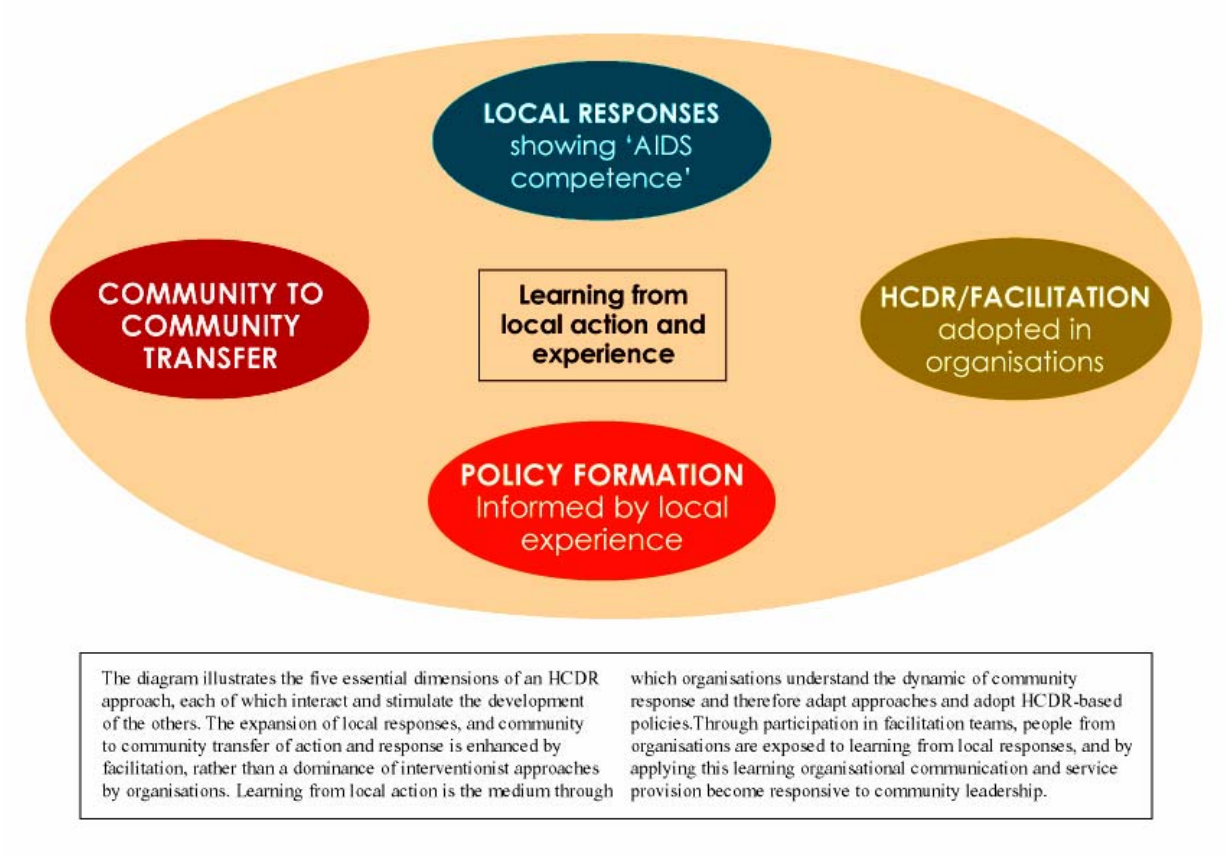
response, and for promoting mutual healthy accountability for care, support and change.

Not all religious organizations or congregations are responding – many have not yet taken it as their concern, yet at the same time, congregational and personal response has been happening which is more difficult to accumulatively measure than the more visible organizational response. The perception and reality are not always matched.

(2) ***Some distinctions***

- There is a difference in context between religious organizations, religious leadership and personal faith. All are valued facets of religious identity, yet the fact that most people hold some form of personal, spiritual faith is too rarely acknowledged within international policy that is concerned with societal response. Why is this so? Is it that personal spiritual faith is the ultimate intimacy? Has spirituality been left out of the term 'wholistic health'? Is this why reconciliation and spirituality linkage is insufficiently acknowledged.
- 'Morality' can be received as affirmation of the mutual good, without assumption or judgement or exclusion. It can be an expression of solidarity, containing beliefs that are offered and often owned by the wider community. Articulation of religious values and norms can be part of the community identity rather than an imposition.
- There can be dysfunction between beliefs and practice, in any organization. With religious leaders, vision is not in question generally, because it is not difficult for people to easily subscribe to the concepts of loving care and the need for hope. However, corresponding practices are often in question. For example, instead of a participatory approach, an imposing or provider approach is dominant.

4. Human capacity development – a framework for expanding responses



The diagram illustrates the five essential dimensions of an HCDR approach, each of which interact and stimulate the development of the others. The expansion of local responses, and community to community transfer of action and response is enhanced by facilitation, rather than a dominance of interventionist approaches by organisations. Learning from local action is the medium through which organisations understand the dynamic of community response and therefore adapt approaches and adopt HCDR-based policies. Through participation in facilitation teams, people from organisations are exposed to learning from local responses, and by applying this learning organisational communication and service provision become responsive to community leadership.

Some key elements for going to scale in a country on HIV/AIDS and reconciliation processes:

- *Local responses* demonstrate capacity for care and change. These responses can and should be the voice of conscience for organizations exploring their responses.
- *The facilitation working culture* by organizations, in contrast to assumption of the right to impose knowledge, expertise and implicitly, desire for control, no matter how obscured by philanthropy.
- *Commitment to experientially based mutual learning* by communities and organizations, e.g. district level programme to programme visits based in

local neighbourhoods and homes, can rapidly catalyse concept transfer and practice design and action on returning.

- *Community to community transfer* Lamboray[3] says "*Community competence is contagious; combined with a shared ambition it can be shared to community to community".*
- *Exploration of collaboration with other organizations*[4] [5] through the pathways of shared vision, shared ways of working, and shared desirable results
- *Policy formation by inclusion*, involving local community experience of people

Within the desperate need to 'scale up' approaches, there is temptation to replace participation with intervention and externally determined expectations. Yet participation is necessary to bring about community determined change. Communities and programmes are often invalidated because the approaches that have helped bring out capacity of local communities, even within situations of high stress, to name, act for and measure their own change, have been undervalued.

In particular the team approach to home care, and the connection the team and the participants in the home environment make to the wider community for prevention, have not been recognised. This connection happens through complex circles of confidentiality and in association with a synergistic process of community counselling that depends often non-verbally and almost invisibly on the authenticity of the caring approach for its success.

There is opportunity to strengthen the local community capacity development approach and that opportunity needs to be taken now. It is relevant not only to countries of the south but to the north, where a dilution of a relational approach to linkage of care with change has happened to a greater extent than in the south, related to the availability of treatments and associated complacency about prevention.

The surprising finding by people in the organizations that truly do facilitate, is that mutual learning is possible, the burden lifts, and this in turn can enhance the capacity and the environment for environment for reconciliation.

5. **Some key operational research questions**

- Within the local community experience, how can local capacity for care and for behaviour change be explored, respected and affirmed as a fundamental strength for community response?
- What are the characteristics of an integrated approach to care and change that allows for conflict resolution and stigma reduction?
- Regarding partnerships of the religious sector (with other organizations), how can theological principles and identity be expressed respectfully, and linked to practices that are encouraged by the partners?
- How can organizational responses be improved by learning from the local response? How can policy be proactively informed? How is conflict in local settings influenced by HIV/AIDS related accumulating loss in communities and families? How can human capacity development approaches help resolve conflict, foster reconciliation, care and prevention?

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