

## Editorial

# Community action to end paediatric HIV infections

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### Abstract

Virtual prevention of HIV transmission from parents to children is possible. This is cause for hope and renewed energy for prevention in general. The Global Plan is the most concerted and ambitious plan to date to protect children and to promote their care. But the inspiring and much appreciated global targets cannot be achieved, nor will they be realized in spirit in addition to form, without joint action between health services, affected women, their partners, families and communities and the wider society. In turn, this engagement is only possible under enabling political, legal, material and social conditions. Much has already been achieved, and community engagement can everywhere be seen in efforts to increase demand, to supply services and to create and improve enabling environments. Some of these initiatives are highly organized and expansive, with demonstrated success. Others are local but essential adjuncts to health services. The nature of this engagement varies because the challenges are different across countries and parts of countries. To be sustained and effective, community action must simultaneously be inclusive and supportive for those people who are affected, it must be appreciated and assigned a place within the broad systemic response, and it must promote and defend social justice.

**Keywords:** PMTCT; community; engagement; paediatric HIV.

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### Introduction: virtual prevention of HIV transmission from parent to child

By the turn of the century, it was clear that the vertical transmission of HIV to children could effectively be prevented with the appropriate use of short courses of antiretroviral therapy (ART). In their landmark paper on the issue, De Cock *et al.* noted that few other aspects of HIV had, by that time, demonstrated results as dramatic as perinatal prevention [1]. This remains true in 2012. They argued that prevention of infection among children “requires HIV and AIDS to be addressed as a disease of the family and the community and leads to consideration of other interventions, such as reproductive health care for women and support for children orphaned by the epidemic” [1, p. 1181].

At the time, the critical policy and programme issues needing to be addressed were highlighted as: increased HIV counselling and testing, expanded use of the most effective drug regimens and the prevention of transmission through breastfeeding. Since then, all three issues have been resolved to the point of creating conditions feasible for the virtual prevention of HIV transmission from parent to child through pregnancy, delivery and infant feeding. More effective drugs are available, there is more integration among services and the drug regimens recommended are more comprehensive and better targeted.

HIV counseling and testing (HCT) no longer depends only on individuals stepping out of the line to be tested and risking gossip and stigmatization for doing so. In 2007, the World Health Organization (WHO) recommended

provider-initiated testing and counselling (PITC) [2] to streamline and normalize the process [3]. PITC also helps to increase the uptake of prevention of mother-to-child transmission services (PMTCT) [4], more appropriately called prevention of vertical transmission (PVT), in order not to place blame unintentionally on women. Home-based testing similarly expands services and provides for families to be tested together [5,6], as does couples testing, guidelines for which have recently been published by WHO [7].

Up until recently, PMTCT programmes predominantly focussed on the prevention of HIV transmission to infants. However, successfully enrolling eligible pregnant women into treatment and retaining them on treatment is proving to be the most effective approach to protecting mothers, their children – as well as their partners. The 2012 WHO PMTCT technical update [8] recommends a single universal regimen both to treat pregnant women living with HIV and to prevent transmission to her baby (so-called Option B). This approach simplifies service delivery, aligns and links with ART programmes enabling women to more easily transition between services and specifically targets the prevention of maternal mortality and vertical transmission – both of which are disproportionately attributable to the poor health of pregnant women in need of treatment [9]. Extended prophylaxis given to infants or the continued treatment of their mothers also renders breastfeeding safer [10]. Given the dramatically increased vulnerability of young children whose mothers die or who suffer serious ill-health, treatment for women not only protects women’s wellbeing but also safeguards their

children [11]. Moreover, providing early treatment reduces HIV transmission between serodifferent couples [12].

Scientific and technical knowledge and programme evaluations of PVT have increased dramatically, as indicated by an overview of published literature on the topic between 1990 and 2010 (Figure 1). No other area of HIV prevention appears so achievable. Yet multiple hurdles remain.

Despite PITC, some 10% to 20% of women refuse testing and another 20% or so either directly or indirectly avoid PVT prescriptions, procedures and follow-up [4]. When women are not fully informed of the benefits, they may perceive PITC to be coercive [13]. The need or perceived requirement to get their partners' consent [14] and the cost of transport and out-of-pocket expenses are some of the reasons women give for declining PVT prescriptions and procedures [15]. A recent review highlights the loss of women between vertically provided pregnancy- and HIV-related services and stresses the need for both integration and "family-focussed care" [16]. Together with health service characteristics such as the availability of test kits and drugs and the negative attitudes of some healthcare providers towards women living with HIV [17], progress to prevent HIV infections among young children and to ensure the wellbeing of their mothers is slower than was hoped.

We believe that what is needed, in addition to developments already highlighted, is to implement recommendation by De Cock *et al.* that HIV and AIDS be addressed as a disease of the family and the community and that HIV interventions be integrated across the lifecycle of women, families and children [1].

### Countdown to Zero: the Global Plan

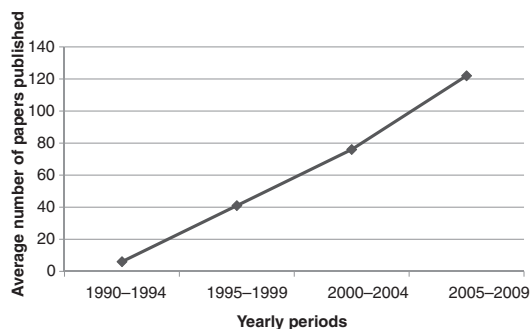
Assessments of progress towards the Millennium Development Goals show that the effects of HIV and AIDS are especially severe for the survival and wellbeing of mothers and young children [18]. In addition, PVT is central to global HIV prevention efforts and remains the one area of prevention in which resounding success can be achieved. However, given current knowledge and technology to prevent almost all parent to child transmission of HIV, scale up of PVT and universal access to prevention and treatment has been slow,

with especial concern for women and children's health in the worst affected countries [19].

Support for a concerted global effort to prevent HIV transmission from parent to child has been growing [20–23]. At the 2011 United Nations General Assembly High Level Meeting on AIDS, world leaders committed to work together to achieve this goal. The aims of "Countdown to Zero: Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping their Mothers Alive" are to achieve a 90% reduction in the number of new HIV infections among children and a 50% reduction in AIDS-related deaths among pregnant women [24]. This is the boldest plan to date to protect children from HIV and to safeguard their families, and it offers unprecedented opportunities to change the way the health sector, donors, governments and others work with affected people and communities to change the course of the epidemic.

However, a modelling exercise, published before the launch of the Plan, laid out how high a mountain had to be climbed to reach the targets. Based on data from 25 countries with the highest numbers of pregnant women living with HIV, Mahy *et al.* estimated that even if: (1) more effective drug regimens were implemented, (2) the current unmet need for family planning among women living with HIV was wholly met and (3) breastfeeding was limited to 12 months to curb HIV transmission, the number of new child infections averted (reckoned to be 79%) would still fall short of the target [25]. What is critical, they argued, was for high coverage to be reached on all aspects of the PVT programme (with far fewer women lost to follow-up at each stage of what is called the "PMTCT cascade"), safer feeding practices adopted and implementation of a comprehensive approach. Such a comprehensive approach must include meeting the family planning needs of couples affected by HIV and reducing new HIV infections among women of reproductive age. That is, giving effect to all four prongs of PVT. These are (1) primary prevention of HIV among women of reproductive age; (2) reducing the unmet need for family planning among women living with HIV; (3) scaling up more efficacious ARV regimens for women living with HIV and HIV-exposed infants and (4) expanding treatment and care for women, children and their families [24].

The challenges to expanding comprehensive approaches, even in the highest burden regions, differ by country and by area within countries. Ninety-one percent of pregnant women living with HIV in 2009 are in 22 countries, all but one in Africa [23]. However, huge differences exist between these 22 countries, with some classified as middle-income (such as India and South Africa) and others low-income (Malawi and Mozambique); some stable states (for example, Cameroon and Ethiopia) and others with fragile political regimes (Democratic Republic of Congo and Zimbabwe). There are also differences in health service access (at least one antenatal visit: 97% in Botswana, 39% in Chad), HIV incidence (1.68 in South Africa, 0.02 in India), unmet need for family planning (41% in Uganda, 7% in Namibia), coverage with any ARV regimen (95% in Botswana, 6% in the Democratic Republic of Congo) and median duration of breastfeeding in the general population (34 months in



153 papers were published in 2010. Databases searched were MedLine, PubMed and PsycLIT, using the terms PMTCT OR prevention of mother to child transmission OR prevention of mother-to-child transmission AND vertical transmission. The electronic search yielded 1910 papers, from which 1402 papers with a clinical, public health or programmatic focus were retained from a hand search.

**Figure 1.** Average number of clinical, public health and programmatic papers on PVT published every five years from 1990 to 2009.

Rwanda, 16 in South Africa) [25]. It is obvious that no one approach will work everywhere.

UNICEF has developed fact sheets on the status of national PVT responses in these 22 countries as at 2010 [26]. From the assembled data, it is clear that some countries, such as Angola, must increase PVT services in antenatal care, especially in rural areas. Others, such as Nigeria, must expand the low reach of and access to antenatal services – most of which are relatively well provisioned for PVT programmes – especially amongst poor and rural women. South Africa must bolster the prevention of new HIV infections among young women and improve the quality of PVT services, including the retention of women across the range of vertical prevention services. In all countries, big gaps, inefficiencies and poor quality services must be addressed.

As has been recognized for some time, though, to reach the targets requires actions, not only within and by health services but also by affected women, their partners, within families and communities and in the wider society. In turn, this engagement is only possible under enabling political, legal, material and social conditions. The choices of women are affected, and their options limited, by their husbands and partners, their families and what they perceive other people think about them and how their neighbours and friends treat them. In turn, social norms are influenced by laws and policies, cultural beliefs, economic conditions and the range, quality and helpfulness of the services they have at their disposal. The same concentric circles of influence have been noted in other areas of health intervention, with the following quotation taken from cardiovascular disease: “Just as we have learned that it is difficult to change the behavior of individuals without changing the communities in which they live, we may be learning that it is difficult to change the behavior of whole communities without changing their broader social environment as well” [27, p. 1391].

For these reasons, guidance for global scale-up emphasizes the importance of supporting community-based programmes and achieving integration with family planning, as well as other aspects of sexual and reproductive health and tuberculosis services, in order to create or enable facilitative conditions for individual and social actions (demand) to complement health service provision (supply). These programmes include the following:

1. Developing policy and legal frameworks, guidelines, tools and competencies to link services to community-based providers;
2. Defining standard packages of services to improve maternal, neonatal and child survival and health, at both health facility and at the community level;
3. Building capacity with technical and financial support to community-based organizations to deliver PVT and HIV services at facilities and in communities;
4. Promoting the active engagement of people living with HIV in advocacy and planning and delivering services;
5. Promoting male-friendly models of delivering HIV services and the participation of men in PVT and in HIV care for children; and

6. Developing and implementing policies and programmes to reduce HIV-related violence, stigma and discrimination in the context of PVT and HIV care for children, including supporting women to disclose their HIV status to partners and family members [19, p. 22–23].

There has been no assessment of country responses to these guidance points or progress in achieving greater women, family and community involvement in PVT. It is troubling that recommendations for community action are considerably diluted in “Countdown to Zero” [24]. They include less specific strategies, such as developing community charters, ensuring participation of all stakeholders, maximizing community assets and identifying solutions to stigma.

There is an emerging consensus that many HIV prevention programmes do not succeed specifically because they do not engage communities. Instead, they “are conceived by external experts and imposed on communities in ‘top-down’ ways. As a result, they fail to resonate with the worldviews and perceived needs and interests of their target groupings, or to take adequate account of the complex social relations into which programmes are inserted” [28, p. 1570]. Too often, suggest Campbell and Cornish, target communities are seen as passive recipients, as “objects” of intervention [28]. But community engagement and participation is essential for several reasons: (1) because it is the most effective way to deliver acceptable messages and services to “hard-to-reach” groups; (2) because it is one of the main ways of engendering a sense of agency with which to build individual and collective health promotion; and (3) because the overall shortage of health workers means that community volunteers and workers are needed to help deliver HIV prevention, treatment and care to those who need it. The AVAHAN experience in India, the largest prevention programme ever undertaken, demonstrates the value of involving communities, including the private sector, an oft-forgotten constituency in the public domain [29]. At a broader societal level, laws and policies within which health services are funded and delivered emanate from social values and are subject to public opinion – which, in turn influences and is influenced by all forms of media.

### **Community engagement and action**

Given the importance of engaging women, families and communities to achieve an end to HIV transmission from parent to child, this special issue takes stock of current knowledge and good practice in community action to create an enabling environment, expand access and improve care of women and children in PVT programmes, as well as to reach men. The papers review and organize what is known to date, document examples of community mobilization, and the reach and effectiveness of community workers linked to health facilities. They draw attention to gender inequalities, the ways in which affected groups and their networks can expand services and the importance of their experiences and voices to unsettle complacency and compel changes in attitudes and behaviour.

Several things stand out from these papers: firstly, how determined community groups are to be part of the response to HIV and how energetic and innovative are their practices. Secondly, how large-scale some community activities are: for example, in Uganda, 750 groups of people living with HIV, working in larger coalitions, assisted 1.3 million people to access HIV-related health services (Gitau-Mburu, this issue); *mothers2mothers* reports having more than 250,000 patient encounters per month, seeing nearly 24,000 new HIV-positive women per month in 714 sites [30]. Thirdly, how comprehensive community-based services try to be as they integrate their activities to meet individual needs and family concerns (see Kim *et al.* and Patel *et al.* this issue), and fourth, the urgent need that community actors have for financial, policy, programme and personal support for their work (see Dhlamini *et al.*, this issue). However, what is also evident, especially from the review papers, is how little published research there is and, as a result, how limited our knowledge and use of community processes in increasing demand and supply of services and their role in the creation of an enabling environment.

In addition to the papers, including the reviews and helpful conceptual frameworks offered by, amongst others, Buzsa *et al.* and Gulaid and Kiragu, there are two unique features to this special issue. Firstly, the joint initiators of the Global Plan, Dr Michel Sidibe, Executive Director of UNAIDS, and Dr Eric Goosby, Global AIDS Coordinator responsible for the implementation of PEPFAR, have provided a foreword. By doing so, they emphasize the importance of community engagement and action, and their commitment, within the Global Plan, to achieve it. It is a massive expression of support for community action, and it manifests the seriousness of their determination.

The second unique feature is that, in addition to academic peer-reviewers, nine women living with HIV, recommended for their professional expertise and personal experiences by the International Community of Women with HIV/AIDS (ICW) and the Global Network of People Living with AIDS (GNP+) were invited to review terminology. Their perspectives demonstrated the ways in which language can distort understanding, fuel discrimination and deeply hurt those who are directly affected by HIV. Although the comments of this group of reviewers were discretionary unless independently endorsed by the journal's standard editorial process, all authors responded seriously to the issues raised. This is the first time, of which we are aware, that a scientific journal has engaged the people at the receiving end of science, policy and service in a mutual effort to find common ground and move forward together. In this sense, the special issue embraces the commitment to include *community* even though the common ground between science and experience is uneven, a consequence of both low use and potential misunderstanding. The special issue closes with an account of the experiences of people living with HIV, male and female recipients of our services, and an annotation by women living with HIV and their networks on "Language, Identity and HIV."

Almost all the papers take as their starting point the role of community engagement in the following areas: expanded

reach and supply of services, increased uptake, enhanced adherence to treatment and care regimes, improved retention in programmes and better psychosocial wellbeing of women, children and their families within an enabling environment. Reviews of published research and of best practice experience endorse the need for community action in PVT. They also conclude that the evidence, although limited, is promising. Community action strategies can expand the reach of services to women and their families, increase access, boost adherence and retention, and support affected children and ensure they receive treatment.

By and large, the mechanisms for community action involve the engagement, enrolment and collaboration of a diverse range of community-based volunteers, workers, counselors and social actors through independent and integrated community- and facility-based programmes. Stand-out examples from the papers themselves and the work they cite are couples and home-based testing and prevention programmes [31–33], mentor and peer counselors [34,35]; support groups and community forums [36] and community-based financing mechanisms that address barriers due to transport and other costs [37]. More and more effort is being made [38], with success [39], to involve men, a strategy strongly endorsed by affected women (Anderson *et al.*, this issue). Less apparent, although model studies and programmes can be found, are efforts to substantially change the social and policy environment through legal reform, mass media, community activism and demands for and implementation of mechanisms to increase accountability at the local and international levels.

In a recent review of community accountability mechanisms, Molyneux *et al.* identify three basic approaches: committees and groups, report cards and patient charters [40]. While some impressive findings are reported for committees and groups, patient charters are less promising, offering only guidelines rather than consequences for abuses of patient rights and poor quality of health services. One of the most impressive effects of the use of report cards to improve healthcare is given by Björkman and Svensson from a randomized field experiment in fifty communities in nine districts in Uganda [41]. Local organizations facilitated agreements between community members and private and government health providers on which submitted reports were based. A pre- and post-survey of 5000 households after one year suggested that the accountability mechanism was highly effective. Health workers were rated as making more effort, there were large increases in utilization and health outcomes, including in child growth and a reduction of under-five mortality by 33%.

It is clear that research in this area needs to be done and project and programme evaluations must be improved to pass the scrutiny of peers and be published. While there are many promising practices of the effectiveness of community action, the evidence base is still very limited.

### Quo vadis?

In this special issue, several different conceptual frameworks are used to review and or describe community approaches. Busza *et al.* (this issue) employ a social ecological framework that links the individual with peers and family, community

and the broader social, cultural and economic environment in overlapping concentric circles. As they indicate, such conceptual frameworks are useful for illustrating the relationships between determinants that are proximal (downstream) or distal (upstream) to the person as previously described by Latkin and Knowlton [42].

Gulaid and Kiragu (this issue) use the distinction made by Rosato *et al.* between participation, mobilization and empowerment in an analysis of their roles in maternal, newborn and child health [43]. Rosato *et al.* see community empowerment being built up through layers of personal and collective action, starting from the individual, to small mutual groups, community organizations, partnerships and coalitions and social and political action. However, they conclude with several fundamental questions, unanswered also with respect to PVT. Is community participation an essential prerequisite for better health outcomes or simply a useful but non-essential companion to the delivery of treatments and preventive health education? If essential, then is it only a transitional strategy for the poorest and most deprived populations but largely irrelevant once healthcare systems are established; or is it the critical missing component and the reason we are failing to achieve (in this case) the Millennium Development Goals 4 and 5 regarding maternal and child mortality?

Community action is, however, a muddled conceptual and terminological terrain. Community means many different things and we speak simultaneously of the international or donor community and a particular local community; we refer to community-based, community-oriented and services delivered in, for and by community (as opposed to health facility). McLeroy *et al.* refer to four categories of implicit constructions of community in health projects: community as setting (usually geographic), community as target (groups as compared to individuals), community as resource (frequently in terms of participation and support) and community as agent (meeting day-to-day needs) [44]. Writing in 1968 of his attempts to develop a unitary approach to community intervention, Jack Rothman notes "It was as if I had packed a large and assorted pile of conceptual clothing into a cognitive suitcase and found there was a sock or the end of a tie sticking out after I had pressed it closed" [45, p. 27].

Criticized for ignoring culture as a factor in determining the shape of community responses [46], Rothman's conception remains a cornerstone for understanding community action [45]. In short, Rothman argued that community action can be grouped into three approaches or models. The first aims to improve service delivery through community development, bringing people together to solve local problems on a cooperative self-help basis. In this approach, participation, inclusion and consensus are critical. The second is a rationalistic approach used in policy and planning as evidenced, for example, in task shifting arguments for the role of community action [47,48]. The third approach, social action, aims to "aid the oppressed, promote social justice, and change society" adopted, for instance, as the foundation of many AIDS activist groups [45, p. 27]. In practice, the three approaches may be interwoven and differentially phased, with one approach giving way to another [49]. The Treatment

Action Campaign [50], GNP+ [51] and Physicians for Social Justice [52], as examples, combine assumptions, goals and processes of all three approaches, in different ways and at different times.

These approaches, argues Rothman, "can all be applied in a way to pursue social change and human betterment" [45, p. 60]. In fact, they have to draw from one another because each has inherent limitations for which the others can compensate. Campbell and Cornish also argue for alignment of different approaches to community action but draw attention to the contexts in which such action can flourish [28]. Funding, though needed, may impose expectations and constraints that undermine the participatory ethos that is necessary for community action. Similarly, mass media approaches frequently represent the views of western agencies, for example, of gender or sex work, and may miss opportunities for affected groups to challenge stigma and establish their symbolic legitimacy. Lastly, community action depends also on a relational context, in which marginalized groups must have opportunities to interact with powerful local actors in their efforts to protect their health and receive services.

Campbell and Cornish advocate what they call "fourth generation" social mobilization, mobilization for supportive conditions for community action at local, national and international levels [28]. Here there is a role for donors, development agencies and governments to consider how their policies and actions support or sabotage community action. In addition, they suggest, this will require that researchers also shift their attention "upwards" to examine, explicate and hold accountable the international community, as well as focussing "downwards on the successes and failures of marginalized local communities" [28, p. 1578].

What is clear is that community engagement and action is necessary for the Global Plan to succeed. Communities, holding hands with health services, are needed to contribute to creating demand for services, to help supply services and to assist in establishing an enabling environment for both to occur with maximal effectiveness.

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#### Competing interests

The author has no competing interests to declare.

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