

Community Based Chagas Control Program

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In 2012, World Health Organization published the first ever Neglected Tropical Diseases (NTD) Roadmap, entitled “Accelerating Work to Overcome the Global Impact of Neglected Tropical Diseases: A Roadmap for Implementation.” This report brought international attention to Chagas and other NTDs and provided a framework to guide implementation of policies and strategies set out in the Global Plan to Combat Neglected Tropical Diseases 2008-2015. Chagas disease, endemic to Bolivia, is considered the third most common parasitic disease globally, after malaria and schistosomiasis. It is estimated that six to seven million persons are infected worldwide. [1] Bolivia has the highest rate of endemic Chagas disease in the Americas. Chagas disease is both a disease of poverty and, like other neglected tropical diseases, poverty promoting. [2] Chagas disease is associated with multiple social and environmental determinants in communities marked by poverty. Salient among the main determinants are poor-quality dwellings, social instability, the combined presence of certain environmental factors, such as the Chagas vectors, mammals that serve as reservoirs of the disease and human exposure, creating the conditions for perpetuating the effective transmission of the infection and its endemicity. These challenges put pregnant women, young children and children with disabilities at especially high risk for contracting Chagas disease. Left untreated, Chagas disease can lead to serious heart, digestive and neurological conditions.

Going upstream for Chagas control in Bolivia

MAP International in Bolivia has been using the community-based strategy for Chagas control program as part of what is called upstream paradigm that seeks to invest efforts and resources where the community has the greatest potential to positively influence health. This strategy contrasts from the traditional approach that tends to focus only in management of the pathology (treatment and/or prevention). This upstream approach pursues actions that increase the health determinants that fosters protective factors. It is now recognized that community-based strategy plays a critical role to make effective even in biomedical interventions such as massive rapid tests, blood testing to confirm diagnosis, and use of medicines to treat patients among many others.

Since the First International Conference on Health Promotion in Ottawa in 1986, there is a public health movement around the world exploring strategies fostering processes of enabling people to increase control over, and to improve, their wellbeing and health. This movement is a departure of previous strategies of delivering

health services to needy or passive recipient’s communities. These efforts have led to health promotion actions that reduce differences in current health status and ensure equal opportunities and resources so that the individual can achieve his or her fullest health potential. On Chagas control programs, these types of new strategies play a central role in securing a supportive environment, access to information, life skills and opportunities for making healthy choices. “People Cannot achieve their fullest health potential unless they are able to take control of those things which determine their health. This must apply equally to women and men.” [3]

MAP Bolivia has effectively used a community-based strategy as a means for population health approach to generate sustainable changes in communities and society. This approach has been also used for the neglected tropical disease of Chagas control.

“Under a population health approach, evidence about “what makes and keeps people healthy” and effectiveness of interventions guides the identification of priority actions. Evidence establishes the parameters for health investment decisions. A population health approach directs investments to those areas that have the greatest potential to positively influence health. It also seeks to maximize the potential for health-related cost savings. Population health approaches are grounded in the notion that the earlier in the causal stream action is taken (the more “upstream” the action is), the greater the potential for population health gains.” [4]

An upstream approach helps to redirect prevention efforts that leads to investments on those areas or situations that have the greatest potential to positively influence health. The more “upstream” the action is, the greater the cost-benefit ratio of the intervention and far more effective than multiple prevention efforts we may do down the stream. Therefore, the greatest gains in prevention of many social, economic, political, and mental problems individuals, families and society experience exist going upstream to address those critical factors that create protective conditions for society that diminish risks and fosters determinants for well-being and health.

In this document, we will describe three main aspects of on-going upstream approach MAP has been using in Bolivia as a population based approach to resolve several public health programs including Chagas disease: a) fostering transformation **from within**, b) giving special consideration to early infancy, and c) intersectoral engagement of different actors.

A population based approach should foster transformation from within

Those who live with the problem are the most suitable to bring transformational processes to overcome the problem if they count with the proper knowledge, critical analysis capability and progressive self-empowerment processes to lead the needed changes. In nature, organisms respond to change by changing themselves. They adapt or perish – either meet challenging new conditions that requires innovative responses, or pay the price. In similar way, true communities have never been built from the top down or from the outside in. Communities are fruit of their own intertwined processes and the ability they develop to care for themselves and to proactively dialogue and interact with the other communities or cultures keeping the power to maintain their own identity and control of their own history. Sustainable changes in a culture should come from within and this can be only achieved by local people in the process of transforming themselves and their culture. Therefore, Chagas control programs should foster concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health through maximizing local initiatives, local resources and ownership and control of their own endeavours and destinies.

Sustainable changes in a community should come from within. Transformational processes should be based in the community's worldview rather than in an outsiders' worldview. It is necessary to depart from previous traditional model of making changes from the locus of power: 'top down' and recognize the value of change 'from within'. True development and health is a matter of "people" and not necessarily a site to provide healthcare or other services, nor measuring statistical data about biological, economical or production phenomena. Although these services and data play an important role, it is crucial to acknowledge that true transformational process are fruit of increased awareness and organizational processes that build local capacity to assume responsibility to deal with their own problems and play an active role by writing their own history. Solutions from outsiders tend to fall short and proven to be unsustainable. History has shown that significant sustainable community development happens only when local community people have developed their capability and responsibility to invest in themselves and in the resources needed to build their own wellbeing. Each person and community must actively participate in the process of change. For a new worldview to evolve, a broad engagement is necessary of all insiders. When self-agency and self-empowerment processes are highly intertwined and committed to surrendering power in order to build consensus and common wellbeing through co-agency, these processes generate profound changes that benefit everyone.

A population based approach should give special consideration to early infancy

Infants have the largest potential for the upstream strategy for building local capacity. Neuroscience research has shown how early infancy experience determine the potential development of the individual and how crucial is the protection and care of those infants. The largest social wealth a community has is the brain development its population has.

Any type of intervention that erodes local capability for self-agency and co-agency of the efforts to overcome problems and to develop potentialities will only further harm the communities. Community health programs has acknowledged well-known variables to foster

community ownership and responsibility over the change process such as access to relevant information, capacity development for self-organization and self-agency, access to governmental and other sources of support, community participation, among others. Unfortunately, there are other critical factors that are not well known such as those that hinder the personal and community capacity to self-agency their own life for multiple problems on early infancy. For example, the lack of appropriate nutrition, socioemotional nourishment and safe and enriching environments may seriously hinder the brain architecture development that obstructs the potential development of that child, their families and communities. Early child development environments before preschool are more and more recognized as critical for the potential development of the person.

“A vital and productive society with a prosperous and sustainable future is built on a foundation of healthy child development. Positive early experiences provide a foundation for sturdy brain architecture and a broad range of skills and learning capacities... Advances in neuroscience, molecular biology, and genomics have converged on three compelling conclusions: Early experiences are built into our bodies, creating biological “memories” that shape development, for better or for worse. Toxic stress caused by significant adversity can produce physiological disruptions that undermine the development of the body's stress response systems and affect the architecture of the developing brain, the cardiovascular system, the immune system, and metabolic regulatory controls. These physiological Disruptions can persist far into adulthood and lead to lifelong impairments in both physical and mental health.” [5]

A Chagas control program with upstream strategy needs to include a component for identification of pregnant women and couples, and those with infants, to engage them in the different activities related to Chagas control at the same time they can be part of a good parenting program. Lack of early support to parents to foster parental competences in the first months and years of life (upstream in their lives), seriously hinders the ability for a community to solve their own problems. Chagas disease is present in very impoverished communities and Chagas is just a manifestation of complex socioeconomic and political problems that have trapped those communities in poverty. Effective and sustainable changes will come only if those impoverished communities count with a new type of citizens that develop capacity to bring the needed changes. The gap these impoverished communities experience with other better off communities in urban setting will reproduce and even worsen in the coming generations unless there is a clear strategy for facilitating programs for early infancy development.

“Ability gaps between advantaged and other children open up early before schooling begins. Conventional school based policies start too late to completely remedy early deficits, although they can do some good. Children who start ahead keep accelerating past their peers, widening the gap ... Early advantages accumulate, so do early disadvantages ... The best way to improve the schools is to improve the early environments of the children sent to them.” [6]

Pregnant women and infants are not only one of the most vulnerable people for Chagas disease and its impact in the community; they are the group with the largest potential to bring lasting changes to those communities. Efforts to build local capacity in communities to solve their own problems should pay special attention to these population groups. Research shows that the return on investments

in children's early years are far more effective compared with equivalent investments made later in life. [7]

Further exasperating, self-empowerment and capacity development processes are seriously obstructed as result of their early child adversities increasing their brokenness as individuals, families and communities. Adversities that impact on the parents or caregivers have a negative effect on brain development in the young child and therefore act as a risk factor for optimal health and development, family functioning, and the ability to fully participate in the community.

Chronic or toxic stress seriously disrupts brain architecture in infants and leads to stress management systems that have lower thresholds of activation through life. This disruption increases the risk of stress related physical and mental illness and limitation for problem solving skills. A key element is to go upstream in the life of the infant to build the foundations of social capital and reducing toxic stress and adversities in infants as well as building local capacities for families to care for and foster comprehensive development of those infants.

“Adverse childhood experiences determine the likelihood of the ten most common causes of death in the United States... Adverse childhood experiences are the most basic cause of health risk behaviours, morbidity, disability, mortality, and healthcare costs... Many chronic diseases in adults are determined decades earlier, in childhood. [8]

Adverse childhood experiences are also clearly related to mental health. For example the conclusion of an Adverse Child Experiences (ACE) study related to prescribed psychotropic medications in adults states:

“The strong relationship of the ACE Score to increased utilization of psychotropic medications underscores the contribution of childhood experience to the burden of adult mental illness. Moreover, the huge economic costs associated with the use of psychotropic medications provide additional incentive to address the high prevalence and consequences of childhood traumatic stressors.” [9]

There are multiple forms of trauma that are transferred from generation to generation and it is crucial that individuals, families and communities may see trauma and stand to acknowledge that brokenness and to see how that has disabled them to experience wholeness and true community. Trauma has impaired them to release their capacity to work synergically and take control over their own history. We all need a journey of healing and reconciliation with ourselves, others, nature and God. Going upstream also implies breaking the silence over their own brokenness as individuals and families, and to engage in a journey of healing. The healing and reconciliation process must be fundamental to any other type of projects, otherwise the foundation of living in family, co-laboring communities or any other type of organized groups will be broken and changes built upon that brokenness very easy will collapse.

That is why it is crucial to establish and monitor process objectives in order to care and monitor for those transformational process that need to happen inside the person, family and community groups. As we have seen, efforts done for community health or community development should also pursue changes within the person, within the dynamics of that person with his/her partner,

within the parents-children interactions in the family, within neighbours, local organizations and community. It is not much about the material things, the increase of production, reduction of mortality or technological advancement, but from what happens from within the person (including infants), the family, local organizations and the community in general. Caring for the processes that projects generate in individuals, families and communities is what will allow an excellent stewardship of all the other objectives of the project and guarantee sustainability of the good things that a project will bring.

Intersectoral engagement of different actors

MAP International has been using community based strategy to resolve many public health problems in Bolivia. For two decades, we have implemented Community Based Chagas Control programs focused on building community capacity to understand and diagnose Chagas, treat and follow-up on patients. This strategy requires the identification and engagement of the different groups, institutions, organization and governmental agencies that interact within that geographical territory.

The World Health Organization has clearly acknowledge the importance of intersectoral actions to achieve effectiveness on health outcomes as result of synergic efforts engaging sectors outside the health sector, in collaboration with the health sector. [10] MAP's efforts bringing to the table these different sectors has allowed great achievements on Chagas control overcoming myths that reproduce conditions for Chagas, prevention measures such as changing the vector's (vinchucas) ecosystem niche, introduce sanitary and hygiene practices, and building local capacity of the local health system for diagnosis, treatment and follow up of patients, among others. The Chagas control program uses a set of indicators to establish an epidemiological map of presence of the disease, presence of risk factors, including presence of the vector (vinchuca), and identify patients and support provided to complete their Chagas treatment. Community authorities and members play a central role in building local capacity to engage the health system and synergically make the program sustainable. Our Chagas control program seeks to explore different alternatives to engage communities and government officials. It also uses indicators for surveillance and monitoring achievements and impact. Simultaneously, the program seeks to pursue a variety of integrated community based activities for Chagas control, such as training families, health promoters and local authorities; environmental changes and home improvement to eradicate the vector; screening populations in the communities, confirm diagnoses, and follow up with patients; family and community support for patients; fostering networks between government agencies and grassroots organizations; mobilization for Chagas control, and other related subjects.

In support of government efforts and with a mission to partner with people living in conditions of poverty to save lives and develop healthier families and communities, MAP's community programs support the Bolivian government's *Plataforma de Chagas*, a network of initiatives managed by the Ministry of Health, SEDES [11, 12], *Programa Departamental Chagas, Cochabamba*, and *Red Interinstitucional de Lucha Contra el Chagas*. AbbVie Foundation has also played a very important role supporting MAP's Chagas prevention and control program using the community based strategy.

MAP works at the community level to tackle the root causes of Chagas disease. MAP's unique and innovative community-based

approach towards Chagas disease control aims to enhance the capacity of local families and grassroots organizations to understand what Chagas disease is and how to best organize and combine their resources and efforts to reduce Chagas risk factors and increase accountability for local government involvement. These efforts aim to increase screening of people for Chagas with treatment and case follow-up as well as increase awareness and prevention measures by local communities and government authorities under their own capacity to decrease the prevalence and burden of Chagas disease in Bolivia.

Public education and social mobilization campaigns in Bolivia have been met with varied resistance from communities. Myths, misconceptions, and misinformation about the disease continue to put a strain on the fight against it. It is against this backdrop that MAP's programs are evolving and growing. In our effort to combat Chagas disease, MAP employs prevention and control activities that align with whose recommended public health strategies. MAP's efforts focus on increasing case-detection and case management in collaboration with the Ministry of Health, improving vector control by increasing community awareness and remediating homes for vulnerable families, increasing community awareness surrounding environmental factors (veterinary and sanitation and hygiene) and related social determinants of health.

MAP focus its efforts on strengthening actions on prevention and control of Chagas by local authorities and members of the target communities through community outreach and education, community health worker and health provider training, building disease surveillance and testing capacity and strengthening healthcare capacity for early diagnosis and clinical management. Home visits have been a very valuable strategy to raise awareness and to engage individuals in the community efforts to control Chagas. Through different advocacy activities, MAP seeks to foster that local authorities assume responsibility of the program to ensure sustainability and scalability. One example of this advocacy and political incidence is strengthening the capacity of the local Municipal Council for Chagas through knowledge exchange and support for key council leadership. The council consists of representatives from the local Ministry of Health, Ministry of Education, Child Protection Office, municipal authorities, representatives of grass root organizations and NGOs, authorities from different communities and civil society. Trainings for the council includes participatory planning skills, synergistic planning and implementation of community programming, monitoring and evaluation. This committee also seeks to maintain on-going training activities of key Chagas program components including periodic testing with rapid tests, identification of potential infected person, confirmation of diagnosis, initiation and termination of treatment, and a variety of sanitation, hygiene and prevention measurements for the presence of the vector.

Through MAP's work in Chagas, it is clear that the primary determinants of Chagas disease are mainly economic and social, and therefore, its remedies must not be limited to biomedical solutions and should include economic and social interventions. Going upstream to integrate medicine and politics is the most effective and sustainable strategy to overcome Chagas and most of other public health problems.

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