



## Who Defines Culturally Acceptable Health Access?

Universal rights, healthcare politics and the problems of two Mbya-Guarani communities in the Misiones Province, Argentina

A.Sy

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## Abstract

This paper seeks to analyze the problems and barriers encountered when public policy health programs are implemented within indigenous communities. The initial stumbling block for such programs is precisely the idea of health as a universal right, around which emerges a characterization and stereotype of the indigenous population who are consequently addressed as a homogenized unit subsisting below the poverty line, and marginalized. A result of this is that the particular ethno-cultural register of such populations fails to be acknowledged and form part of a systematic public health policy. Consequently, health policies become generalized in character, unable to variate and differentiate according to the culturally specific contexts within which health outreach and access is needed. In this sense, based on the results of an ethnographic study carried out in two Mbya-Guaraní indigenous communities of Argentina, our study highlights as to how public policies of indigenous health are perceived, their impact value measured, and the meanings which emerge locally about the policy practices implemented.

Lastly, our study identifies problems that can be avoided in fulfilling the goals of universal policies and certain questions to consider at the time of policy design and implementation.

**Keywords:** *Indigenous Health; Public Policy; Ethnography; Mbya-Guarani*

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## 1. Introduction

A great stock of research which was developed during the 1930s highlighted crucial differences between the ways in which health-illness processes are perceived by ethnic groups and the way biomedical knowledge is practiced and implemented. In contradistinction to the rationale of bio-medicine, it was principally observed that certain ethnic groups did not, and indeed still do not, consider disease as a suffering: diseases were, and are, indeed recognized, yet not evaluated and categorized in the same way as natural scientific medicine (Menéndez, 1997). What a morbid entity represents for the pathologist and medic, can therefore be strikingly differently to what a disease represents for members of ethnic, indigenous communities. Not only does this mark a tension between different ways of seeing (that is between the biomedical and the indigenous), but also between the natural scientific and cosmological, between medical anthropology and cosmo-anthropology.

Between 1940 and 1950 the first attempts of collaboration between Anthropologists and Program Managers of Health and Social Development (both public and private) occurred, mainly as a consequence to the failures or the limited impacts of programs and projects which had sought to target ethnic populations. These first attempts of shared work implied a tacit recognition of the need to incorporate dimensions of knowledge that go beyond the domain of a biological frameworks in the management and identification of health problems. Consequently, the 1950s and 1960s witnessed an increasing body of anthropological knowledge reveal the existence, in all societies, of singular institutions; roles; procedures; concepts; depictions and values of pathological entities commonly called “illnesses”.<sup>1</sup>

An increased interest in the comparative and comprehensive study of such knowledge and indeed its impact upon medical practices and epistemology thus produced an important challenge to the so-called "universality" of the western medical paradigm and the rationality, measures and interventions it had instituted (Torres, et al., 1994).

Health problems affecting a community or population began to be viewed in their social and cultural contexts, and the causal definition of illness and the possible solutions began to include the perspective of the community, its values, construction, norms and behaviors. Since the 1970s, and most notably in the wake of the Alma Ata conference (1978), social participation has come to be recognized as a core activity in the design and

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<sup>1</sup> The work of A. Kardiner, Ralph Linton, DuBois Edward Sapir, Margaret Mead, and Ruth Benedict, are examples of this.

implementation of primary health care policy.<sup>2</sup> Along with self-care, the role of women, traditional medicine and popular knowledge, social participation continues to be recognized as one of the substantive actions to solve or at least limit the main problems affecting health (Menéndez, 1994, 2009).

Numerous national and international instruments indeed emphasize health as a Human Right flagging the discrimination suffered by people who do not have territorial or social access to health services, owing to factors of geography, ethnicity, sex or socio-economic status. In this sense, it is the concerted promotion of self- and co-management of health programs, with culturally respectful actions and solutions which can mark the contemporary and ethical framework of policy, its design and practice. For example, the United Nations Declaration of its 36<sup>th</sup> session regarding the Rights of Indigenous Peoples (August 26<sup>th</sup> 1994), sets out in article 23 that:

(...) Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programs affecting them and, as far as possible, to administer such programs through their own institutions.

Similarly, the 169 OIT Convention on Indigenous and Tribal Peoples of Independent Countries prioritized the participation of indigenous peoples in the protection of their rights (e.g. articles 5 and 6) and in the establishment of their social and traditional priorities (article 7). Article 25, referring to health and social security, stated:

The health care system shall give preference to the training and employment of local community health workers, and focus on primary health care while maintaining strong links with other levels of health care services.

The Indigenous Population Health Initiative (SAPIA) orchestrated by the World Health Organization (WHO) and the Panamerican Health Organization (PHO) have defined five key principles to be taken into account when working with native, indigenous peoples. These are: (1) the necessity for an integral health approach; (2) indigenous population self-determination; (3) systematic participation; (4) sensitivity to the indigenous culture and its revitalization, and (5) reciprocity (OPS, 1994).

In 1999 the Traditional, Complementary and Alternative Medicine and Therapies Work Group was created through the rationale of SAPIA. This was a collaborating activity involving the Health System and Services Development Division from the OPS as well as the Traditional Medicine Group from the Essential Medicines and Medical Policies Department of the OMS. The Work Group was established to advise on the promotion of traditional knowledge, complementary and alternative medicine and therapies. In this way strategies contributing to

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<sup>2</sup> The International Conference on Primary Health Care was held September 6-12, 1978. The consequent Alma-Ata declaration included the maxim *Health for all in the year 2000* and reflected an ambitious effort to transform the entire Health System. The conference called for urgent and effective global action to develop and implement primary health care throughout the world and particularly in developing countries in a spirit of technical cooperation and in keeping with a New International Economic Order (NIEO). It urged governments, the WHO, UNICEF, and other international organizations, as well as multilateral and bilateral agencies, non-governmental organizations, funding agencies, all health workers and the world community to support national and international commitment to primary health care and to channel increased technical and financial support to it, particularly in developing countries. The conference highlighted the inequity between the developed and the developing countries and termed it politically, socially and economically unacceptable.

the organization could be identified and delivery of integrated and cultural appropriate health systems and services in the Americas could be defined (Health Systems and Services Development Division, 2003)

In 2005, FISA (the Argentinean Health Research Forum) was created to work on the elaboration of a sanitary priority agenda. In 2007, owing to the limited information on the health situation of native people in Argentina, several meetings took place involving national and international institutions. Several of the conclusions which emerged from these meetings highlighted the need to actively consult with indigenous communities and the difficult task of defining appropriate parameters to select people considered representative of original communities. Coupled with this was the absence of data regarding native people's health; the lack of systematization of existing information; the poor knowledge of the indigenous population's health conception, and the lack of coordination between professionals and programs.

According to the OPS, an indigenous population's epidemiological profile is defined by high poverty indices such as unemployment; illiteracy; migration patterns; landlessness; ecosystem destruction and marginality. The demographic profiles of Latin-American native populations, furthermore, are characterized by the high prevalence of maternal and child mortality; malaria; tuberculosis, and AIDS, in addition to health problems derived from limited of access to basic services (health, housing and sanitation) (OPS, 1994).

A recent publication in *The Lancet* on the health situation of aborigine populations stated that around 400 million indigenous people worldwide suffer from a low standard of health associated with poverty; malnutrition; overcrowding; poor hygiene conditions; environmental contamination and prevalent infections. Likewise the aborigine population has a higher rate of infectious disease than any other. Moreover, the coexistence of respiratory and gastrointestinal infections, which are usually more severe in non-indigenous populations, is one of the primary causes of high child and adolescent mortality. A deficiency in health services, failing promotion and inconsistent outreach initiatives means that disease prevention and social impact are in a critical condition (Gracey, et al., 2009 y King, et al, 2009).

That the health statistics in Argentina are not ethnically determined increases the difficulty of measuring the situation of indigenous health. According to the Indigenous Population Complementary Inquiry (ECPI 2004-2005) 4% to 5% of Argentinean people declare themselves as either native or first-generation descendants. Public health policies and programs tend to consider native people as "poor", or even as the "poorest of the poor". But at the same time, there is the differential of "social capital" where specific traditions and cultural practices can differentiate one BPL sub group (Below the Poverty Line group) from another (Lorenzetti, 2006).

In local diagnostics, there is the general use of epidemiological variables such as sex, social stratification or employment status, without considering the importance of adjusting such variables to a specific population, its norms, internal trends and cultural specific behaviors. Inappropriate parameters or variables thus obscure the cultural/ ethnic peculiarities and therefore the cultural authenticity of sub-groups (Sy. 2009). As Bourdieu et al. (2008) do well to point out, transhistorical and transcultural factors often exclude key details and particularities that determine the historical specificity or the cultural originality of the problem to be studied. Thus, when such ethnic populations are described, poverty and marginality emerge as characteristic elements of a particular culture, yet there are limits which remain vague, and categories which nullify the diversity of each indigenous population studied (Sy, Remorini, 2008).

### **Research approximation**

Our study surveys public health programs specifically formulated for Argentinean aborigine populations. Here, we aim to analyze the efficiency of programs taking as case examples the population from two

communities of the Mbya-Guarani (the *Ka'aguy Poty* and *Yvy Pytã*) who live in the Misiones Province, Argentina.

We worked closely with this population from 1998 to 2003, undertaking periodic field ethnographic work. Our study included the analysis of local perceptions regarding the health-disease-care process, as well as the relationship between the public health system and the representatives of official medicine. Our study focused on health problems that, from the local perspective, seemed to be more troubling: a group of diseases, symptoms and complaints that can be commonly categorized as “gastrointestinal diseases”. Confronting these data with that from biomedical records (obtained from health centers frequented by the Mbya population), we were able to observe convergences in the most frequently occurring disorders such as enteroparasitosis, diarrhea and many associated pathologies: malnutrition and anemia in addition to respiratory pathologies.

The methodology adopted for the research study consisted of:

- The development of semi-structured and open interviews for the Mbya peoples and health professionals;
- Participant observation of daily community activities;
- A case study to record recent or ongoing gastrointestinal diseases. For this we conducted interviews with those involved in diagnosis and/or undergoing treatment, as well as carrying out scene observations on the elaboration of medicines and the search of plant resources used for respective indigenous treatments;
- Observating health centers frequented by those seeking treatment;
- Recording medical consultations in health centers frequented by the population<sup>3</sup>

The results of the present research enabled us to analyze the extent to which the community participates in public policies, programmatically. Based on the results of the present research, and the nature of the relationship between the Mbya Population and the body of Official Medicine, we were able to measure the reality of policy impact and more specifically, how policy resonates in practice with the ethnic population. This enabled us to highlight key issues that should be taken into account when health policies or programs are designed and implemented.

## II. Formulation of the program

The national state institution responsible for enhancing the implementation of indigenous peoples' rights is the National Institute of Indigenous Affairs (INAI), created through Law 23,302, which details Indigenous Policies and Aborigine Community Support (as of 1985) as decreed by Ordinance N° 155/89. This government agency functions as a decentralized entity with indigenous participation, setting out the following objectives in terms of health and wellbeing:

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<sup>3</sup> Cards from medical visits, medical records of hospitalization and resulting documentation of health campaigns, for the period March-April 2003

- The promotion of community participation in the design of health actions, and the enhancement of community access;
- The promotion of intercultural dialogue between local health groups and communities;
- The promotion and appreciation of traditional medicine, as a valid and indispensable resource to enhancing the capacity of community health self-care;
- The enhancement of community capacity for self-care through training activities, health education, the use of communication media and project management intending to recover and maintain community health;
- The articulation of national, state, regional and local health systems with the aim of improving the health care offered to communities, ensuring community access to universal health policies;
- The prioritization of sustainable development, health promotion and prevention, targeting the control of major incidence diseases in indigenous areas;
- The enhancement and development of comprehensive health projects, addressing the structural problems either causing /or giving rise to disease (INAI. National Ministry of Social Development)

In this regard, the actions promoted are: (1) the financing of projects aimed at fulfilling the stated objectives; (2) to expedite the processing of special pensions; (3) the management of personal subsidies for medical care by the Personal Funding Dept. of the Ministry of Social Development; (4) the monitoring of patients from the provinces: treatment management and medical care supervision (INAI: National Ministry of Social Development).<sup>4</sup>

In June 2000 the National Ministry of Health (Department of Health Programs), through Ministerial Resolution No. 472, created the National Program Supporting Humanitarian Actions for Indigenous Populations (ANAHI) in order to provide continuity and to systematize the health strategy of 1993 and 1994 through the Program to Strengthen Primary Health Care in Aboriginal Communities. As stated, the ANAHI Program objectives were: *to improve the health conditions and welfare of indigenous communities inhabiting our country, most of which are highly vulnerable as consequence of inadmissible extreme poverty conditions.* (ANAHI Program, 2000:13). And yet more specifically:

The Program's main action is to concretize health actions based on the universality of services and access, respecting their [the aborigines] beliefs and value systems, which imply our recognition of indigenous health systems based on holistic approaches (...) (Document ANAHI, Health Ministry 2005).

This Program is geared towards the indigenous communities of Jujuy; Salta; Tucumán; Chaco; Formosa, and the Misiones. The core operative actions are: (1) health prevention and promotion; (2) the training of Aboriginal Sanitary Agents, and, (3) the promotion of community participation. ANAHI prioritized the training of a network of aboriginal health workers (sanitary Agents) that took on the role of "intercultural facilitators". This proved the most

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<sup>4</sup> Although the objectives are appropriate for the present legislation, actions to be developed are somewhat confused in meetings the demands of effective compliance: it is not specified who *is* responsible for the elaboration of projects to be financed. Remaining auxiliary actions emphasize the management of economic resources and health care in the form of welfare strategy.

effective vehicle through which to communicate and develop prevention and promotion actions inside indigenous communities and ethnic sub-group populations. The role of “intercultural facilitators” is intended to overcome certain obstacles, given the *“linguistic, cultural and communication differences ... which make difficult the success of a good service”* (Document ANAHI, Health Ministry 2005). The facilitator is a “translator” and link to the formal health system, making it possible to extend the scope of system benefits for aborigine populations (Lorenzetti, 2006).

During the respective government administration the program had tried to spread its remit of action and responsibility, keeping Primary Health Care services as a priority. In principle, a steering committee composed of Sub-program Community Working Groups for native people was planned, in addition to the articulation with other programs and government agencies (inter-ministerial initiatives for example) (Health Ministry, 2006). The aim, was to centralize the activities in the so-called “Planning Framework for Indigenous Populations” with its rooting in the project entitled Essential Functions and Public Health Prioritized Programs –FESP- (Health Ministry, 2006). Between September 2005 and August 2007, under the auspices of the Community Medical Program, a sub-program on community teams for native peoples was conceived as “a specific model” designed for indigenous populations with the aim to:

Improve the social-sanitary situation ... from an intercultural approach based on a respect for community traditions and habits...[and to]... reduce the gap existing in the health situation regarding the indigenous population and its access to basic health services on the basis of different needs and situations, combining promotion, prevention and welfare actions (Health Ministry 2005a).

The results of this initiative, as evidenced on the website of the National Health Ministry, are reduced to the measurement of quantitative “impact indicators” (the number of medical visits for example). From these plain and simplifying indicators it is inferred that an improvement in the quality of attention, administration, detection and monitoring of families and risk groups was, and has been achieved.<sup>5</sup>

At the national level, the Birth Plan is focused on providing coverage and care for mothers and children. Its Sanitary Objectives, as officially stated, are: (1) early pregnancy detection; (2) effectiveness of childbirth and neonatal care; (3) effectiveness of prenatal care and prevention of prematurity; (4) effectiveness of prenatal and childbirth care; (5) the auditing of maternal and infant deaths; (6) immunization coverage; (7) sexual and reproductive care; (8) child health tracking up to 1 year; (9) healthy child tracking 1 to 6 years, and, (10) the inclusion of Native People (National Health Ministry, 2007).<sup>6</sup>

### **The Mbya Guaraní population in Argentina: a necessary contextualization**

The objectives, as proposed by government groups and existing health programs for indigenous populations, demonstrate symmetrical, common features, namely:

- To encourage indigenous access to official medicine;

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<sup>5</sup> The indicators used to measure these very aspects are not mentioned. Likewise, interdisciplinary working groups of professionals were reported as having successfully intervened with 17 indigenous communities, yet the particular results for each community are neither described nor published. No details of the indigenous communities included provided and/or consequent results of the initiative. .

<sup>6</sup> Regarding the last point, the characteristics of such inclusion are not clarified (Sy, Remorini, 2008)



- To develop intercultural approaches with actions aimed towards health prevention, health promotion, and disease care;
- To involve the population in designing and implementing such actions (strategies of participation)

But with such objectives comes a series of pertinent questions: *who* for example defines the problems to be tackled? *What* does it mean “to have access” to primary health care? *What* are the implications of an “intercultural” approach? *How* is it possible to concretely put into practice such a concept? *What* is the degree of participation in the definition of problems and implementation of programs? And, *how* are values defined and promoted? In short, “problem”, “access” and “intercultural” are buzzwords not defined through a consensus which guides actions and underlying values, but sooner employed to eclipse issues.

The Mbya, the Kayova and the Ñandeva are groups that represent the majority of the Guaraní population from South America, whose language belongs to the linguistic family of the Tupí-Guaraní. According to recent estimations (Assis and Garlet, 2004) the total number of Mbya in the territories of Brazil, Paraguay and Argentina stands at approximately 19,200. In Argentina, the Mbya-Guaraní population has inhabited the Misiones province since the latter 19<sup>th</sup> century, mainly occupying the territory along national routes N° 12 and 14 and provincial route N° 7. According to the latest Census, 4,083 people from Argentina identify themselves as belonging to first generation descendents from Mbya Guaraní populations. Of these, 3,684 live in a Mbya community which in terms of demographics is characterized as being a young population with 2,071 people aged between 0-14 years and only 114 aged 65 and over (ECPI 2004-2005. INDEC).

Our research was developed within the *Ka’aguy Poty* (Flower of the Mount) and *Yvy Pytã* (Red land) communities which according to a Census (conducted by the authors on May 2003), boasts a total of 280 people (189 and 91 respectively), with 64% aged between 0-14 years old. This population has a high birth rate and a short period between births.

People from these communities live in the Valley of the Cuña-Pirú stream, located in the center of Misiones province, between the regions of Cainguas and Libertador San Martín. The houses are set out along Provincial Route N° 7 that connects these communities with the urban localities of Aristobulo del Valle and Jardín América, as well as other Mbya communities that live near the Cuña Pirú I and II rivers.

Mbya history is characterized by a constant displacement exploiting rain forest resources in the procurement of habitable land for the ends of *Mbya reko*, or rather, “the Mbya life style” and “Mbya habits” (Remorini and Sy, 2003). The periodic movement within this ecosystem made possible the recovery of previously occupied land. Today, this circulation continues but only on an individual or a small family scale, with the main Mbya population progressively building more stable, permanent dwellings. This process of sedentarization was favored by different factors such as the establishment of geopolitical borders that made displacement difficult through the assigning of housing ENDEPA (Equipo Nacional de Pastoral Aborigen<sup>7</sup> (Crivos et al. 2003). At the same time the rain forest has been subjected to numerous modifying economic activities – wood extraction, replacement of the native forest by exotic forest plantations, construction of hydroelectric dams and agricultural settlement (Crivos et al., 2002).

The concept of a “mount” with the characteristics of virgin forest refers to places located at an increasing distance from settlements. At present for the Mbya, difficulties are encountered in the development of traditional

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<sup>7</sup> ENDEPA is the executive organization from the Indigenous Episcopal Pastoral Commission, a catholic task force concerned with inter-faith dialogue.

practices due to the shrinkage of forest and the consequent shortage of certain plants and animals that were previously available several decades ago. Economic subsistence has in turn diversified, where traditional activities such as hunting, fishing, gathering and swidden horticulture, are complemented with craft marketing and temporary jobs in the colonies.<sup>8</sup> Such activities have favored fluid contact with the rest of society introducing money into the (micro)-economy of the group. This has led to numerous changes in lifestyle, enabling the acquisition of new products or goods, such as processed foods, and the access to alternative health care.

The decrease of horticulture meshed with the reality of scarce wildlife resources; the replacement of traditional food with its industrialized parallel; the precariousness of settlements and poor sanitation (lack of sewage disposal systems and water networks) are all among the most important factors heightening the incidence of disease in the current populations (Remorini and Sy, 2008, Sy, 2009). But the Mbya population itself holds part responsibility where changes in the environment and the consequent change in what was previously a traditional way of life have led to the emergence of new health problems, qualifying biomedicine and the established paradigms of medical anthropology as a necessary resort.

### III. Health Care in Mbya Communities

The researched communities had a health post, located in Ka'aguy Poty, which provided basic health care provision. In 1998, a nurse visited daily, and together with an Aborigine Sanitary Agent, was in charge of the administration of certain controlled medicines. The distribution of milk powder was provided by the provincial government for pregnant women and children under two years. On these occasions, weight and height were recorded to monitor the health of the child or woman.

The coverage of this health post included the two studied populations and the *Ka'a-Kupe* community. These communities were also sporadically visited by a doctor (from a Sanitary Unit in Aristóbulo del Valle) in charge of Primary Health Care. The oldest records of activities are from 1993 through to 2000, when the Sanitary Unit stopped activities due to the lack of staff.

In our study we found that most health problems affecting the Mbya population were sooner solved in the domestic environment, i.e. within the patient's social network, wherein knowledge is used and experience acquired through the successful treatment of similar cases. As one interviewee recounted:

when I was 7 years old I was near dead by the tacho (parasites), but my uncle prepared a good medicine, called horqueta,, we call it chapirangy (...) it's very strong, to take out all the tacho (...) now I'm 26 years old (...) before we used to live together, when I was 7 years old (...) (and now, when the tacho appeared again two months ago, did you prepare that very same medicine?) yes, I prepared it myself, because I know (...) the same my uncle prepared it, 20 year's later. (RR)

In general, people use medicinal plants available near the settlement. However, community members – especially elders – recognize that the transmission of knowledge regarding the treatment of different diseases is discontinuous. Today, the use of biomedical resources is more frequented, as one elder affirmed:

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<sup>8</sup> During the harvest season, the population is found working in plantations of yerba mate (*Ilex paraguariensis*), snuff and tea (Crivos et al., 2002)

Before, the medicines were easily found in the mount, now people only go to the hospital to buy pills, before it was different. (AC)

A change in practices reflects the change in group social structure. Such changes are frequently attributed to changes in the forest ecosystem, and the consequent reduced availability of traditional resources boasting therapeutic properties. The interviewees affirmed that the shrinkage of forest renders Access to medical plants difficult. Nonetheless, today it is still possible to observe a wide use of vegetal resources for the treatment of many diseases even though biomedicine is increasingly the most convenient remedy to hand (Sy, 2008).

If there is a situation that the domestic group cannot solve, it is common practice to consult specialists or group experts, called in Mbya language *Karai* (men) and *kuña kari* (women) o *popopano vae* (“*who know about medicine made with herbs*”). These are frequently elders carrying a group prestige accorded to them by all community members: they are holders of traditional knowledge; experts of the mount medicines (*poã*), priests of healing ritual and prayer (Martínez et al., 2002). Because of this, it is not unusual for some *kari* to be recognized as religious leaders and truth-holders, as *Pai* or *Opygua*, leaders of ceremonies, mystics of the individual life cycle, bestowed with the gift of “communicating” with the “gods”. Those specialist and aged enough, occasionally resort to the use of official medicine:

I know he’s becoming ill, he has diarrhea, but anyway I have to take him to the Opygua, you know, always, that’s our habit (...) if Opygua says, well, you can take him to the hospital, then we have to go to the hospital. It isn’t that if someone is sick I take him to the hospital, no. First we go to Opygua, because it may happen, now many people lose life, many people have lost a child, sometimes they have a small pain [that] is only for Opygua, they go hospital, they die there (...) the doctors don’t know what they have, Opygua knows, that’s the question, so, first, because of that, they have a pipe, our belief is like this, well our god created fist us, and in the same way they gave power to the Opygua (...) (PD)

Here, we see the necessity to communicate and consult the *Pai* or *Opygua*, a necessity recurrent in the language and descriptions of most of the interviewees, affirming the social and metaphysical role of the elder, elsewhere truth-holder and healer (Sy and Teves, 2007). Through the re-elaboration of disease meanings, we observe that biomedicine is an alternative for treatment that can either exclude or complement traditional treatment, depending on the disease affecting the patient.

From the Mbya perspective, some diseases “are only for the Paí or Opygua”, while others are termed “white people diseases” which can only be treated through biomedical intervention. Such categories are, however, artificial if we analyze the health-disease-care process during specific disease situations. Pain, for examples, takes on different characteristics over time, and different terms are used to describe the state of the patient during evolution of the disease. Usually, a “body disease”, is caused by an event that exceeds the biologic and/or is a consequence of a supernatural problem. Symptoms showing an organic dysfunction lead to choose a specific medicine and, at the same time, make it necessary to review daily habits –those that deviate from the ways of life established by “the ancients” – that cause the disease, of which the origin is ultimately supernatural, requiring the intervention of the *Pai* (Sy, 2008):

Because we have two kinds of diseases, you don’t, you have only one, because that never happened to you. (MaG)

And,

Monday was the first day he had diarrhea (...) he had a pain in the lower belly, there ... and after Monday, on Saturday he started to be irritated and also had fever (...) continued with diarrhea, and then, apart from that, it was for a medicine, it was for pai [and what does he have?] he has a headache (...) [and you went to the pai for this?] yes, Miguel is his name, he also knows how to cure, he smokes a pipe, and like this he knows everything [and what was discovered?] he had a small stone, a small stone [and this caused the diarrhea?] no, it's something else, more complicated, (...) first there was only diarrhea and then there were more complications. [Miguel (opygua from the community) told you what he had?] yes, yvy regua puru ojou (...) yvy is soil regua puru that penetrated the soil (...) oju is that it takes, it takes you (...) it found him/ her, ojou is also that (...) I brought him in the evening and in the morning too, because he was asked to return daily (...) only with the pipe he cured him (...) he touched here [showing the forehead] the little stone, but took off a lot and from here [showing the chest] yes, because the guri had a strong pain (...) when one day he is fine like this and then he is *a bit unhealthy* like this, with a small flu, I know, he has fever, something like this, there immediately (...) he can have that (...) it is more dangerous when he is *a bit unhealthy*, like this, sometimes it appears even when he is healthy [why is he affected by this disease?] that's from some time ago, before our great-grandfather died, the oldest from before, and well, this is the spirit, I don't know what you call it (...) Mbogua, yes, mbogua, and angue also (...) yes, it bothers a lot when he is sick, you cannot sleep. (RR)

In this sense, we observe that the disease cannot be attributed to a unique diagnostic category, and even when the patient resorts to official medicine and/or medicinal plants, on many occasions it is necessary to consult specialists or experts in traditional medicine to be able to recuperate fully from the disease and to re-establish a “traditional order” that has otherwise been altered.<sup>9</sup>

### Access to the official health system

Most modern medical consultations are done through community visits. Occasionally, the community will also be visited by doctors specialized in Primary Health Care (PHC) who belong to different governmental organizations and the Sanitary Unit in Aristóbulo (Sy, 2007; 2008). Of 163 records<sup>10</sup>, it is evidenced that 80.4% of consultations are undertaken during PHC visits. The remaining 19.6% are community members who are admitted by health institutions. There are three official sites for health care: (1) the Sanitary Unit in Aristóbulo del Valle (SU.AV.) 10.4%, at a distance of 14 kilometers from the communities; (2) Hospital Jardín América (H.JA.) 8.6%, at approximately 30 kilometers from the communities, and, (3) the Sanitary Unit of Ruiz de Montoya (SU.RM.) 0.6%, one of the closest points of health assistance.<sup>11</sup>

It is the emergency medical services which are most widely used by the communities (53.1%). A lower percentage was recorded for pediatric consultations (28.1%) and lower still was the percentage for general clinical consultation (18.8%). But as one doctor expressed, “*they [the Mbya population] arrive at 11.30 [AM], when doctors are leaving the place, and are assisted there, without recording anything*”. The doctors' availability in the Health

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<sup>9</sup> Here we refer to the ritualistic restoration of balance through means of traditional care provided by the Opygua (traditional healer) see: Sy, 2009.

<sup>10</sup> Records from consultation folders, medical records from hospitalizations and documents from sanitary and vaccination campaigns: March through to April 2003

<sup>11</sup> Owing to poor public transport it is first necessary to visit the Aristóbulo del Valle and then walk approximately 5kms to the SU

Center and the possibility of obtaining an appointment (especially later in the day) are two aspects that affect access, not least because of the logistics of public transport. In this regard, staff from public service institutions (mainly health care centers or hospitals) commonly assume that people should arrive early in the morning in order to be assisted, and consequently treated. This restriction reflects the lack of consideration given to the difficulties communities encounter in arriving before 7 or 8 o'clock in the morning. Thus, Mbya people frequently have to return home without having had the possibility of consultation, either having to return the following day or, as in most cases, being forced to choose an alternative treatment (Sy y Remorini: 2008).

Regarding the motives for choosing a particular health center, some prefer the SU.A.V because of its location and accessibility: *"you can arrive quickly"*, while others choose the H.JA: *"it's easier, when you get off the bus it is there. In Aristóbulo you get off the bus and you have to walk [the bus stop is about 2km from the hospital]. Other people say that at H.JA there is a doctor known to the communities, and consequently, "there you receive better attention"*, in addition to the availability of some free of charge services that are not offered at SU.A.V, as recounted: *"I wanted to do x rays to see what he has, [at the SU.AV.] they didn't do it because you have to pay for the plate ... Before you didn't have to pay, now yes", "sometimes there's medicine at the Hospital but they sell it, cheaper, but anyway ... and the same with the vaccines, you have to pay 50 cents to take them. In Aristobulo, in Jardín it isn't like there"*. The sanitary agent from Yvy Pytã confirmed that laboratory analysis and ultrasound during pregnancy have to be paid for: *"aborigines have to pay 8 pesos, the rest 10 pesos ..."* and although *"the control is free for pregnant women, sometimes they don't go, sometimes they don't go because they don't understand (...) in Jardín they give you the medicine if they have it, you don't have to pay for the ultrasound ... in Aristóbulo ... they give you an order for ultrasound and at the clinic you have to pay 30 with the order."*

Notwithstanding costs of clinical analysis, community members opt for the SU.A.V because they can have access to the Mayor,<sup>12</sup> who provides medicine which may not be available. Thus, the choice of a particular Health Center is influenced not merely by the geographical question of accessibility but also by affinity or relationship with the professional, and as to whether the services are offered free of charge. Numerous community members also mention the Hospital from Posadas as another option, although research did not find recorded evidence from its use. To get there is more time consuming and expensive (the bus ticket is more expensive), however some advantages can be gleaned: *"they give you the medicine, and if you have to pay for it you can ask help from the Guaraní Affairs"*. The Organization of Guaraní Affairs is situated in Posadas (the capital of the Misiones province), and has hosting accommodation for the aborigine people.<sup>13</sup>

From the vantage point of the professionals, there are many difficulties encountered in treating the aborigine population, not least because the medical post is seen as a last resort. The use of Traditional Medicine (provided in the domestic ambit and/or by a local expert) is more frequent than the use of official intervention and when symptoms persist and/or the illness become more critical, a doctor is consulted, but as a point of final call. It is also important to take into account the huge difficulties in accessing such institutions, from a psycho-social standpoint.<sup>14</sup>

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<sup>12</sup> He is a recognized doctor from Aristóbulo del Valle

<sup>13</sup> This Organization is officially responsible for the distribution of medicine for the Mbya population. However, such an option is only selected if the health problem remains without solution, requiring services of higher complexity in other institutions.

<sup>14</sup> For social access we understand: the resource approval from its social recognition, which implies knowledge positively valued and shared by the community (Sy, 2008)

And at times, from the Mbya community perspective, “going to hospital” does not always result in adequate attention:

They didn’t perform a checkup...they asked how I felt, that’s all. (PD)

If you don’t tell him [the doctor] you won’t know, I realized I was sick and that I have problems, they have to know, as a doctor, as a male nurse, as a professional, they should say, and at the end they asked me what I had. They have the machines to know what I have (...) but they don’t use if they notice I’m poor and that I won’t be able to pay, they offer the service to those with money and who pay for it. (FD)

It is common for community members to not return for follow-up visits, should symptoms disappear. However, if the health problem persists, other centers are sought, contrary to that expected by the doctor: (1) health care at the emergency service and/or in the community; (2) followed by a visit to a clinical doctor or a specialist appropriate for the detected health problem.

In terms of hospitalization the doctors note: “*when they start feeling better they go away*”. In the medical record it is also written: “*voluntary discharge (left hospital premises without medical consent,)*,” or, “*the parents insist in removing the baby.*” Duly true are situations where: “*the patient is not in his room, he fled*”. The Mbya are not aware that leaving the hospital is against medical recommendation; they analyze the health situation and take a decision appropriate from their point of view.

(...) he stayed one night there, hospitalized, then, on Sunday morning he left the place, when there were elections [the presidential elections in 2003], he came to emit his vote and he had the prescription for the medicine (...) he came with all that. (PD)

The recorded period for hospitalization never exceeds 24 hours. In the case of children, they are immediately taken back to their community, mainly when there is recovery and a treatment plan to follow. We can visualize that these situations are consequences of mutual ignorance, grossly lacking clinician-patient dialogue. The difference in the concept of disease is evidenced by what is expected from “the other” through the imaginary imperative of the “must be”:

- Regarding the Mbya population, they expect to undergo checkups; to be subjected to clinical or laboratory analysis; to receive adequate medicines, etc.;
- The doctors expect the patient to behave accordingly with the established rules of scientific conduct: to respect timeframes; to obey medical recommendation, to follow clinical instruction, and to return for specialized treatment when and if required.

From their privileged scientific position, clinicians need to, and must, communicate the assumptions and knowledge that constitute medical science in accessible fashion for the native people, and in doing so facilitate an improved and “common” understanding of the role of biomedicine, recognizing its potential and limitations. In this way, native communities may acquire some degree of autonomy in decision making processes, and may indeed be able to reclaim, or denounce, situations that do not enable health system access.

### **When the space for health prevention and promotion becomes a place for the treatment of urgency: the PHS**

The PHS (Primary Health Service) is the community space where we expect to find activities related to health promotion, outreach and public prevention strategies. In *Ka’aguy Poty* and *Yvy Pytã* communities it was

observed (2003) that such facilitation is by way of the Organization of Guaraní Affairs and health institutions such as the S.U.A.V and the H.J.A (these, specifically linked to vaccination campaigns).

Through such community access portals a doctor will undertake daily (outreach) visits, with the support of local sanitary agents, who convene the population. A local school is the space within which patients are received and children are weighed. Medicine for the most common health problems, as well as food, is provided to families of an underweight child. In cases of sickness and ailment the doctor examines patients, the check-up consisting of auscultation; observation of mucous build up around the eyes and/or mouth and throat, depending on the problem. The clinician will also question the patient in order to aid in diagnosis.

Such outreach and access initiatives are, however, sporadic, making it difficult for the community to know when this service will be available. Community visits tend to take place during vaccination campaigns managed by the “cacique” or sanitary agent, or tend to hallmark community initiatives in the run up to local and regional elections. Consequently, for the communities, health visits often represent and entail more than public outreach, and are underwritten by political interests.

Given this, during April 2003 (coinciding with stage-3 of our fieldwork) news spread of child mortality owing to the crisis of malnutrition in Fortín M’bororé, one of the most populated communities in the province. Several days later child deaths were reported in the Sirí community (the *Delicia colony*). The national media were soon to report the recent death rate, with headlines in the popular press stating that 10 children were hospitalized with 3<sup>rd</sup> grade malnutrition (considered irreversible) and 20 families were at risk with 1<sup>st</sup> and 2<sup>nd</sup> grade malnutrition. In May 2003, 20 children had been detected as being at risk (López and Aramendy, 2004).

The provincial newspaper “El Territorio”, leveled responsibility at the Fortín M’bororé population, stating that the Aboriginal Populations lacked a “political vision” which otherwise could allow for proper communication among the communities, “this, a consequence of geographic and mainly cultural characteristics.” The sudden explosion of facts, figures and criticism coincided with an intense electoral period, giving birth to a strong mobilization of assistance resources targeting the Mbya communities. Doctors quickly arrived to undertake weight and height checks and provide food to those families with underweight children. But more than anything else, what such a situation flags is that a lack of continuity and articulation among policies and health campaigns from different public agencies is a barrier to cultivating community trust for official medicine, its procedures and interventions.

#### IV. The participation of the population

Our research did not find evidence indicating the joint planning of activities by public health agencies within the concerned communities. Only the Aborigine Sanitary Agents are the “intermediates” between the community and the biomedical personnel, facilitators and communicators between two seemingly disparate worlds and *ways of seeing*. Such a role inside the community is thus conflictive and even contradictory. For one of these Sanitary Agents – “BB”, initially trained as a nurse, intervention into the ritualistic lifestyle of these communities implies a stark conflict of interests:

I don’t know, now that I started working (as sanitary agent), I don’t know if this is bad for people, I mean, I think (...) I don’t know if this may be bad for the aborigines (...) since they always worked like that, with the pipe and, I mean, waiting with the pipe, with all that (...) aborigines are good for that. (BB)

BB's work is at times at odds with the community she seeks to serve, a community which has traditionally succeeded in having a different approach to, and perception of, diseases. BB further mentions "*them*" and although she is a member of the Mbya Guaraní community, it is not difficult to see a certain degree of alienation at play within her words. The personage of the Sanitary Agent can thus be contrary to the culture of the Mbya, and often difficulty further arises when the lack of supposedly guaranteed biomedical resources have not arrived. Coupled with this is the fact that BB earns a salary, and we are left with a tapestry of community tension and mistrust. BB's role is difficult, for she is both *within* and *without* the community. But there is a flipside, albeit tendential, for the Sanitary Agent is the only point of contact the community holds with health services, and will often be able to secure funds for the community to travel to health centers. In this sense, from the local perspective, the Sanitary Agent is not conceived as intermediate figure favoring the relation with the doctor, but as a facilitator (Sy and Remorini, 2008)<sup>15</sup>.

### **Access to a culturally accessible health paradigm**

It is not uncommon in our day for social policy to experiment with semantics where the focalization, the provision of basic packages, the strengthening of "capacities/capabilities" and the instauration of the idea of an agency satisfying "basic needs" are, among others factors, the main characteristics (Álvarez Leguizamón, 2005). Yet the lack of concrete actions within the community; lacking geographical accessibility; the lack of promotion and strengthening strategies, and the lack of community autonomy in decision making processes, remain, for the most part, off the policy radar.

As our research has sought to demonstrate, there exists a tendency to homogenize population needs, and that the course of management "from above" for the aborigine health situation in general falls short of the community necessities "within". Although programs have been re-defined from the point of view of scope and interference, adaptation to local scenarios is still a difficult challenge. The possibility to develop program actions depends on present situations/conjunctures and, given the difficulties that arise when developing program measures, strategies remain far from those envisaged and planned.

Often, the inappropriate background and training of professionals and technicians working in communities are reflected in poor interaction strategies, and the creation of indigenous Sanitary Agents is ineffective in realizing outreach and assessibility. The need for a "translator" to understand the aborigine language imposes a barrier in the fluid communication between the indigenous people and the health service members. At times, these difficulties arise from the lack of resources (material and human) that are theoretically assigned but are not available when truly needed (Sy and Remorini, 2008).<sup>16</sup>

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<sup>15</sup> Sanitary Agents must be of the indigenous population and possess and understand their behavior in order to facilitate the communication of health promotion and prevention. The community, however, is without autonomy in decision making processes, and often the needs felt by the community are not taken into account. At the same time, these Agents (State community delegates) have the responsibility to deal with the difficulties and contradictions existing in local Health Centers and the instability of the public policies. In this context, their role inside the community is highly limited.

<sup>16</sup> Programs such as ANAHI emphasize the training of indigenous sanitary agents as "cultural facilitators", to better increase psychological and physical access to the formal health system. Their expected role as "translators" and "connectors" between the community and the formal health system is in correspondence with the general aim to extend biomedical services, without modification, to aborigine populations. In this context, the sanitary agents are subjected to a program they must follow and, at the same time, they have to answer to the demand of health care from within their respective community. We agree with Lorenzetti (2006) when she states that



The difficulties emerging, on the one hand, inside the communities and, on the other hand, in the dynamic of the health centers and hospitals, need to be taken into account. Different proposals and intentions coherent with the constitutional rights are proposed in the programs, but eventually a standardized, if not diluted, model is expected to work appropriately.

As Spinelli et al. (2004) assert, although the concept of necessity in the context of public health has been used to distinguish the “needs felt or perceived” by the population from the “needs defined” by professionals, the latter are the most important in terms of the programs and actions to be developed. In this study the results have been presented taking into account the needs *felt* and *expressed* by the population, which are not always explicit. Often they are associated with personal experiences of illness and cure; sometimes they emerge as specific quantitative/logistical data, e.g. the distance to the hospital and the availability of public transport.

According to the ECPI (2004-2005), the mbyá guaraní population see an “indigenous healer” (88%) and a doctor with equal frequency (88% and 84% respectively). In this sense, from our results we can highlight the fact that offering health care inside the community population or the population attending health institutions does not guarantee effective health care provision. Since such actions are not based on consultation and participation processes, acceptance and access (in the wider sense) are not experienced. This should be taken into account when health programs and policy successes are measured in terms of the number of medical consultations/services; the breadth of population covered by the program, and the number of sanitary agents trained in the context of the program. Investing in more resources may indeed increase the number of consultations, but if program success is not evaluated in terms of the impact factor of health actions and the wellbeing of the population, then indicators remain nothing other than ideological symbols.

Knowledge of the representations and practices in processes of health, disease and care in particular local contexts needs to form part of modern policy consciousness. Likewise, the assumptions that underlie medical practice, and the biomedical representations and practices natural to the biomedical paradigm which obstruct the possibility of dialogue and mutual knowledge creation, must be explicated. In this sense, the role of health professionals is both complex and challenging, necessitating cultural sensitivity at the same time as pathological knowledge. Ethnographic studies developed in each native population are fundamental for designing and executing policy, programs and actions that guarantee culturally acceptable health access and a strategy of health equity incorporating traditional knowledge; practices; diversity; heritage and inter-cultural dialogue as instrumental factors.

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the function of these agents, which in principle should contribute to the “adaptation” of a community-accessible formal health system, has been converted into an “adaptation” of the community to the requirements of the formal health system itself.

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