

An Introduction to Haitian Culture for Rehabilitation Service Providers

Erik Jacobson



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**Culture Brokering: Providing Culturally Competent
Rehabilitation Services to Foreign-Born Persons**

**An Introduction to Haitian Culture
for Rehabilitation Service Providers**

Erik Jacobson

*(In collaboration with the staff and families
of the Haitian Family Support Program)*

CIRRIE

Center for International Rehabilitation Research Information and Exchange

University at Buffalo
The State University of New York

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This publication of the Center for International Rehabilitation Research Information and Exchange is supported by funds received from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133A990010. The opinions contained in this publication are those of the authors and do not necessarily reflect those of CIRRIE or the Department of Education.

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AN INTRODUCTION TO HAITIAN CULTURE FOR REHABILITATION SERVICE PROVIDERS

Preface

Haiti is one of the principal countries of origin of immigrants to the United States. Many have come for economic reasons to escape one of the poorest economies in the Western Hemisphere. Others have fled for political reasons.

Haitian culture is quite distinct and less familiar to most Americans than many other cultural groups (Latino cultures, for example). Haitian culture and language is also quite distinct from that of other Caribbean peoples. Often these distinctions are not recognized. Most people in the U.S. have very little information about Haitian culture and history, and their perceptions of it are often influenced by simplistic Hollywood depictions.

For disability service providers who work with Haitians it is imperative to understand Haitian perspectives on the nature of disability, including the shame and social stigma that are often attached to those individuals in the Haitian community who have disabilities. These attitudes prevent Haitian families from seeking support and social inclusion of their sons and daughters in community activities and programs. Families may never take advantage of social programs and services that are available. Many of these children become socially isolated, and the families live a life apart from their community. Educators and health specialists that have an understanding of Haitian beliefs about disabilities will be in a better position to build bridges for Haitian families, and to shape programs and services that account for their belief system. A better understanding of the nature of the social stigma that parents and children live with will also allow non-Haitian professionals to join forces with Haitian colleagues who are attempting to change their community's attitudes towards disability.

The author of this monograph, Erik Jacobson, is a literacy and community-based education specialist working at the Center for World Cultures and Languages at the University of Massachusetts in Boston. He has worked with the Haitian community of Boston for nine years in a variety of capacities. Most recently, he has coordinated collaborative activities between the Center and three community service agencies (the Haitian American Public Health Initiative, The Somali Development Center, and the Capeverdean Association of Brockton). He is currently working with the Haitian Family Support Program to develop outreach materials, such as videos in Haitian Creole to raise awareness of disability issues within the Haitian community of greater Boston.

This monograph on Haitian culture is part of a series developed by CIRRIE -- the Center for International Rehabilitation Research Information and Exchange

-- at the University at Buffalo, State University of New York. The mission of CIRRIE is to facilitate the exchange of information and expertise between the U.S. and other countries in the field of rehabilitation. CIRRIE is supported by a grant from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education.

In addition to developing this monograph series, CIRRIE conducts workshops on providing disability services to foreign-born persons. We hope that this monograph will be useful to you in your work with persons born in Haiti. We welcome your comments that will help us to deepen our understanding of ways to increase the effectiveness of rehabilitation services for persons born in other countries.

*John H. Stone, Ph.D., Director,
Center for International Rehabilitation Research Information & Exchange (CIRRIE)
Series Editor*

AN INTRODUCTION TO HAITIAN CULTURE FOR REHABILITATION SERVICE PROVIDERS

INTRODUCTION

The goals of this monograph are twofold. The first priority is to provide service providers an overview of Haitian history and culture along with recommendations regarding working with Haitian clients. The need for such an overview is clear. News about Haiti is often limited to AIDS, voodoo, or political violence. This scarcity of information leaves service providers and others with less than a full picture of life in Haiti. This monograph does not attempt to capture every aspect of Haiti or of Haitian immigrant life in America. The Haitian community in the United States is diverse, and differences in social class and regional variations make it impossible to generalize about the population. However, there are patterns and customs that provide guidance in interacting with Haitian immigrants in the United States.

The second goal of this monograph is to encourage research on disability in the Haitian context. Unlike many of the other communities represented in this series of CIRRIE monographs, disability issues in the Haitian community have not been a focus of research. Most of the research on Haiti and Haitians has tended to deal with immigration patterns, language use and health and sexuality issues. One reason for this is the lack of a rehabilitation or special education system in Haiti. Since the country does not have the resources to provide basic services, it is not surprising that there is little or no research on disabilities issues in Haiti. This monograph is a beginning and should help point to some important avenues of future research. It is our hope that service providers and researchers will take up this challenge.

This monograph was made possible through the work of Dr. Renald Raphael of the Haitian Family Support Program in Boston. I relied upon Dr. Raphael's insights on Haitian culture and on his experiences dealing with disability issues. In addition, this monograph would not have been possible without the input of the families of the Haitian Family Support Program. Their experience in trying to provide for family members with disabilities has taught me a great deal. I thank them for sharing their thoughts, dreams and disappointments with me over the last five years. I developed this monograph on their behalf, with the hope that their children can achieve their own dreams.

HISTORICAL AND SOCIOCULTURAL BACKGROUND

Geography

Haiti occupies the western third of the Caribbean island of Hispaniola, which it shares with the Dominican Republic. Haiti is slightly smaller than the state of Maryland and lies just southeast of Cuba. Haiti is very mountainous. In fact, the word "Ayiti" was a Taino (the original inhabitants of Haiti) word for "land of mountains." The capital of Haiti is Port-au-Prince, which lies in the center of the country, on the coast. Other important cities include Cap Haitien, which is in the northeast coast of the country, and Les Cayes, which is on the southwest coast.

Historically, 90% of Haiti was covered with forests. Now that figure is 4% or less. Most trees have been cut to make charcoal. This deforestation has led to erosion rendering much of the land unharvestable. Runoff into rivers has also affected fishing. The economic and environmental downward spiral results in poor farmers harvesting more trees to earn money. Environmental conditions continue to deteriorate. What was once called the "Pearl of the Antilles" is now an ecosystem on the point of collapse.

Colonial History and the Haitian Revolution

The original inhabitants of Haiti were the Tainos who were part of the Arawak people. The island first came to the attention of Europeans when Columbus landed on it, thinking that he had arrived in India. Almost immediately, the colonizing powers of Europe set their sights on this island, rich with natural resources and stunningly beautiful lush forested mountains. During its early history of colonization, France, Spain and England struggled to control parts of the island. Within decades of landing, Europeans wiped out the Tainos through outright slaughter and through the introduction of diseases to which the Tainos were not immune. This genocide meant that colonizers did not have the labor to collect the resources they wanted, so they imported slaves from the west coast of Africa. These slaves came from many different tribes, and melded together to form the African population of Haiti.

There was long period of struggle between European colonizers. By the early 1700's, France had established control over the western side of the island (Haiti), while Spain ruled the eastern side (the Dominican Republic). At this time, there were 40,000 colonists and almost 500,000 slaves within the French colony of Haiti (Farmer, 2003). There was also a sizable mulatto population. They played an ambiguous economic and political role between the French and the African slaves. Slave owners, who for the most part owned large planta-

tions, were known to be the most brutal of their class throughout the region. It was common practice for slave owners to torture and maim their slaves. While there had been sporadic resistance to French Rule, the final series of rebellions began in 1791. A former slave named Toussaint L'Ouverture took command of an army that consisted of rebellious slaves and mulattos. The army killed thousands of colonists and chased the rest away. However, it was not an overnight success. It took years of violent struggle. Eventually, L'Ouverture was tricked into visiting Paris where he was immediately jailed. He died in prison. Jean-Jacques Dessalines led the revolution to its conclusion, uniting the country and driving out the remaining vestiges of French colonial power. His rule was short. After his death in 1806, the country was ruled in the north by Henri Christophe and in the south by Alexandre Petion. Their control was short lived as well. Soon the country was reunited under Boyer (James, 1989; Ros, 1994).

This pattern of events has repeated itself throughout Haiti's history. During the 19th and 20th centuries, regime change was common. Often, rulers were violently forced out. The use of force was not limited to Haitians. From 1915 to 1934, the country was occupied by American troops. Diplomatic missions requested U.S. occupation in Haiti, because they were concerned by the power vacuum created when a mob lynched President Vilburn Guillaume Sam. While the willingness of the U.S. to intervene could be explained by its desire to protect the lives of Haiti's foreign residents, the fact is that the U.S. already had gunboats in Haitian waters. Occupying Haiti was one part of a larger U.S. effort to create an exclusive sphere of influence in the Americas. (Dash, 2001; Smith, 2001).

François Duvalier (known as Papa Doc) took control of the country in 1957. He ruled the country until 1971 when he stepped down in favor of his son Jean-Claude Duvalier (known as Baby Doc). The Duvalier regimes were marked by political violence conducted by Duvalier-associated militia known as the *Tonton Macoutes*. Violence and the economic conditions of the country caused thousands of Haitians to emigrate. After Baby Doc's exile in 1986, there were another series of governments. Some were sponsored by the military while others were attempts at democracy. In 1990, a charismatic and politically progressive Catholic priest named Jean-Bertrand Aristide was elected President. Ousted by military coup, he returned to power in 1994 with President Clinton's support and was re-elected in 2001. Tensions between Aristide's party and a confederation of opposition groups who are calling for another election have created a political deadlock. This rift prevents the Haitian government from receiving promised international aid meant for development.

Population

In 2000, the estimated population of Haiti was 8 million. Racial demographics are 95% black and 5% mulatto. Port-au-Prince has a population over 1,000,000.

Across Haiti, 33% of the population lives in cities, while 67% lives in rural areas. With 700 people per square mile, Haiti is second only to Barbados for population density in the Caribbean. In the city, women give birth to 3 to 4 children, and in the countryside, they average 7. Infant mortality is 97 per 1000. There is one doctor per 4,000 inhabitants. Haitians have a life expectancy of 49 years (Arthur, 2002).

Hundreds of thousands of Haitians have created new Haitian communities in countries all over the world. After Port-au-Prince, New York City has the second largest Haitian population of any city, followed by Miami and Boston, with Cap Haitien ranking fifth. These immigrant communities have been referred to as Haiti's "10th Department." This is a reference to Haiti's nine official governmental regions. Regardless of their distance from Haiti, the population of the 10th Department remains involved in Haitian politics and society. For this reason, the nation of Haiti is not geographically limited to the island of Hispaniola.

Economy

Haiti is often described as the poorest country in the Western Hemisphere. In terms of per capita income, it is the lowest. Approximately 80% of the population live in poverty. Many people do not have a steady job or income. There are large areas of Port-au-Prince occupied by people who left the countryside to look for work. Sections of the city, such as Cité Soleil, are infamous urban slums.

While manufacturing plays a role in the Haitian economy, factories provide only a small percentage of jobs. Almost 70% of Haitians depend on agricultural work done mostly on small farms. The environmental devastation mentioned earlier leaves this workforce especially vulnerable to variability in weather, and crop erosion. Much of Haiti's economy depends on foreign aid and the resources of volunteer aid organizations. The track record of foreign investment and support is spotty. There is a history of large amounts of money being spent with little to show for it (Smith, 2001). Critics suggest that aid efforts have not focused on developing capacity in the long term. Projected development stops soon after the aid agency and its administrators leave the country.

Haiti's economy has been directly affected by policies of the United States, including a disastrous attempt to import American pigs. The pigs replaced Haitian pigs thought to have swine flu. However, the American pigs would not eat local food, and poor farmers were forced to buy expensive feed from American corporations. Many families went bankrupt trying to care for pigs that eventually died. This case is not an isolated example. It points to the fact that while Haiti may be the poorest country in the Western Hemisphere, its economy does not exist in isolation. Haiti is particularly vulnerable to policies generated in Washington.

One notable aspect of the Haitian economy is the role that group work plays. Communities engage in what is called a *konbit*, where work and resources are shared. This is often called working "*men-nan men*", or working hand in hand. For example, on one day the whole community will help a single farmer harvest his crops. The next day, the same group may help a different farmer build a new farmhouse. Also notable is the key role played by traveling saleswomen called *Madan Sara*. These women go from town to town selling, trading and exchanging goods. They are an informal distribution network. This aspect of the Haitian economy provides some independence for women. The currency of Haiti is the *gourde*. In the past, 5 *gourdes* were referred to as a Haitian dollar due to the exchange rate. This term is still used.

Languages

Haiti has two official languages: Haitian Creole (also known as *Kreyòl*) and French. *Kreyòl* is spoken by 100% of the population, while 8-10% of Haitians can speak French. Like all French-based creoles, *Kreyòl* is a mixture of French and the African languages that Haitian slaves spoke. It is incorrectly described as a French dialect or worse, as "broken French." In fact, it is a distinct language with its own vocabulary and grammar rules. This negative comparison to French is a legacy of colonialism. Even after Haiti became independent, French has been the language of government and of power for most of Haiti's history (Valdman, 1984). While *Kreyòl* has increased in status, French continues to provide access to power and prestige. Not surprisingly, French is more likely to be spoken by urban elites than by farmers in the countryside. Due to the fact that French appears to have more prestige than *Kreyòl*, many Haitians identify themselves as French speakers when they are not truly fluent in the language. This may create problems, if parents in the U.S. introduce their *Kreyòl* speaking children to bilingual teachers as French speakers. In some cases, children who underperform because of a linguistic mismatch are misdiagnosed as having a disability. Similarly, because of a lack of diagnostic resources in *Kreyòl*, some Haitian students in the U.S. are misdiagnosed as having mental disabilities because they are tested in languages they have not mastered (such as English).

Education

Access to education varies greatly. Although the Haitian Constitution states that primary education is free and compulsory, primary school enrollment is about 65%. Overall, only about 56% of children are enrolled in primary and secondary schools, with less than 15% graduating from secondary school (U.S. State Department, 2001). In rural areas there are virtually no schools. The literacy rate in Haiti is about 45% (Arthur, 2002). Approximately 90% of schools are private, with 10% run by the state. Urban French-based schools have been privileged over rural *Kreyòl*-based schools. In fact, these schools were operated by different government ministries. For a long time, education in the city was over-

seen by the Ministry of Education, while rural schools were administered by the Department of Agriculture (Fleishman, 1984). This division was created in 1922 during the U.S. occupation of Haiti. (Berry, 1975). Due to renewed protests, this system has been reformed.

Even though primary school is free, costs of uniforms and textbooks make it difficult for poorer families to send their children to school. At times, families will ration their money and send only male children to school. The schools often lack basic resources and the school buildings may not be in good condition.

Private schools vary in price and can be very expensive. Many are run by the Catholic Church. While private schools are thought to provide a decent education, many are unregulated with few resources and unprepared teachers.

Regarding special education, the Haitian Constitution states that "persons with disabilities shall have the means to ensure their autonomy, education, and independence" (U.S. Department of State 2001). Given the state of the typical education system, usually these means are not provided. Indeed, "there is no legislation to implement these constitutional provisions or to mandate provision of access to buildings for persons with disabilities" (U.S. State Department, 2001).

In America, Haitian immigrants with enough resources continue to send their children to Catholic schools or other private schools. Low-income families (whose children did not attend school in Haiti or who had limited schooling) rely upon the public school system. These parents are concerned about placing students in classes based upon age rather than on educational experience and abilities. Without special considerations, they sense that the gaps in their children's education will never be filled.

Regardless of social class, Haitian parents share a perspective on education that differs from what is expected in the United States. Haitian parents trust schools and teachers completely. They do not believe that they have a role in their children's education. They tend not to ask questions of people in authority. They are not accustomed to being proactive regarding their child's schooling and may not understand requests to attend meetings with teachers or administrators unless their child is in trouble. From the Haitian parents' perspective, education is the responsibility of the school while discipline and moral development is the responsibility of the parents. In general, Haitian parents place a high value on education and have very high expectations of schools. Many immigrate to the United States in order to give their children a chance at a good education.

Media

There are two French-language newspapers in Haiti: *Le Nouvelliste* and *Le Matin*, with a combined circulation of less than 20,000. Newspapers are beyond

the reach of many citizens due to language differences, illiteracy, and cost. Print media in Kreyòl has been limited due to regional variations in the language and orthography. Kreyòl has had a standardized orthography for only the last two decades. There is a growing collection of texts written in Kreyòl and many newspapers include a page of news in Kreyòl.

Within Haitian culture, oral forms of communication are preferred over written. Communication often takes place on audiotape rather than through letters. Word of mouth (*teledjòl* in Kreyòl) is used to disseminate a wide range of information from gossip to political analysis. There are a limited number of television stations in Haiti. Radio is the most important medium. Stations broadcasting in Kreyòl provide a way for Haitians to stay informed about national and international news. There are a few hundred private radio stations with programs varying from music and entertainment to talk shows. Due to political constraints, talk shows allow Haitians to express themselves in ways that they might not in interpersonal settings. This use of media has continued in the United States. Cities with large Haitian populations have a number of radio stations. Cities like New York, Boston and Miami also have Haitian related programs on local community access television stations.

Immigration to the United States

While often thought of as one of the United State's newer immigrant communities, Haitian immigration to the United States began almost as soon as the United States became a country. Haitians also played a key role in early American history. A small group of Haitians (the *Chasseurs Volontaires*) saw action in Georgia during the American Revolution. Jean-Baptiste DuSable, a Haitian explorer, was the founder of the settlement that became Chicago. By the early 1800's, there were significant Haitian communities in Louisiana, Baltimore, and Philadelphia. These communities helped elect Haitian immigrants to the United States Congress and created social clubs in each of these places.

From 1804 to 1898, Haiti was an immigrant receiving nation (Fouron, 1983). In the early 19th century, runaway slaves from other colonies made their way to Haiti. At the end of the century, approximately 15,000 immigrants from the Middle East settled in Haiti (Arthur, 2002). However, as the 20th century brought continued economic and political violence, Haiti's emigration increased. In fact, 15% of the population left between 1957 and 1984 (Glick-Schiller, et. al. 1987). From the 1950's to the 1960's, Haitian immigrants to the United States were mainly mulatto elites and rural landowners. Because they were escaping what they thought was short-term political turmoil in Haiti, they did not think of themselves as permanent residents of the United States. Since the situation in Haiti did not improve, they were forced to remain here. For the most part, they have been completely subsumed into American society (Fouron, 1983).

During the mid-sixties, there was a large scale revision in immigration laws in the United States, resulting in increased immigration from all over the globe. Encouraged by employers in the United States who had lost their low-wage workforce to the Vietnam War, many Haitians made their way to the United States. This wave of immigration was a demographically mixed population of Haitians. On the whole, they were less skilled than individuals in the previous exodus (Fouron, 1083).

In the early 1980's, the exodus of the "boat people" began. Once they reached the shores of the United States, these unwanted and unpopular immigrants were put into detainment camps, often for long periods of time. Some of these camps were located in upstate New York and Texas, far away from family and friends. In 1982, 10,000 people marched in Washington, D.C. to protest U.S. government policy and to ask for the release of the "boat people."

When news of Duvalier's retreat from Haiti reached America, 25,000 Haitians gathered in the streets of New York City and sang in Kreyòl (Glick-Schiller et. al, 1987). However, most Haitians did not return to their homeland. While they can travel back to Haiti, most cannot stay there permanently. Life in Haiti is still difficult. With no money or credentials, many members of the diaspora remain trapped outside of Haiti. These Haitians have built lives in the United States while remaining in touch with Haiti. Rather than having a single identity, Haitians in the United States have a dual focus - a transnational identity.

For many Haitian immigrants, ethnic identity within the United States is not the defining element of their lives. At times, they identify as an ethnic minority (Haitian) and at other times they identify as black. In Waters's (1996) study of immigrants from Haiti and the Caribbean, Haitian informants thought of themselves as "hardworking, ambitious, militant about racial identity, but not over-sensitive about race, committed to education and to the family." Immigrants in this study saw black Americans as "lazy, disorganized, and obsessed with racial slights and barriers" (Waters, 1996). Life might be hard here, but in many ways, it is better than anything they could expect in Haiti. A deep sense of relative deprivation serves to mitigate some of the oppression they experience. In this way, Haitian immigrants compare their current position to the economic situation in Haiti, rather than to their peers in the United States (Woldemikael, 1989).

While subjects in Waters' study identified positive aspects of Haitian identity, for example "hard working," some Haitian immigrants do not self-identify as Haitians. In reaction to prejudicial attitudes towards Haitians, some have become "undercover Haitians", who identify as anything (e.g., Canadian, French, Jamaican) other than Haitian (Zephir, 2001). While this is the experience of a small portion of the Haitian immigrant population, it is significant. Outreach efforts aimed at Haitians may not reach all of the intended population. Some individuals and families may not want to seek service at a center defined as a "Haitian" center.

A current concern is the different treatment Haitian refugees receive compared to others from their region, such as Cuban refugees. Cubans who reach American shores are granted the status of political refugees. This is not the case for Haitians. Currently, Haitian refugees who come to the United States without documentation are kept in INS facilities while awaiting their hearings. Most are sent home at the end of the legal process. This difference in treatment is a key concern of the Haitian community in the United States.

CULTURE

Eating Habits

Grains are a staple of the Haitian diet, and rice is eaten at almost every meal. It is often cooked with beans and served with sauce. Fried foods are very popular, and many meals include fried plantains or fried meats, such as pork or turkey. Stews, such as one with conch meat, and soups, such as squash soup are commonly eaten foods. Squash soup is eaten on Sundays and on January first. Haitian food can be spicy, but perhaps not as spicy as Indian food. While Haitian immigrants have adjusted to the type of American foods available here, if you are serving a group of Haitians, American staples such as mashed potatoes or eggs may not be popular. Some Haitians believe that a healthy baby is a fat baby, and this perspective on nutrition and health continues into adulthood. Since weight is associated with health, good nutrition means eating a lot.

Religion and Taboos

Like language, religion in Haiti is a very complex and sensitive topic. Most people would describe themselves as very religious, and religion affects almost every aspect of Haitian society. While 90% of the country is Catholic and 10% is Protestant, Haiti is most famous (or infamous) for voodoo. Voodoo exists side by side with Christian faiths. Many Haitians see no contradiction in calling themselves Christians while engaging in voodoo practices. This is more often the case with Catholics. Catholicism in Haiti is very ritualistic and has adapted itself to local ritual. It is less likely that Protestants would describe themselves as believers in voodoo. There have been some Protestant-lead attempts to diminish the role that voodoo plays in Haitian society.

Voodoo is a mixture of African and Haitian beliefs. It has a complex cosmology made up of a large number of supernatural spirits. These spirits are believed to have great influence on human beings and for that reason, they must be respected. The term in Kreyòl for a spirit is *lwa*. Each family has a *lwa* associated with it. Daily life is conducted according to what would make these spirits happy. Voodoo practitioners believe *lwa* make their desires clear by possessing some-

one and speaking through them. *Lwa* also make their presence known in dreams. Often *lwa* will ask a mother to dedicate their newborn or unborn child to them. If the *lwa's* request is not honored, the *lwa* may possibly punish the mother or child by giving them a disability. Nobody wants to make a spirit angry, for the *lwa* will punish those who do not obey and respect them.

Voodoo has played a key role in Haitian history. Slave uprisings began with a secret voodoo ceremony. Voodoo helped provide some unity for the rebellious slaves. When Duvalier came to power in the late 1950's on a nativist platform, he used voodoo to support his position and power. The close association between the Duvaliers and voodoo continued throughout both men's regimes and complicates attitudes towards the religion now. The word voodoo conjures up Hollywood images of zombies and bizarre ceremonies. Many Haitians, particularly in America, are sensitive to being seen as voodoo worshipers. Yet the practice continues in the United States.

National Holidays

National holidays in Haiti are a mix of religious and historical celebrations. As is the case in many other Caribbean or South American countries, Haiti celebrates *carnival*. Carnival, like Mardi Gras, leads up to Ash Wednesday. In Port-au-Prince, the streets fill with moveable parties of music and drinking all over town. Many bands create floats that move through the city playing music. Social tensions are relaxed, and many times dangerous political sentiments are expressed through singing. A similar event, called *rara*, takes place just before Easter in the countryside. *Rara* includes people making music and dancing as they move through the streets. For some Haitians, the revelry at carnival or *rara* offends their religious sentiments and they reject the holidays as evil. They may participate in more locally based voodoo festivals and holidays that focus on visiting sacred spaces or noting certain events.

The most important national holidays are:

January 1	Independence Day (<i>Joudlan</i>)
January 2	Ancestry Day
April 7	Death of Toussaint L'Ouverture
May 18	Haitian Flag Day
August 15	Assumption of the Blessed Virgin Mary
October 17	Death of Jean-Jacques Dessalines
November 1	All Saints
November 2	All Souls
November 18	Vertières Day (A famous battle)
December 5	Discovery of Haiti
December 25	Christmas Day

Family Structure and Role of the Community

In Haiti, households often consist of multiple generations. Adult siblings (and their families) may live together in a common space. The Haitian *lakay* (home) is geared towards the needs and strengths of the extended family. Usually, individuals do not dream of owning a house that is separate from their family. This preference for extended families living together causes problems for Haitian immigrants in the United States who cannot replicate their Haitian living arrangements due to economic pressures. It is not always possible for Haitian families to find places where they can all live together under one roof.

Haitian communities often consist of a dozen or so *lakay* grouped together to form a *lakou*. These families work together to complete their daily life tasks, such as farming or building new houses. This communal sharing of work is known as *konbit*. For many grassroots organizations, the *konbit* is the best way to accomplish their goals. Once a task has been defined as one that is shared by all, it is much easier to find people who are willing to work. There is a Haitian saying "Ayisyen se krab," which translates to "Haitians are crabs." As with crabs in a bucket, when one person looks like they are going to escape, the others pull him back down. Haitian community life is complicated and sometimes contradictory. On the one hand, there are communal efforts like *konbit* and on the other hand, there is the idea that people will pull each other down.

The Haitian family and community have been described as transnational (Laguerre, 1998). The suggestion is that Haitians in the United States do not identify themselves solely as residents of America or of Haiti, but instead live a life that bridges both countries. This transnationality functions at a metaphorical or psychological level in terms of how Haitians think about their affiliations and concerns. It is true in a physical sense, as well, since many Haitians make frequent trips between the two countries. Families are transnational in this sense, since family members will shift back and forth between the two countries. Children may have one parent in each country. Haitian parents in the United States may send their children to Haiti during difficult times, or if they feel that the child is misbehaving or picking up bad behavioral habits in the United States.

Gender Differences

Within the family, there is a traditional patriarchal dynamic (Bell, 2001). Men are considered to be the breadwinners. Their responsibility is to find paying work to support the family. At home, men typically do not get involved in child care. For this reason, men do not usually interact with the school system regarding their children's education. Both parents may consider education to be the job of schools and not the parents.

In Haiti, there are men who live with many women. These men may maintain

more than one household. This type of polygamy is unsanctioned but not unusual. This pattern is particularly important to note when it comes to families with individuals with disabilities. After a woman gives birth to a child with a disability, the father of the child may intentionally go out and impregnate another woman. He believes that if the second woman gives birth to a "normal" child, this provides evidence that the first child's disability is a function of that child's mother rather than himself. In these cases, the mother of the child with a disability is left on her own. In fact, many Haitian children with disabilities are cared for by single mothers. This behavior takes place in the United States, as well. During community meetings for Haitian families that have children with disabilities, the vast majority of the participants will be women.

PERSPECTIVES ON DISABILITY

"The stress inflicted on me by society is compounded by the stress I am already experiencing on a daily basis at home in dealing with my child's behavior."
- Haitian parent of a child with a disability (1/2003)

The Cultural Concept of Disability

It is rare for people in Haiti to discuss disabilities whether acquired or lifelong. Disabilities are thought of as mysterious and dangerous. Typically, disabilities are perceived as having origins in the interaction of the natural and supernatural worlds, rather than being a medical issue. For example, a disability may be the result of a curse from a *lwa* who is upset. Disability is a punishment - a sign that a *lwa* was not obeyed. While *lwa* are voodoo in nature, the same type of explanation holds true within the framework of Christianity. Haitian Christians believe that going against God is the same as going against the *lwa*. God punishes those who do not obey. Disability may also be the result of a spell cast by an enemy. In this case, a disability may be a sign that the disabled individual mistreated someone else. Again, disability is a punishment. While Protestants have campaigned against voodoo and belief in *lwa*, many still believe in spells. For this reason, regardless of religious orientation, disabilities are seen as supernatural in origin.

This supernatural origin holds true for both physical and mental disabilities, and for lifelong as well as acquired disabilities. Even when a traffic accident leads to a physical disability, it may be that an offended spirit caused the accident. It could also be the result of a spell. In this case, it was not really an accident, since someone set it upon the person. If there is a rumor about an individual's misbehavior, a disabling accident is taken as confirmation. This framework applies to both children and adults. If a baby is born with a disability, it is believed that someone in that baby's family, most likely a parent, did something wrong to a

lwa or to another person. The child is innocent, but must pay the price for their family member's transgression. Innocent adults may also acquire a disability because of a family member's misdeeds.

Most Haitians are afraid of disabilities and are uneasy around people with disabilities, who may be called "crazy," "stupid," or "possessed." They may also be labeled "non-functional" or "worthless." Since the disability may have been caused by an angry spirit, there is always the chance that the spirit may come after anyone who makes contact with a person with a disability. Similarly, people may be reluctant to touch an individual with a disability because the spell may transfer to them. Disabilities are treated as if they are contagious. Epilepsy is believed to be contagious, and people may be reluctant to come to the aid of a person having a seizure. A pool will be considered contagious if someone with a disability goes in. Parents may not want their child socializing with a child that has a mental disability for fear that their child may develop the same condition.

Since people are afraid of disabilities and believe them to be a type of supernatural punishment, many parents keep their disabled children away from the public view. They do not want to expose their children to public ridicule, mocking or teasing. This is true for both mental and physical disabilities, though perhaps it is a bit worse for mental conditions. They also do not want to expose their family to unwelcome questions. Evelyn Milorin, an activist for disability rights in Massachusetts, reports that her son Reggie was called an "animal" when she took him to her local church (5/2002). They were soon forced to leave. She remembers clearly the words of the parishioners, "When you have an animal like this, you don't come to church." In response to these attacks, families may keep a child at home. Some even go as far as keeping the child inside a closet inside the home. This happens across social classes since both the elite and the working class have the same ideas about disabilities. For Christians, people with disability have sinned against God. Within voodoo, a *lwa* has been upset. In this way, there is always a reason for disabilities. It is never just an accident or just genetic. Disabilities are part of the overall balance between the natural and the supernatural.

Haitian parents who have children with mental disabilities may be devastated by the fact that their high expectations about their children's education will probably not be met. They may think that their child will be a failure for life, and not see of point in education or rehabilitation. Their frustration and disappointment may make it hard for them to consider any options.

What may be considered a disability in the United States may not be thought of that way in Haiti. For example, a child with an emotional disability would be thought of as willfully misbehaving, rather than dealing with a psychological condition. Gina Compère, a mother and community worker, explained that "as Haitian parents raised in a rigidly disciplined environment back home, we tend

to interpret such child's behavior as rebellion or lack of submission. This is because disciplining a child in our culture is often perceived as complete submission of the child, and there is often no communication taking place to understand the reasons behind the child's behavior" (1/2003). Similarly, a person with learning disabilities would not be recognized as needing supports but would be dismissed as "slow" or "stupid."

— *The Concept of Independence/Overprotective Parents* —

Haitians with disabilities want to lead independent lives. They value the same things other Haitians value, such as children, religion and work. However, the path to independence is sometimes blocked by their families. Haitian parents have been described as overprotective with regard to both typical children and those with special needs. Even though they love their child dearly, parents view children with disability as "worthless." Parents feel that these children cannot do anything and that they must do everything for them. This is especially the case with physical disabilities.

Many Haitian parents do not feel comfortable when their children turn 18 and are described as adults who are capable and responsible for their own lives. This feeling is more intense for parents of children with disabilities. Many Haitian parents who have children with mental disabilities choose to become their children's legal guardians so they continue to make decisions for them.

REHABILITATION

— *Beliefs About Rehabilitation* —

When an individual has a disability, any decisions about rehabilitation are made by the family as a whole. Each member of the extended family is consulted. The preference is to address the needs of the individual with the disability through a support system within the family itself. There are times when individuals do not go beyond the family support system to explore other options for rehabilitation. They remain solely in the care of the family. If they seek help outside of the family structure, they typically choose from two options: religious or institution-based rehabilitation.

Since disabilities are typically believed to be the result of an angry God or *lwa* or of a spell cast by an enemy, one option for rehabilitation is to turn to religion. Individuals or family may turn to Catholic priests or Protestant ministers to talk about their situation and condition. By becoming correct with God, the curse or spell may be lifted. This is also the case with voodoo-related beliefs. The individual or family may go to a *bōkō*, a traditional healer, or a *oungan*, somebody

who knows about spirits. With the *bōkō* or *oungan's* advice, they will use traditional medicines (such as herbal mixtures) to treat the disability.

If the family cannot provide support, and the religious approach is not successful, individuals or family may turn to institutions that provide rehabilitation. For the most part, this means working with Westerners who staff and fund the few voluntary institutions that exist in Haiti. As part of the legacy of colonialism, many Haitians put faith in foreign-based non-governmental organizations, particularly if staffed by whites. Often, there is the expectation that these institutions will provide miracles. Friends pass along stories of quick and complete recoveries at NGO centers. These miraculous recoveries are the result of taking medication, so there is a belief that any medication that does not bring an immediate result is not worth taking. There is no understanding of rehabilitation as a process. This attitude may make it difficult to convince a Haitian client to follow a medicinal regimen.

A Haitian client who is taking medicine prescribed by a Western doctor may also be using traditional medicines prescribed by a *bōkō* or an *oungan* or given by the family. Depending upon the medicines being taken, this doubling up may create harmful interactions.

— *Existing Rehabilitation Services* —

Given the level of poverty and political instability, little infrastructure exists to provide rehabilitation or to survey the needs of the population. Hiding individuals with disabilities makes it impossible to know with any certainty how many people are affected. In one estimation, there are over 100,000 people with an amputation, and virtually no orthotic and prosthetic services (Ray, 2002). While there are some initiatives, such as the Handicaps' Association of Carrefour, not much has been done. As with many other social issues in Haiti, international non-governmental agencies have been very active. Various domestic and international church organizations provide services. Organizations and resources come from many different countries. While the United States provides many of the volunteers and funds, support also comes from countries the Netherlands and Germany. These efforts appear to be a step in the right direction since they provide direct service and training, but they have been criticized for helping to privatize public responsibilities. The same criticism has been made of the religious organizations. By taking over the responsibility of the government, an official, public infrastructure is prevented. While this is a valid criticism, those receiving the direct services are happy to receive them. It is a question of long term goals versus short-term needs. Perhaps this debate will continue for some time.

The most famous school in for people with disabilities is St. Vincent in Port-au-Prince. St. Vincent serves blind, deaf and motor handicapped children. It pro-

vides education and rehabilitation services for 300 children, some of whom board at St. Vincent. Run by the Episcopal Church, St. Vincent offers clinics (e.g., orthopedics, neurology) and workshops that produce braces and prostheses.

Another church based service agency is the *Siloé* project's *Pazapa Center*. This center was started in 1982 by volunteers working with Mother Theresa's Missionaries of Charity. The center's goal is supporting the integration of children with disabilities into the community. The children who receive services have physical and mental disabilities. The Pazapa Center offers a wide range of programs, including education and recreation. According to the Center's mission statement, "All children enrolled at the Pazapa center receive health care, nutritional supplements, hot meals and family education on hygiene, first aid and nutrition" (Pazapa Center). The center also offers programs for the parents of children with disabilities, including information about home care, family planning, and Creole literacy. In addition, it also has two interesting projects:

- independent, small commercial ventures, such as a fruit drying project with a goal to provide job opportunities for Pazapa client families, and
- an outreach program with rural communities to assess and support special-needs children.

In southern Haiti, *Hopital Lumière* houses the Enabling Project, a collaboration between the hospital and the faculty and students of the University of Tennessee at Chattanooga Graduate Physical Therapy Program. American volunteers provide training for the nursing staff and physical therapy inpatient and outpatient services. This is organized by the Lumière Medical Ministries, which is supported by governmental organizations (e.g. US Agency for International Development) and religious groups (e.g., *the Mission Evangélique Baptiste du Sud d'Haiti*).

Smaller centers include *Le Berceau de Jesus* (the Cradle of Jesus) in Carrefour Lison, a little town on the outskirts of Port-au-Prince. This institution houses 14 young children. The project was initiated by the office of the Archbishop of Kingston as part of the Mustard Seed Communities initiative. It is operated by Jamaican and Haitian staff.

Non-religious efforts include Healing Hands for Haiti, a nonprofit group that sends a medical team to a clinic in Port-au-Prince four times a year. The clinic itself is a three-story house with beds for 22 patients. Volunteers provide assistance to people who need medical help, especially prosthetic services. Due to limited resources, the clinic is staffed one week per month for four months per year (Ray, 2002). As part of a rehabilitation technician training program, Helping Hands is working with Physical Therapy Overseas training local

Haitians in basic nursing, physical therapy, occupational therapy, and public health.

Haitian families in the greater Boston area participate in the Haitian Family Support Program. This program is sponsored by the Massachusetts Department of Mental Retardation. It is governed by the philosophy that the family knows how to best meet the needs of its disabled family member. This means that families are the most qualified to seek and determine how to use resources available to them. A Family Governing Board, composed of consumers and parents is responsible for the overall direction of the program. Since its inception in 1994, the Haitian Family Support Program has worked with 80 families that include children or young adults diagnosed with developmental disabilities. Services include support group meetings, social events, self-advocacy training and individualized support. Support group meetings provide a chance for people to get information, share concerns about key issues, and break the isolation many families feel. In 1997, the program expanded its services to young adults (age 22 and up). This program includes skills training, job placement and family counseling.

Interaction Between Consumers and Rehabilitation Service Providers

Five key themes emerge when thinking about the interaction of Haitians with the rehabilitation service system:

1) Haitians in the U.S. do not fully utilize the existing rehabilitation system.

Recent immigrants focus on the survival issues of money, food and work. Health and disabilities are not viewed as priorities. Due to time constraints, parents cannot utilize the system. They may work two or three jobs and do not have time to go to meetings, or to explore the system. The extended family that exists in Haiti is not necessarily replicated in the United States. There are many single parents (especially mothers), with limited time and resources. For those who do have the support of their family, Parents may still not interact with the system because of their preference to try to work through the family first. People may not go outside the family at all to look for support and rehabilitation. Certain problems arise when individuals are not aware of their rights or responsibilities.

For example, many Haitian parents find it difficult to understand the legal ramifications of their child turning 18. They believe that, regardless of their children's age, they are still the parents and have the right to make decisions on their behalf. This is especially true when the child has a disability since parents may believe that the child is totally non-functional. It is difficult for them to grasp the legal aspects of independence. Parents who are acting as their child's guardian are confused by the idea that their status has to be recognized by authorities. They think that since they are already acting as a guardian, there is no need to

make it official. Problems arise when these parents try to sign financial documents for their adult children.

2) Institutions Are Used as a Refuge from Stigma

For many people in Haiti, institutions that provide rehabilitation are important because they provide refuge. Due to the stigma of disability, some parents send their children to institutions to protect them from abuse by society. This could be seen as isolation. Placing children in an institution serves to hide them from the rest of society. In addition, parents view such a placement as creating a space for themselves. While they would be happy if their child made progress towards rehabilitation or independent living, that may not be first and foremost on their minds. As one Haitian parent explains, "I tend to carry the negative feeling of isolation and shame, because of the way my child's behavior is regarded by society, which presses me to look at my child as a burden, rather than as any normal human being" (10/2002).

3) Parents May Expect Immediate Results

For many Haitian parents, rehabilitation is not perceived as a long term process that is achieved in incremental steps. Rehabilitation is seen more as a miraculous, instantaneous cure of what has plagued the individual (due to the supernatural origin of disabilities). This is true whether service is being provided by a religious figure (such as a priest or an *oungan*) or by doctors and teachers in a hospital or school. Parents have complete faith in Westerners and expect outside experts to be able to diagnose and cure their child quickly. With physical conditions, it may be possible to see progress such as walking. More abstract concepts like mental functions are harder to grasp and measuring progress is difficult.

4) The Role of Consumers and Family In Rehabilitation Is Not Recognized

Josette Beaubrun, a Haitian disability rights advocate, believes that "Our Haitian parents need to be able to understand how to help their children and themselves and not to rely solely on the professionals to solve their problems for them. They need to learn to be involved and to be more confident and independent in the choices they will have to make for their children" (5/2000). This is one of the greatest cultural differences Haitian families face. Haitians who receive rehabilitation are not proactive about their therapy. Since they have utter faith in the service provider, they do not ask questions. They will not ask the provider institution or the school questions about services. Self-advocacy is not traditionally practiced. Gina Compère notes that Haitian parents are not accustomed to "a system that expects constant direct interactions with the provider." (1/2003). Haitian parents have no experience with a system that allows the right to disagree, and to seek a second opinion.

Individuals or parents have no idea what they can offer as part of the rehabilitation process. They do not see themselves as possessing the resources or knowledge to participate and make a difference. This is less true of the rehabilitation of physical disabilities since individuals may see that they can help in terms of motor skills such as walking. However, if rehabilitation involves mental disabilities most individuals do not see how they can participate. They may not view their attendance at a planning meeting for their child as crucial or even relevant.

5) Crosscultural Tensions Often Impede Service Provision

There may be crosscultural miscommunication between a rehabilitation provider and a client. Two possible issues need to be addressed. First, due to their preference for oral communication and the rather high illiteracy rate, Haitians clients may not have the experience with documentation that providers expect. They may not be used to obtaining and submitting official documents or keeping certain records. This can frustrate providers who cannot provide service without complete records. Second is the existence of what Haitians call "Haitian time." This refers to Haitian's sense of time management which does not emphasize punctuality. It is not uncommon for a client to arrive thirty minutes after an appointment is scheduled. A Haitian client may not see this as an issue. Failure to be on time can cause many problems when dealing with service providers in the United States. As Dr. Renald Raphael notes, "Haitians often do not take time to plan, and so timing becomes an issue" (12/2002). He also states that Haitian clients are likely to drop in without having made an appointment and will expect to be seen by the service provider.

RECOMMENDATIONS

"It takes me so much resiliency and patience dealing with such a complex system, foreign to my language and my culture. And this journey never ends, because you face it every day at every corner of the system unless you find an appropriate place where you can pause and share your daily emotional and psychological struggles with those experiencing the same issues and sharing the same culture." - Haitian parent (11/2002)

Places where individuals and families share the same culture can be positive, supportive and healing. There will always be times when people in need of rehabilitation will be in places where service providers do not share their culture. However, it is possible for non-Haitian rehabilitation service providers to create places and programs responsive to Haitian's needs. A few recommendations are listed below:

Outreach

- Service providers need to recognize that outreach is necessary to get Haitian clients to come in for service. It is not enough to advertise a program and expect Haitian clients to attend. Haitians may not even be aware of rehabilitation programs. They may be relying upon a close family network to provide support. By receiving such services, clients and their families are admitting that a disability exists. Given the Haitian perception of the nature of disabilities, the decision to receive rehabilitation may be associated with fear of being shunned by the community.
- The best places for outreach may be places that need to be educated about disabilities. Since most Haitians attend church at least weekly, churches are perfectly positioned to promote a program or service to the Haitian community. Given the prejudice that exists within the church membership, it is not an easy task to conduct outreach in this manner. The difficulty makes it necessary to raise the consciousness of the community.
- To be most effective, outreach efforts should be done orally (such as radio or announcements at meeting places) rather than through flyers or brochures. Whenever possible, Kreyòl should be used with English as a second choice.

Encouraging and Sustaining Participation

- Given the lack of rehabilitation programs in Haiti, clients and their families may have limited understanding of what the possibilities are for rehabilitation. They may need to be convinced that a mental disability does not mean "permanent failure" (as one Haitian parent put it). Clients and their families need to be informed about programs and supports.
- Potential clients and their families need to be introduced to new ways of looking at disability. For example, the nature of emotional or behavioral disabilities needs to be explained to clients or their families before they agree to start rehabilitation.
- Clients and their families will have to be encouraged to be proactive during the rehabilitation process. Providers should be explicit about being asked questions. It may be necessary to model asking the kind of questions that make for better service.
- Consumers and their families may expect quick results and benefits. They will discontinue a program if they think that it is a failure. If results are not what the consumers expect, they will feel deceived and not provided for. From the first meeting, it should be emphasized that rehabilitation is

not quick. The results of the program, and how these results can be recognized, should be explained.

- Take time to review the documentation that will be necessary for clients and their families to have and maintain. Read the list of required documents with the clients and families, rather than suggesting that they read it at home on their own. Explain the need for each document and stress that service may be impaired if proper documentation is not provided when requested.
- Be aware of issues related to the prestige of French within the Haitian community. For example, a request for a French interpreter does not necessarily indicate fluency in French. At the same time, a client may be offended if you begin by offering a Kreyòl interpreter. Understanding a client's true linguistic background and current needs is necessary.
- If a Haitian client arrives late, it is appropriate to provide service at that time. However, it should be stressed that the expectation is that they arrive on time. While some accommodation may be made, providers should be explicit about their policies. This is also true about unscheduled visits.

Interpersonal Interactions

- As with all consumers, trust is a key issue. One way to establish trust is to sympathize with the pressures that Haitian immigrants are facing. Acknowledging the specific stressors that exist (language issues, being separated from extended family, etc.) calms a Haitian consumer's fears. Just listening without saying anything brings positive benefits.
- Be sensitive to the specifics of Haitian identity. Recognize Haitians as distinct from other Caribbean people, and distinct from African Americans. Note that all creoles are not alike. Do not confuse Haitian Creole (a French-based Creole) with Capeverdean Criolu (a Portuguese-based Creole). Many Haitians report being frustrated with service providers who do not have a clear sense of who they are and where they come from.
- Be sensitive to religious topics and be aware that religion may arise in any conversation. Consumers may expect you to share their views about God's role in rehabilitation ("God willing") and the value of prayer. For this reason, you will need to be comfortable talking about religious issues, regardless of how you feel. At the same time, do not preface your comments with thoughts about religion. Wait for the consumer to introduce the topic. Remind yourself not to assume or generalize. This is particularly true regarding voodoo. While some Haitians embrace voodoo history and faith, it is a sensitive topic. It is best not to ask questions about it with

clients that you do not know very well. You may come across as yet another non-Haitian who wants to find out about zombies.

RESOURCES TO LEARN MORE ABOUT HAITI AND ITS CULTURE

This section provides some sources that may be useful for understanding more about Haitian culture.

Books about Haiti

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Haiti Links http://www.re-cycle.org/Haiti/Haiti_Links/haiti_links.html
Windows on Haiti <http://www.windowsonhaiti.com>

Newspaper

Boston Area Haitian Reporter
(Monthly Newspaper) <http://www.BostonHaitian.com>
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Notes