

Providing Rehabilitation to Persons from El Salvador: *Cultural Information for Service Providers in the U.S.*

Eileen Giron Batres



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

**An Introduction to the Culture
of El Salvador**
for Providers of Disability Services in the U.S.

Eileen Giron Batres

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AN INTRODUCTION TO THE CULTURE OF EL SALVADOR FOR PROVIDERS OF DISABILITY SERVICES IN THE U.S.

Preface

Many people might be surprised to learn that El Salvador, the smallest country in Central and South America, is among the top ten countries of origin of foreign-born persons in the United States. Two decades of civil war in the 1970s and 1980s, as well as continuing high unemployment rates and population density, have resulted in high rates of emigration from El Salvador, most of it north to the U. S. In 1997 there were 607,000 persons living in the U.S. who were born in El Salvador. (Shmidley and Gibson, 1999).

Although many native-born Americans find it difficult to distinguish among different Latino and Hispanic cultures, and tend to regard them as essentially the same, there are significant differences among them that are reflected in many ways, even in variations of the Spanish language. The purpose of this monograph is to provide an introduction to Salvadoran culture, especially as it relates to disability and rehabilitation services.

The author, Eileen Giron Batres, is well qualified to write on this subject. Born in El Salvador, she contracted polio as a child. She attended a regular primary school, but could not continue to high school because it was not accessible. Nevertheless, she pursued her education with the assistance of private tutors. Ms. Giron Batres became active in the disability movement in 1979. She is the manager of Asociacion Cooperative del Grupo Independiente Pro Rehabilitacion Integral (ACOGIPIRI), a Salvadoran organization of persons with disabilities that operates a ceramics cooperative. Ms. Giron Batres has served on the regional and world councils of Disabled Peoples' International.

This monograph 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 rehabilitation services to foreign-born persons. We hope that this monograph will be useful to you in your work with persons born in El Salvador.

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*

Reference:

Schmidley, D and Campbell, G. (1999). U.S. Census Bureau, Current Population Reports, Series P23-195, *Profile of the Foreign Born Population in the United States: 1997*. U.S. Government Printing Office, Washington, DC.

AN INTRODUCTION TO THE CULTURE OF EL SALVADOR FOR PROVIDERS OF DISABILITY SERVICES IN THE U.S.

Introduction

This monograph provides an overview of the people of El Salvador and their culture. It explains why so many Salvadorans want to emigrate to the United States, their preferences in life style, their values, hopes and dreams. It is written from the perspective of a person who has a disability, and is intended to provide an understanding of the impact of Salvadoran immigrant culture on the lives of persons with disabilities. The monograph is dedicated to the rehabilitation teams that work every day, sometimes for years, to help persons with disabilities become independent. It is written with the hope that it will lead to the design of more effective programs and intervention models.

Salvadorans living in the United States may have been born in El Salvador, or in the U. S., although the parents may be native El Salvadorans. As a member of an organization of persons with disabilities who has worked for more than 20 years in the field of development, advocacy and public awareness, I think it is wonderful that immigrants with disabilities can benefit from the same services available to native-born Americans. with disabilities enjoy.

Salvadorans have a reputation as excellent workers. They were part of the labor force that helped to build the Panama Canal, and in the 1970s were invited to work in Saudi Arabia. They have migrated not only to the U.S. and Canada, but also to Europe, Sweden, and Australia. I feel great respect for those thousands of Salvadorans who have emigrated in search of a better future for themselves and their children, despite the risk involved. They do it not only for themselves, but to support families who remain behind. In 1997 family remittances to El Salvador totaled \$1.2 billion (Chislett, 1998).

General background about El Salvador and its culture

El Salvador means "The Savior" in Spanish. It is the smallest country in Central America. By comparison, Uruguay, the smallest country in South America, is seven times larger than El Salvador (Nakawaga, 1975). The current population of El Salvador is 6,154,000 (Arias, Van Acker and Bini, 1999). The most densely populated of all Latin American countries, it is located in a volcanic region and has a tropical climate.

San Salvador, the capital city, was founded in 1525 by Pedro de Alvarado. Ethnic

mixing occurred quickly in El Salvador because the Spanish conquerors, who were almost entirely male, quickly mated with the indigenous female population. The term *Mestizo* has a meaning that goes beyond the biological mixture of Spanish and indigenous people. It speaks to the mixture of two different civilizations; one from the "The Land of Cuzcatlán" (land of jewels), and one from Europe.

The Pipiles were once one of the most important indigenous groups in El Salvador. They occupied a large portion of territory west of the Lempa River, the major river dividing the better-off western half of the country from the eastern half. Other native groups were the Zinca, Lenca, Cacopera and Mayas. Their native language was Nahuat, which has all but disappeared from all areas.

The colonization process was often brutal. The indigenous populations were decimated during colonization by various diseases the Spanish brought with them from the Old World. When the Spanish first came, the indigenous peoples were agriculturists growing corn, beans and squash. At the time of the conquest, cacao beans were used as currency. With the decline in the indigenous population, cacao and some other native crops were no longer planted, and in their stead came indigo (Indigo Fera Tinctoria), a plant that yields a natural blue dye called "*añil*" in Spanish. It was produced almost everywhere in El Salvador and exported to Europe, becoming a very important income-generating product for the Spanish. El Salvador achieved its independence from Spain in 1821 along with the rest of Central America, which remained a single nation for a short period of time. Out of it arose the five modern republics of Guatemala, Honduras, El Salvador, Nicaragua and Costa Rica.

The wealth of the country is based on an agricultural economy of cotton, sugar cane and coffee. During the recent civil war, many of the cultivated fields disappeared and today the only agricultural activities still carried out in rural areas are in the sugar cane fields and on coffee plantations. El Salvador used to be the fourth-largest coffee producer in the world. For various reasons, including low prices, armed conflict and urban expansion, many of the coffee plantations have been converted to other purposes. The reduction of agricultural production has dramatically reduced employment opportunities in the rural areas and severely affected the poorest levels of society.

——— *History of immigration to the U.S. and its causes* ———

I was once coming back from renewing my passport in San Salvador when someone said to me, "Are you trying to go north?" He asked in such a way that the echo of that question remained in my ears for a long time. For a large number of Salvadorans, "the north" (U.S. and Canada) has a special meaning. Going

north means to reach for a sense of security, a sense of self-esteem, and to be life insurance for the family. This urge to "go north" is so strong that people are prepared to overcome great difficulties to find their way to the United States. For some, the "American Dream" ends at Tapachula, Mexico (on the border of Guatemala and Mexico) when the police arrest them. After spending some days in prison, if they have any money left, they return home until they find a way to try again. Once their dream of making a living in the north is realized, another dream begins - the dream of coming back to El Salvador to spend their final days and to die in their homeland surrounded by friends and family.

According to Guadalupe Martínez, one of the guerrilla leaders in the recent civil war, the armed actions started in 1972. Hundreds of Salvadorans began to emigrate about the same time. An even stronger stream of immigrants began to flow north in the eighties (García, 1994).

El Salvador has had a long history of natural disasters and earthquakes, combined with social struggles. In 1932 there was a leftist rebellion of the *campesinos*. President Martínez put an end to it by killing 30,000 people, insurgents and non-insurgents alike. He was a brutal dictator for more than ten years. In 1969, there was a war against Honduras known as the "Football War" due to its supposed origin during a soccer match. This war lasted one hundred hours and forced many Salvadorans who had been living in Honduras to return home with nothing in their pockets, producing a tremendous shock to the Salvadoran economy.

El Salvador's most recent civil war lasted 19 years. It finally came to an end in January, 1992, with the signing of the Peace Accords. Approximately 80,000 persons died in this war.

The El Salvadoran military forces, supported by the United States, fought against several leftist groups integrated into one army - the *Frente Farabundo Martí para la Liberación Nacional* (FMLN) - The Farabundo Martí Front for National Liberation. The war was provoked by a rebellion against abuses of power by the military governments that had been in control for more than sixty years. These governments were the strong arm of El Salvador's "14 families," an oligarchy responsible for gross inequities in the distribution of wealth. (90 percent of the national wealth was in the hands of five percent of the population.) Hundreds of Salvadorans left the country as political refugees, their lives in serious danger.

El Salvador has a serious underemployment problem, particularly in the urban areas. In 1998, the unemployment rate reached 31.5 percent. (Arias, Van Acker and Bini, 2000). In terms of education, there are great differences between urban and rural areas. The average years of schooling achieved in urban areas is

6.33 years, compared to 3.14 years in rural areas. There are also gender differences. In rural areas boys attend school longer than girls.

El Salvador has a high rate of pregnancy among women under 20 years of age, an average of 116 per thousand women. According to the El Salvadoran Ministry of Public Health, one of three babies are born to a woman under 19 years of age (Arias, Van Acker and Bini, 2000), many of them are single.

Natural disasters have had a strong negative effect on life in El Salvador in recent times. In 1998 Hurricane Mitch left a large number of the population homeless. Earthquakes in January and February 2001 destroyed 90 percent of the houses in some villages and affected more than one million people. In recent years earthquakes have leveled many villages and damaged towns and cities, leaving thousands shelter. Earthquake victims with families in the U.S. often contemplate going to work there to make money to repair their homes.

According to a study by Mejía and Silva (2000), the most common reasons that El Salvadorans emigrate are poverty, social insecurity, profit from illegal drug trafficking and the geographical proximity of the U.S. and Canada, where informal networks provide assistance to new arrivals. According to the U.S. Embassy in San Salvador, twenty thousand immigrant visas are approved every year and ten thousand are denied (Mejía and Silva, 2000). Juan José García, a consultant in immigrant populations, says there are two kinds of immigrants, those who left after they were 18 years old and have a close link to El Salvador and those who left when they were young children. The latter group is not as attached to El Salvador as the former group.

Concept of disability within the culture

For people with disabilities and their families, life in the United States is like living in paradise, in terms of available health care, access to education, employment, public transportation and the possibility of having a handicapped-accessible home and adaptive technology. It is easy to understand why persons with a disability would not want to leave the U.S. once they have lived there.

There is little documentary information available regarding persons with disabilities in El Salvador, aside from the kinds of services available for them. There is however, some information about the programs developed for disabled persons as a result of the civil war. To obtain information for this monograph, I conducted a number of interviews and used information compiled from testimonies of persons with disabilities who have participated in group discussions during the past ten years.

A woman with a disability who has spent the last twenty years advocating for the

rights of people with disabilities stated, "The first time that I was interviewed by a man from the press, I was telling him that we, people with disabilities, needed access to education as a means to get a good job, and in order to be economically independent."

The man listened quietly, and when I finished, he just stared at me. "Why do you want that?" he asked, "are you not happy that, in spite of what you have gone through, you are still alive? What do you need to go to school for?"

The old concept of disability-as-a-disease is very prevalent throughout Salvadoran society. Among the general population, it is very common to hear that persons who are deaf are "ill" or such phrases as "the poor blind". Women with disabilities face double discrimination because, as women they are already discriminated against in this "macho" (chauvinist, patriarchal) society. Being disabled adds one more layer of discrimination. For a woman with a disability, going to school, finding a job, or having a family are life challenges, particularly in a world where things are easier for men, including men with disabilities. Men with disabilities, have less difficulty getting married and having a family of their own whereas women with physical disabilities face many problems finding a partner and having a family.

Usually people will associate persons with disabilities with beggars because for some, the easiest way to survive in an indifferent society is by begging in the streets. Unfortunately, when people get used to begging, they may not make any effort to change their life styles.

People with disabilities are not thought of as consumers of the services they receive like the rest of the population. It is considered very normal for someone who has a disability to stay at home and do nothing. It is unfortunate to realize that in most of the rural areas or small villages, there is not much that people can do because there are few basic rehabilitation services available anywhere in El Salvador.

The following testimony was given to the author by a woman who used to go with her husband to the rural areas describes this situation.

I visited the home of one of my husband's co-workers. The family had three children; a girl and two boys. I saw that the boys were going to school. When I asked why the girl stayed at home, the mother said she could not learn anything because she could not hear. I asked if she had ever taken her to the doctor and her answer was negative. I recommended that she take her child to the doctor, to find out what happened to her. After a few months I visited the family again. The family was very happy, because the child had nothing wrong with her. She only needed the wax removed from her ears. After this minor medical pro-

cedure; she was able to hear perfectly well. She was going to school and she was an excellent student.

Attitudinal barriers are very difficult to eliminate since they are passed from generation to generation. Among people with disabilities with no access to any information at all, there is a general attitude of passivity, which can be changed only through the strong leadership of other persons with disabilities. This could be supported by ongoing public awareness campaigns.

A woman who was left paralyzed from her waist down after giving birth to her third child, had to stay a year in the hospital recovering from severe pain. When she tried to go back to her job as a secretary, her immediate supervisor did not want her back and she had a very difficult time returning to work. Being a secretary, it was not difficult for her to perform the same tasks as before her illness. She had the courage to advocate for herself and recovered her old position. Similar things happen to other women, but their employers buy them off with compensation instead of bringing them back to the workplace.

It is difficult to convince the business community that people with disabilities can perform at any task, provided the work place is accessible. People with psychiatric disorders are simply considered "mad." Their families confine them to institutions where their conditions will probably never improve.

————— *Views on acquired disabilities in comparison with* —————
lifelong disabilities

There are differences between persons with lifelong disabilities and those with acquired disabilities. Persons with lifelong disabilities tend to think about the disability as part of their bodies, or as a part of themselves, whereas persons with acquired disabilities often think of themselves as "different" for a number of reasons. Persons with paraplegia, paralysis of the lower limbs, who have gone through a good rehabilitation process can usually be very independent and may have very good self esteem. At the same time, they are not willing to interact with persons who have disabilities such as polio, cerebral palsy or others that oblige them to be highly dependent upon others.

Every case is different. There are persons with acquired disabilities who will never get used their different living conditions. They don't want to interact with those who have had a disability all their life. It is like a mirror for them. They don't want to see themselves in that mirror. They will go through different stages as part of the process of acceptance.

The following case studies are interesting examples of this concept.

A young woman, an architect, had an accident at work and became a paraplegic. After completing a rehabilitation program, she went back to her previous job. In the work place, everything was adapted for her. She never experienced any discrimination. When invited to discuss problems that most disabled persons face, she never attended meetings. When asked the reasons why she didn't want to join the group, she said her life was different from that of the others. Discrimination exists even between persons with disabilities.

In another instance a woman who was a very active salesperson had a car accident a few years ago. After the accident, her husband abandoned her, leaving her with two small children. She said, "I just can't get used to seeing myself in a wheelchair. I never go out. I don't let anyone see me with my children. I feel ashamed of myself. I should have gone out as soon as I had the accident, I don't know how to overcome this problem now."

————— *Concept of independence within the culture* —————

Professionals in the field of rehabilitation in the United States working with Salvadoran immigrants or the children of Salvadoran immigrants might face some attitudinal barriers around the issue of independence. Service providers must have the ability to help the whole family understand that when living in the U.S., the best thing that can happen to their child is to be independent.

In any Latin American country, as in other parts of the world, independence has different meanings for men and for women, for different ethnic or cultural groups and for people in different socio-economic groups. For disabled men in El Salvador, independence often means being able to make decisions for themselves without asking anyone permission to do so. However, disabled women are hardly ever able to decide anything by themselves. There is always a masculine figure who decides for them. He can be a father, a brother, a husband or a partner. There is a major gender difference with regard to independence.

Usually adult children remain at home with their parents until they marry. A woman who never marries will usually live with her parents until she dies. After her parents' death she might live with a close relative, often a male. Very seldom would a disabled woman live by herself if her parents were alive.

The philosophy of *independent living*, so widespread in the United States, Canada and Europe, is virtually unknown in El Salvador. The concept of *independent living* is not a factor in social policies regarding disability in most developing countries. The concept requires a recognition of personal civil rights. In El Salvador people don't even talk about civil rights. The extreme poverty of the population in general, makes survival challenging, especially for the segments at risk, such as people with disabilities.

For instance, when someone needs technical aid, such as a wheelchair, the cost may be equal to two minimum wages, or three hundred dollars. Usually people who use a wheelchair have no income at all except for those who were disabled later in life and are registered in the social security system, or are war veterans and receive a subsistence pension barely large enough to survive. In both cases such disabled individuals would receive a wheelchair.

For people with severe disabilities who need assistance in their daily activities, such as transferring from bed to the wheelchair, taking a bath, or getting dressed, there are no personal assistance services available. Only a small percentage of the Salvadoran population can afford to have an assistant. That means that most of the time, a family member must care for the disabled person and dedicate his or her life to taking care of that person. In most cases it is the mother who dedicates her life to assisting her child. It is also likely that persons with severe disabilities will have to spend most of their lives in the house unless someone comes to take them out occasionally. For persons with severe disabilities, it is almost impossible to have any sort of independence. There have been cases in which new-born babies were abandoned at hospitals by their parents when they were born with a disability. The parents just don't know what to do.

The following persons were interviewed on this subject: Dolly, a 28 year old polio survivor and a law school graduate said, "Independence is the ability to make my own decisions". Roberto, a 50 year old psychologist who is blind said, "Independence means the capacity to satisfy my personal needs in terms of subsistence, work, love, and sex. It is closely related to socio-economic conditions." Tita, a 26-polio survivor said "Just because I have a disability does not mean that I don't have goals and dreams in my life. But it is very difficult to accomplish them if I have to depend upon other persons to reach these goals. One of my precious dreams is to be independent to do things I want to do in life." When other individuals with disabilities were asked what independence means to them, they said, "The right to decide by myself," "Freedom to go wherever I want to go, in spite of negative attitudes." "I don't want to live locked up inside," said one young man.

In the rural areas, people with disabilities, especially women, tend to live at home, totally isolated from the rest of the community. After spending most of their time indoors, they get so used to it that they don't even think of going out. The community considers this normal. It is easier for men to integrate. They meet their friends and share common interests. In rural areas close to small towns, the streets are unpaved and it is difficult to move around in a wheelchair. In some cities, ramps are being built, at least in the parks, which are the meeting places for everybody.

Number of persons with disabilities

Persons with disabilities have not been visible in any census to date. That is the case not only in El Salvador, but in most Latin American countries. The Pan American Health Organization, however, estimates that in El Salvador 600,000 persons or ten percent of the population have disabilities.

REHABILITATION SERVICES TYPICALLY AVAILABLE IN EL SALVADOR

Medical Services

There are several rehabilitation service providers in El Salvador. One is the *Instituto Salvadoreño de Rehabilitación de Inválidos*, (ISRI), founded in 1957 (www.isri.gob.sv). It is the principle institution serving the general population, with branches in the eastern and western parts of the country. ISRI is funded by the Ministry of Health. It provides physical rehabilitation and operates a few special schools. One is the school for blind children, *Escuela de Ciegos* (school for the blind). Once children master Braille and are mobile, they are mainstreamed into a regular school. Blind adults can also learn Braille in the same school. Blind women learn household activities such as cooking, home care, etc.

There is also a Center for the Deaf that is part clinic and part school. For the hard of hearing speech therapy is available, and classes are given in Salvadoran Sign Language. The Center was established around thirty-five years ago, by parents of deaf children. Until recently, the school was oral-language oriented. The change to the use of sign language came about as a result of much advocacy and continuous efforts by the Salvadoran Association for the Deaf.

There are special education schools for children with moderate mental retardation and one for children with Cerebral Palsy. The Center for Cerebral Palsy provides early stimulation therapy for infants.

The Center for the Physically Impaired has a residence program for persons who live away from the capital city, San Salvador. Residents stay at the center for anywhere from four months to the time they are able to take care of themselves. It is a small facility that has a maximum capacity of 40 individuals at a time.

When someone has gone through the process of rehabilitation, he or she can register with the Ministry of Labor's Employment Department. One of the main tasks, and the most difficult one for this department, is to establish links with the business community so as to find jobs for disabled persons. Once a placement is

made, ISRI provides follow-up services to the person who has been placed. ISRI primarily benefits disabled individuals not registered in the Social Security system and who cannot afford to pay for private rehabilitation services.

The *Instituto del Seguro Social* (Social Security Institute) pays 3.5 per cent of the salary of an employed disabled person. It is a privilege to be registered with this institution. Registrants receive health care, medication, hospital services, rehabilitation services and, in some cases, transportation. They also receive equipment, such as wheelchairs, crutches, walkers, and cushions. The ISSS is very supportive of wheelchair sports. There is no charge to the individual for any of the services provided by the institute.

A woman who is a polio survivor, on the other hand, was disappointed with the rehabilitation services at ISSS. She is a psychologist, with a Master's Degree in administration of human resources. She has some scoliosis and wanted to know if it was stable or worsening, because she often had back pain. The ISSS doctor said she needed to be referred to the psychologist, because she had a fixed idea about her disability that she had to overcome.

Another major service provider for the disabled in El Salvador is CERPROFA, which stands for Rehabilitation Center of the Army. It was founded in 1985, to assist soldiers who needed rehabilitation services during the war. Once the war came to an end, CERPROFA remained active, offering vocational rehabilitation programs.

In 1993, the National Council for Persons with Disabilities was created. It is the first attempt to bring together private and governmental agencies and consumers' organizations on behalf of persons with disabilities. The main task of this institution is to coordinate resources for persons with disabilities. The Council created a National Policy on Rehabilitation, that will oversee the implementation of new legislation designed to equalize opportunities.

The medical service providers described in this chapter have the capacity to serve less than 10 percent of the total population of persons with disabilities. According to a physical therapist working at ISSS it sometimes takes a long time before someone who needs services actually receive them. The process is very bureaucratic, and there are many consumers and not enough personnel. It can take up to five months to be served in some cases. Once the process begins, however, it usually goes smoothly until completion. Clients are seen three times a week. If the case is not urgent, the sessions will be twice a week. If therapy is urgently needed, it will be provided daily.

Organizations of Persons with Disabilities

Organizations of persons with disabilities also provide services that are very important, if different from those previously mentioned. These include peer support, and referrals. They also organize workshops and conferences on issues such as leadership development and writing project proposals. Most members work on a voluntary basis and few organizations receive local funding. They hold fundraising activities throughout the year in order to survive.

There are also organizations of service providers, most concentrated in the capital city, founded by parents of children with disabilities. There is a school for children with Down Syndrome and a rehabilitation center for persons with cerebral palsy that offer vocational and physical therapy. There are a few sheltered workshops for mentally retarded youth.

Private Special Education Services

There is only one private school of special education for children with learning and cognitive disabilities and is one of the most expensive schools in the country. It does not receive governmental subsidies. Parents must pay the school fees.

Transportation Services

Public transportation is a challenge for the government in El Salvador. Transportation services are run by private businesses that receive government subsidies for the purchase of fuel. There are three very powerful associations of bus owners. They have no interest in providing accessible transportation for persons with disabilities. There is a major discussion underway on this issue between bus owners and the government. The bus companies say that they need loans at a low rate of interest in order to be able to buy accessible buses. The government says that they should negotiate directly with the banks.

The National Council on Disability has organized several workshops with international experts on the subject of transportation. Businessmen and women have participated in the discussions, but there is still a long way to go before transportation will be accessible for persons with disabilities.

This is the odyssey that a 30 year old mother of two goes through daily to go to work. She uses a wheelchair and is very well-known among bus drivers of a specific route between Soyapango, an industrial city located north east of San Salvador, and the capital city. She is one of the few persons, if not the only one, who takes the bus every day to work. She takes a large bus from her home to work. Approximately 50 buses drive the route she has to take but only eight are

accessible. A bus stops at her stop every five minutes, but she has to wait for one of the eight she can enter. Sometimes she waits up to an hour and a half. She has to be lifted up to the back door in the wheelchair. Then she transfers herself to a bus seat and folds the chair. Going back home, she rides in her wheelchair for about 22 blocks on the street, not on the sidewalk, through heavy traffic. Then she takes a mini bus, which is easier, but charges her a double fare because her wheelchair takes up a seat. At the end of the day, after all she has gone through, she does not mind paying a little more on her way home.

There is no other transport available, except for taxis, which are expensive. For someone who lives below the poverty level, it is impossible to use them as a daily means of transportation.

— *Typical patterns of interaction between consumers and rehabilitation service providers in El Salvador.* —

The services available in El Salvador are totally different from those available in the United States. The staff that works with persons with disabilities in El Salvador have no opportunity to learn new methods, nor is there access to advanced technology. Usually service providers follow their own work guidelines without asking for the opinion of the person with the disability. It happens very often that the relationship between the consumer and the service provider is not ideal. In a very few cases a person asks to be attended by another physician. In theory the consumer should not only be a recipient of the rehabilitation services, but an active participant in the whole process. Unfortunately, from the very beginning, when the service providers are being trained, they are taught that they are dealing, not with persons, but with "medical cases."

Special education as a university program began at the first Salvadoran university in the early 1980s. By 2000, it was part of the curriculum at three universities. According to a student pursuing this major, however, the possibility of learning anything practical is very low. Part of the problem is that what is taught at the university is pure theory. When she had to face the real world, she did not know what to do. What she had learned at the university were general concepts of special education, not specific topics relating to specific disability groups.

— *Family structure* —

Women in El Salvador tend to begin living with a partner at a very young age, and often begin having children as teenagers. In El Salvador most of the households are headed by women according to CRLP (2000), that studied abortion among women. CRLP stands for the Center For Reproductive Rights and Public Policies, the organization that performed the study. Until the civil war, the typical family in El Salvador was a nuclear family. Since that time there has been a

drastic shift in family makeup. It is very common to see families with only a mother and children plus extended family members such as grandparents. Often, the grandmother is a very important person in the family, especially when parents have to go to work. "Granny" is the one who takes care of the children and the housework.

It is the immigration process that caused the traditional family unit to break down (Lungo and Kandel, 1999). The father, or sometimes the mother, emigrates in search of a better future hoping that, once settled, they will make enough money to bring their spouse and children to join them. That process can take from five to fifteen years, however, and sometimes it is never accomplished. Often the family structure falls apart because one or both of the spouses finds someone else. The following case illustrates this situation.

The mother of a deaf and autistic child could not take him to a special education school. Her husband had emigrated to the United States, telling her that he was going to send her money. He not only did not send anything, but instead he started to live with someone else. Since the wife had to work full time, she did not have any time to take the child anywhere. The child had to stay at home with no assistance for his special needs.

Children left with a family member are known as "dejados," which literally means, "left behind." They hope someday to join their families (Lungo and Kandel, 1999). These children feel abandoned by their mothers or fathers on whom they depend economically. Even though they may receive money from those in the north, they are often frustrated and think their parents don't care for them.

— *Role of community* —

The community is not supportive of persons with disabilities. In most cases this is due to a lack of information. People do not know how to deal with disabilities of any kind. For the same reasons, the community is not friendly toward disabled persons. This is one of the major obstacles that persons with disabilities have to face as they strive for full integration in society.

In speaking about the community it is important to mention accessibility. If one has no access, he or she has no way to be part of a specific community. Most public places, such as restaurants, hotels, and governmental buildings offer very limited access for wheelchair users, and the cities are not designed for persons with disabilities.

A sports facility built for the Central American Games held in 1992 is a good

example of official disinterest. The organizations of persons with disabilities wrote letters to the games' organizing committee, asking them to build according to the principles of Universal Design, meaning all facilities would be accessible to anyone - elderly persons, children and persons with limited mobility. They never received an answer. As a result the facilities are full of obstacles.

The International Airport in El Salvador is one of the most important in Central America. It was built to be used by persons with disabilities. Although there are special restrooms for persons in wheelchairs, they are used as storage rooms for cleaning equipment. Usually there is no soap, or toilet paper. To access the concourses and boarding gate, there is only one tiny elevator, which is always locked.

Since 1982, major fund-raising events have been organized by the community to fund a private rehabilitation center. The events are Telethons, just like the one Jerry Lewis hosts in the United States. The Telethon in El Salvador was held every two years. The organizing committee consisted of members of Club 20-30, a branch of the Rotary Club for younger persons; the Telethon Foundation; members of the business community; the Bankers' Association; the media; the national airline; hotels, and a very well-organized team of young volunteers.

The Telethon is a good example of what the community can do in support of specific goal. The problem in this case, however, is that since the very beginning of the planning process, persons with disabilities have been excluded. Their role is to be a source of inspiration for the fund raising. The same industries that give financial support to the Telethon are not willing to hire anyone with a disability. This practice also offers a negative image of persons with disabilities to the general public. It does not help to empower the disabled, but presents them as begging for public generosity.

There is another activity that is held every year in which many institutions participate. It is the four-day Special Olympics for persons with disabilities. The Ministry of Education asks sponsoring schools to support students from visiting special education schools. There are many volunteers that take part in this important activity and they are usually university students. Some fine athletes are selected to compete in the International Special Olympics. There are no other initiatives to include people with disabilities in the community,

Role of religion

Most of the population of El Salvador is traditionally Catholic but it is best to remember that "Catholicism has multiple faces, but it is primarily based in simple and profound faith that has its roots in the world of the indigenous" (Roggenbuck, 1994, page 4).

The Catholic Church was very much involved in the social struggles of its people. In March, 1980 during the civil war, Archbishop Oscar Romero was murdered because he defended social justice for the people at a time when it was not possible to speak out against the authorities. Twenty years after his death, he is still revered as a spiritual guide for thousands of Catholics, Salvadoran and non-Salvadoran alike. However, not all Catholics agreed with the involvement of the Church in social struggles. During the past 30 years many other churches have grown in membership, including the Baptist, Lutheran, Evangelical, Jehovah Witness and Mormon.

Religion plays an important role in the life of most of Salvadorans, regardless of their socio-economic status. Many persons with disabilities who have succeeded in their activities believe that because of their faith in God, their prayers have been answered. The Church itself, however, has a clear tendency to see persons with disabilities as different from the rest, as hopeless, as deserving of pity and consolation. This attitude is starting to change but it will be a long and slow process. The attitude of the Catholic Church towards persons with disabilities is almost the same in other churches, which tend to be very paternalistic, reflecting the attitudes of the rest of society. On the positive side, some churches now use local sign language in their services.

The attitudes of some in the Church regarding disabled persons are illustrated in the following cases.

A woman who had polio was about to get married. She and her fiancé went to the church they had chosen for the wedding to talk to the priest. After they explained to him the purpose of their visit, he remained quiet. He then asked the man, who had no disability, if he was convinced that she was the woman he wanted to marry. The priest kept asking him if he had seen "the way she is." The woman felt very miserable and they just left. They did marry, but in a different church.

There are some positive experiences around the same issue. A young, paraplegic woman, aged 26, said, "I have discovered many things about religion. First, religion helps to bring people together. Second, religion is a way to approach God. I was raised in a Christian home and I thought this sole fact would make me a believer. But it was not that simple. I decided to accept God as my only guide. For me that has been the most important decision that I have made. Through religion I can have a personal relationship with God." A young man said, "Religion has been a positive experience for me, and has given me the strength to face life from a positive perspective".

————— *Gender differences and male/female interactions* —————
in service provision

Most of those working as service providers are women. In fact, in some institutions there are no men at all.

In countries of Spanish heritage, there is a clear tendency for women and men to follow different occupational patterns. Caregivers are usually women. Except for the military hospital, most nurses are women.

————— *Eating habits and preferences* —————

Many different Salvadoran foods and drinks are made out of corn. One of the most popular are tamales, dumplings made from specially-prepared corn dough. The corn dough is then stuffed with chicken, rice and vegetables. The cakes are steamed after being wrapped in banana leaves. Another popular type of tamale is made with plain corn, milk and sugar. These, too, are wrapped in corn leaves and boiled. One of the most popular fast foods is the "*pupusas*", toasted tortillas filled with cheese, beans or pork rind and eaten with coleslaw and a special hot sauce. Many people eat them for breakfast, but most people eat them for dinner on the weekends at the "*pupuserías*," small restaurants, with very simple furniture. Food preparation provides a good income for thousands of women in the country.

Cool drinks (*frescos*) made out of tropical fruits have always been very popular. One drink representative of El Salvador is "*horchata*," made out of roasted rice flour and sweet spices. The powdered rice is mixed either with milk or water. It has a very special flavor that Salvadorans love because they are raised on it. There are also different hot drinks made out of corn, such as *atoll* (corn gruel), which is corn blended and mixed with water, sugar, and spices. It is very popular. People drink "*atol de elote*" (sweet corn gruel) around 5 o'clock in the afternoon after work and it is sold everywhere in disposable cups. The other very popular hot drink is "*Shuco atol*" a gruel made from dark corn, it also contains black beans and powdered pumpkin seeds. This traditional hot drink is usually taken early in the morning, around 5 a.m. although some prefer to drink it in the early evening.

In a Salvadoran home of more than modest means, a typical breakfast would consist of eggs, mashed refried beans, tortillas and fried plantains with coffee. For lunch there might be soup, some kind of meat, rice, salad and fruit for a dessert. A typical dinner might be mashed beans again, rice, tortillas, fried plantains, cheese and coffee. If the family could afford it, it would eat meat again. The variety and quality of foods will vary according to socio-economic class.

As for dietary taboos, there are none. People generally eat every kind of vegetable and meat, fish and seafood. Some people may be afraid of eating pork, because of concerns about hygiene. In other Central American countries that face the Atlantic, turtle meat is eaten. In El Salvador, turtle eggs and iguana meat are very popular. Lamb is not a favorite, but it is available in the markets.

Nowadays, fast foods are becoming very popular, especially among children and teenagers. Hamburgers, chicken, pizzas and sodas are sold not only at fast food restaurants, but also at gas stations that compete with the restaurants.

For the Salvadoran family getting together around the dinner table is very important on special occasions, such as birthday parties, weddings, anniversaries, Mother's Day, Father's Day and Christmas.

Salvadorans living in the United States visit El Salvador and bring fried chicken back with them as gifts for family and friends. They also bring native cheeses, green mangos and anything that reminds them of the flavors and aromas of El Salvador.

There is a popular belief in El Salvador that some foods are aphrodisiac, such as shellfish, especially oysters. Among older people, it is very popular to use certain herbs instead of taking medicines for a specific illness. This is especially true in the countryside. Coconut water is frequently used as a diuretic. For severe burns, people may apply sliced raw tomatoes. For a stomach ache, they may drink mint or chamomile tea.

————— *Recommendations to rehabilitation service providers* —————
for working effectively with persons from this culture

- Ask questions about the origin of the client. Any question that helps as an ice breaker will contribute to developing a friendly relationship. Whatever task needs to be accomplished, it will demand effort from each side. When I was 13 years old, I remember how frightened I was as my therapist came towards me to begin my exercises. I hated her, because she never explained to me why it hurt so much, what she was doing to me or why it was important for me.
- Any treatment or program has to include the closest family members. They have to understand that their cooperation and participation is crucial for the success of the program. They must resist the temptation to prevent useful treatment because of the patient's temporary discomfort or pain.
- Service providers should get together with Salvadoran consumers knowledgeable about issues that affect them, in order to better orient clients and their family members.

- Service providers must be very careful to avoid any discrimination or racism towards their clients. Consumers should be treated with respect and tolerance even if they haven't mastered English.
- Learn some basic vocabulary in Spanish
- Special efforts should be made to provide information to women with disabilities on reproductive health care issues.
- For explanations of a specific program treatment, it would be helpful to involve someone who knows Spanish as it is spoken in El Salvador, not just standard academic Spanish.

————— *Ways in which service providers can become
more familiar with this culture* —————

- Show your interest in your client's culture, by tasting the local foods and asking about their local traditions.
- Visit your client's home. Try to meet the family or others who live with the client. Don't be surprised by a different style of living. Just be yourself and be honest.
- Try to establish some links with organizations of Salvadorans within the community who may provide support for you and your client.
- Organize group discussions among your clients. Taking the role of facilitator, emphasize group participation and avoid lecturing or preaching.

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