Snapshots from the Margin

Women With Disabilities in El Salvador

by Patricia Pardo-Demiantschuk

En décrivant son voyage au Salvador, l'auteure relate l'histoire personnelle de quelques femmes handicapées du Salvador, un pays qui ne procure qu'une aide minime aux personnes handicapées.

Right from the beginning of my trip to El Salvador I felt fear, not so much of the destination but of the journey itself. It has been my experience that, as a person with a visual impairment, travelling on my own has always required a great deal of patience and a willingness to educate. Retaining my sense of independence and autonomy whle requesting "special assistance" has always been a real struggle for me. I shudder as I recall my conversation with the airline porter who met my flight in Miami. It was his responsibility to assist passengers who require "special assistance" and so it took me ten minutes to convince him that, as a blind person, I did not need the wheelchair, but simply a guide to the next gate! Ultimately, the most important lesson I learned was that facing my fears, challenging them, and finally embracing them is the only way to move beyond them.

Certainly, fear played a major role in the lives of many of the consumers I met. I remember feeling incredibly helpless as consumer after consumer told of their life experience with disability. People with disabilities were struggling to stay alive, and as their country wrestled with the overwhelming problems experienced by most "third world" countries, it was blatantly apparent that the issues and concerns of people with disabilities would not soon become top priority. My helplessness soon turned to anger, and then confusion. What right did I have to make judgements? How could I discuss and share the philosophies of consumer control, cross-disability, advocacy, and empowerment when most of the consumers I spoke to were struggling to stay alive? What could I know about being disabled in comparison?

Under my confusion, however, was pride and joy. Pride in the knowledge that all of the people with disabilities were finding their own solutions and making a difference for themselves and for their communities. Joy in the realization that peer support and consumer control transcends social, cultural, economic, and linguistic barriers. Despite fear, consumers came together to share themselves, their knowledge, their experiences, their concerns, and their solutions. And so I had come full circle. I saw my own struggle as a person with a disability mirroring the struggle of other consumers. I had gone to El Salvador expecting to meet strangers and instead found friends.

Like a pheonix rising from the ashes, El Salvador is a country in the midst of rebirth and reconstruction. The years of war, violence, and terrorism have taken their toll not only economically in the loss of millions of dollars worth of real estate investments and business, but also in the decimation of its youth. The country is racked by the legacy of war. Of the seven million Salvadorean citizens, the Associacion Cooperativa Del Gruppo Independente Rehabilitacion Integral (ACGIR) estimates that close to fifty thousand people, including the soldiers from both sides and civilian casualties, were rendered disabled.[1] Many thousands more were left homeless and traumatized by the extreme violence which was the civil strife in El Salvador.

Government and non-government rehabilitation resources, minimal at best and dedicated to the rehabilitation of the disabled community comprised of accident, illness, malnutrition, and genetics, were left fragmented, underfunded, and unable to meet the demand of the disabled veterans.

Issues and concerns of people with disabilities take a very low priority. No financial support (as in disability pension) exists for those who are injured or become ill while employed. A small disability pension ($35 per month) is available during the time of rehabilitation. Persons born with disabilities have received no government support whatsoever. Government and non-government service providing agencies work with limited funds and with outdated technology. The average level of education completed by persons with a physical disability is grade five. Blind and deaf children manage to complete, on average, grade one, as overwhelmed teachers operating in already overtaxed conditions find themselves completely unprepared or indeed unable to integrate sensory impaired children into the classroom. Special education resources are close to non-existent. Blind and deaf children who attend the few available centres of rehabilitation leave them after grade three to become lost in the overcrowded public school system. Deaf children suffer particular discrimination as sign language is totally unaccepted as an alternate form of communication. Deaf children are forced, with physical blows, to vocalize and mimic spoken language with little concern as to the level of conceptual understanding.

In the midst of this disability dynamic, women with disabilities face four levels of discrimination. The first is discrimination on the basis of gender. The second is the barrier of poverty and illiteracy. The third is discrimination on the basis of disability. The fourth is the discrimination of machismo.

Women born with disabilities are shunned, imprisoned in their homes, sexually and physically abused, and left to live their lives at the discretion of the economic resources of the family.

Although more than half the disabled community (not veterans of war) are women, few are represented in consumer and service providing organizations. Fewer still have any direct input into the development of options and services. Women born with disabilities are shunned, imprisoned in their homes, sexually and physically abused, and generally left to live their lives at the discretion of the economic, emotional, and physical resources of the family. Unwanted pregnancies as a result of rape occur often. Intentional abortions brought on by beatings and easily accessible sterilizations are commonplace. In law, deaf women can have their children removed from their care solely as a result of their disability. Women with developmental disabilities, any type of learning disability, epilepsy, and cerebral palsy experience the most extreme forms of abusive discrimination.

Although women who are disabled later in life face many of the same barriers as women who are born with a disability, some other issues arise. Almost always, women disabled later in life are abandoned by their husbands, and left with the care of the children. A corresponding loss in social and economic status occurs. Few ever remarry, as women with disabilities are perceived as "un-feminine" and thus undesirable.

As no financial assistance exists, most women are left to fend for themselves with whatever family support is available. Often the entire family moves into the woman's parents' home where accommodation is often limited. Children leave school to find work to support the family. Few rehabilitation options exist and so, without a husband and limited options for work, the woman disabled later in life is left destitute, and stripped of whatever status and security her past life held.

Betty

Betty has epilepsy. Early in her life, with the onset of her first seizure, she found herself imprisoned in her house. She was not allowed to leave except to attend school to the fifth grade. At the age of 16, her stepfather raped her and left her pregnant. Her mother, not knowing who the father was, blamed her daughter for the pregnancy. In her anger, embarrassment, and frustration, she pelted her daughter with blows so severe that they instigated the termination of the pregnancy. Betty's mother, wishing to control her daughter's "promiscuity" had her daughter sterilized shortly after the premature termination of the pregnancy.

Betty is now twenty-seven. She does not realize that she has been sterilized. She is engaged to be married and is under constant fear and anxiety that once married she will again become pregnant and so invite the blows of her mother. So she postpones the date of her marriage, living with her mother and working in a sheltered workshop which caters primarily to persons with cerebral palsy.

Miriam

Miriam was affected by the polio virus when she was quite young. She has lived almost all her life in a small rural village with her mother, just outside San Salvador. Miriam's home is not accessible. Every time Miriam needs to leave her room, for example to use the outhouse facility, her mother must lift her out of her chair and carry her to the washroom. Miriam spends most of her days sitting alone in the house, a prisoner of her disability.

At twenty-seven, Miriam heard of a ceramic cooperative in San Salvador run by people with disabilities. The only place in San Salvador she could find to live in which was both economically and physically accessible was a residential institution for persons with cerebral palsy. Life in the institution was totally controlled and it was not long before she was desperately looking for another place to live. She finally found reasonable work and a more-or-less accessible apartment. Shortly afterwards, her mother began to harass her for having abandoned her until finally, overwhelmed with guilt, Miriam left her job and apartment to go back to her village to care for her mother.

Cecilia

Cecilia had both legs amputated as a result of an industrial accident at the age of 17. Her family was poor and had limited options with respect to accommodation and support. Somehow Cecilia would have to work. She was able to find a spot in a sheltered workshop run for persons with cerebral palsy. Cecilia was allowed to keep only a small portion of her earnings, the rest went into the family coffers.

One night, shortly after Cecilia started working, one of her cousins raped her, and left her pregnant. Upon discovering Cecilia's condition, her mother beat her with such severity that Cecilia lost her baby. The same sequence of events occurred twice before Cecilia's mother had her sterilized. The sexual abuse continued after Cecilia's sterilization.

Ruth

Ruth has lived all her life with arthritis, but she has managed to cope, supporting her family by working both outside and inside the home. Three years ago, her arthritis deteriorated to the point where a hip replacement was required. Three months after her operation, her husband was gone, leaving her with the responsibility of three children. Her disability now made work impossible, and without support from her husband, she was forced to sell all her possessions and move in with her seventy-four year old mother. At that point her life changed totally. The whole family laboured under great stress, packed into two rooms, accommodating a new disability and the needs of an older woman. As the stress mounted, animosity grew towards Ruth, as the instigator of the family's changed state.

Two of the three children left their studies to earn income for family expenses. Ruth found herself falling deeper and deeper into depression. Her disability, the loss of her economic position, her change in status, and most of all, the guilt she felt for all that had befallen herself and her family, caused her to believe that her husband had every right to abandon her.

With increasing despair, Ruth began the slow process of physiotherapy subsidized by small disability pension. She finally had the opportunity, through her physiotherapy program, to attend a functional literacy seminar for women with disabilities. This was Ruth's first encounter with other women with disabilities. Here she met women, who despite their disabilities, were living their lives to the fullest. These observations had a great impact on Ruth. By simply knowing other women with disabilities and being able to share experiences, Ruth received the support she needed.

Patricia Pardo-Demiantschuk was born with a visual condition known as macular dystrophy. She is currently the Executive Director of the Independent Living Resource Centre of Calgary and a member of the Board of Directors for the Alberta Committee of Citizens with Disabilities and the Alberta Advisory Council on Women's Issues. She has an M.A. in Educational Psychology from the University of Calgary.

À DÉCONSEILLER...	***À CONSEILLER...***
aveugle	quelqu'un qui ne voit pas du tout est une personne aveugle, quelqu'un qui voit un peu a une déficience visuelle, est une personne malvoyante
bégaiement	une personne atteinte d'une déficience de langage et de la parole
confiné/cloué à un fauteuil roulant	utilisateur ou utilisatrice de fauteuil roulant
épileptique	une personne atteinte d'épilepsie
estropié(e)	une personne handicapée
fou/folle	une personne atteinte d'une déficience mentale
handicap auditif	une personne malentendante
infligé	handicapé depuis la naissance
l'autistique	une personne atteinte d'autisme
l'aveugle	une personne aveugle
le sourd	une personne sourde
le sourd-aveugle	une personne sourde-aveugle
l'handicapé(e)	une personne handicapée
l'infirme	une personne atteinte d'un handicap
mongolien	une personne atteinte du syndrome de Down
normal	non handicapé/handicapé
patient	une personne atteinte d'une déficience
retardé	une personne atteinte d'une déficience mentale
souffrant du Lupus	une personne atteinte du Lupus
souffrant de la sclérose en plaques	une personne atteinte de la sclérose en plaques
sourd-muet	une personne atteinte d'une déficience auditive

Ne pas utiliser

Affligé • Souffrant • Victime • Invalidité

Cette liste se trouve dans Le Mot Juste: Lexique des termes appropriés se rapportant aux personnes handicapées. *Ministère des Affaires civiques: Office des affaires des personnes handicapées, 1992.*

---

[1] Statistics cited throughout this article were obtained in personal interviews with representatives from the ACGIR in El Salvador.