

ACTION PLAN:

Personal Assistant System: A Clue To Be Independent



By

(Alternative Capacities in Sorority, CAS)

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I. My organization:

CAS, Capacidades alternativas en Sororidad (Alternative Capacities in Sorority)

CAS is a private organization that works mainly with women with disabilities of the Central Valley of Costa Rica. Nowadays, it is currently formed by 3 main coordinators and 15 members. It can be integrated also for women without any disability that are closely related to our community and have some kind of sensibility regarding our reality. It does not have a pyramidal organization. Everybody plays different roles, depending on the needs of the group. This organization was created in 2003 as a result of the problematic situation that women with disabilities face everyday in the Costa Rican society. We realized that females friends with disabilities needed to find a space to talk freely and comfortable. At the moment they were able to express themselves, we heard different stories that changed the way we perceived the reality of women with disabilities. For instance, one told us that she was abused by a relative and when she tried to ask for help, parents did not believe her. The cases of abuse in the hospital were also very common among them; nurses or doctors mistreated them everything they went to the clinic. Also, a friend has psychological problems because she realized that she can not have kids after a doctor removed her reproductive organs when she was a child. As a matter of fact, people with disabilities have been considered inferior beings inside of our country for many years. People usually believe that we are unable to make decisions regarding our own lives, or to integrate ourselves in the society and participate actively in the community because we are perceived as eternal infants. Society expects us to live with our parents the whole life and deny us the opportunity of being physical and financially independent since we are born. Of course, these social conceptions affect females even more. We (women) as members of a patriarchal society, tend to be placed in a second category. We all know that females have been abused and ignored in many aspects and we have been assigned the role of mothers but not the role of women. This social attitude is even worse when we talk about women with disabilities. In sum, some of the problems that generally women with disabilities face in Costa Rica are the following:

- a) Women with disabilities are denied to have and raise their children and make decisions about them;
- b) The governmental clinics do not have medical equipments according to our different needs; the health service do not take into account women with disabilities when they create the systems;
- c) We are denied to have a pleasant, healthy and active sexual life because we are not considered sexual human beings.
- d) We usually suffer from domestic violence by partners and family members.
- e) In most of the cases, we suffer from discrimination when we apply for a job so, we don not have an income.

As a result of this social environment, CAS intends to give solutions and improve the quality of life for women with disabilities by promoting empowerment. Our mission and vision can be summarized in this way:

Mission: CAS is a group who deals with the defense and promotion of the human, political, economical, cultural, and sexual rights of women with a disabled condition and their families, as well as women without a disability that have sensibility and interest regarding this reality. Creating and promoting some strategies that permit us to get independence, complete development and equal opportunities and conditions we can achieve our goals.

Vision: CAS will be socially recognized is an organization able to understand and satisfy the needs of women with alternative capabilities and the ones who have sensibility about this topic through the promotion and respect of the human rights and the implementation of strategies that permit the participation of women with disabilities in all the aspects of our society.

CAS does not have a financial aid; every member provides what she can, depending on their economical possibilities. It has been difficult to find an appropriate place to meet; so, we make reunions in our own homes. Another problem we have is that public transportation is not very accessible in Costa Rica yet; so, women in our group usually commute by taxi. For this reason, it is impossible to have meetings very often because transportation is very expensive and members can not cover the cost.

Nowadays, we are focusing on making different projects some teach women in our group internet and English but we need a financial aid, so, it has been difficult to start our activities. Nowadays, we are currently focusing in the following issues:

- a) Accessible public transportation;
- b) Active participation in activities related to gender;
- c) "Design for all" (Accessible internet sites);
- d) Advice and support mothers of people with disabilities;
- e) Teaching of the English language to visual impaired people;
- f) Learning of LESCO (Costa Rican Sign Language);
- g) Creation of business to be managed by people with disabilities.

Some of these projects are already been done partially, and other are planned to be implemented in the future.

II. Background

Independent Living and PWDs In Costa Rica

In general terms, people with any kind of disability are not considered really independent in Costa Rica. This fact has to deal with three main reasons: first, when persons are born with a disability or when they become disabled, people assume that that our family will take care of us all the life because we are not able to make decisions about our life, support ourselves and be physical and psychologically independent. Parents who have a daughter or a son with disability are thought as suffering beings because they are supposed to take care of the kid, and forget about their own lives and desires. Although parents of persons with disabilities are considered very misfortunate, they are socially accepted only if they take care of the disabled kid as people expect it. This social issue makes the parents very over protected and even when the PWDs are adults, they are still treated like kids. The second reason why PWDs are not considered independent in Costa Rica deals with the concept of independence. In my country, a person is living independently if he\she can do everything by him\herself, and has

enough economical income to live alone. Therefore, when a PWDs need to be assisted, they become dependent of others, so, they will be never independent. People sometimes do not understand that a person can be independent when she or he does what he/she wants and decide her or his life freely even if the person needs an assistant. I strongly believe that PWDs are taught to be dependent in Costa Rica; society makes us think that we do not have other options because we have a disabled condition. The last reason for not being independent is that the government is not giving PWDs enough social welfare. As a matter of fact, PWDs can not get access to a job very easily. According to a census in 2006, only 28% of the population of people with disability is currently employed and the social insurance pensions are very low in relation to the standard of living in the Costa Rican society. As a result, PWDs could hardly pay a personal assistant in their own if they need it, so; they are forced to live with their family because they do not have another choice.

III. My experience in Japan

In Japan, I learned that personal assistant system (PA) at is very effective to improve the quality of life of people with disabilities. It was not easy to get a PA system, people achieved it because they were very perseverant and demanding but also because they work together as a team. Nowadays, PWDs in Japan can actively participate in the community or they can choose just not to participate if they do not want to. In my home visit, I met a brave man, Mr. KAYAHARA, which has cerebral palsy in a very severe level; he works at the Independent Living Center Akishima, he is married with a not disabled woman and has a child. He has a PA almost all day, that way he can feel really integrated to his family. After talking with him, I realize also that PWDs who have a PA have a better relationship with their families because the members are not forced to take care of the person all day. Therefore, each member can have their freedom to do she/he wants. On the other hand, PWDs can receive assistance without feeling that someone is doing a “big favor” to them because the personal assistant works for them. I was really impressed when I observed the PA service has its own policies and statements to follow. That way, people get money from the government to pay the salary of the PA instead of pay his/her on their own. Also, I realized that it is important to

establish clear limits between the PA and the person that is assisted, they are not friends; they are worker and boss. For the first time, I have observed that a person with disabilities can train a PA, establish the time she/he needs to be assisted. In this training course, I also met a female leader, Ms MURUYAMA that works also for the Independent Living Center Bunkyo. She explained how people achieved PA system in Japan. PWDs decided to be free to manage their lives and they wanted to be integrated to the community. So, they started having volunteers to help them. Little by little, they recruited people with disabilities and PAs and many people with disabilities could have a PA. Nowadays, she is able to live alone with the help of PAs, she achieved total independence. I was impressed because she did not care about what others said. She just knew that she wanted to be independent and she worked for it. She said “you have to work for achieving the things you want, you just has to start”.

IV. ACTION PLAN

This project intends to change the vision of what Costa Rican society has about the independent living of people with disabilities. It focuses more on experimentation rather than on implementation at this stage. First, it pretends to inform society in general about the advantages of having a personal assistant (PA) system for people with disabilities by using the mass media. As I said before, Costa Rican society is not very familiar with the concept of independent living of PWDs because they are considered not able to be independent. For this reason, it is essential to educate society in general about the PA system in other countries as Japan or the United States of America. Also, this project pretends to educate people with disabilities in general about what they could improve in their lives having a personal assistant instead of depending on the family to accomplish everyday needs as well as let people with physical disabilities experience by their own having a PA. For this project, we are going to use volunteers as personal assistants because we intend to see how personal assistant system works in Costa Rica and what changes we may do for future implementation of it in our society.

V. Goals and Objectives

Target group: People with physical disabilities from 20 to 45 years old, who live in the Central Valley of Costa Rica and want\need to have a PA.

Over goal: To promote Independent living for people with disabilities by using PA system.

Aim: To put PA system into practice for people with disabilities by using volunteers.

Objectives:

- To make the society aware of the importance and advantages of having a PA system for PWDs by using newspapers and television.

- To organize meetings or workshops with 40 adults with physical disabilities who live in the Central Valley to let them know the concept of Independent Living and PA.
- To put PA system into practice by recruiting 20 volunteers and 20 persons with disabilities.

VI. Outputs:

At the end of this project, people with disability will be able to:

- ❖ Understand the concept of PA used in United States and Japan
- ❖ Know the advantages and disadvantages of having a PA
- ❖ Know how to use a personal assistant according to his\her needs
- ❖ To reinforce the interaction between people with disabilities and society in general.
- ❖ To reinforce team work between PWDs and PAs.

VII. Scope of work

PA = Personal assistant

PWDs = Person with disabilities

CNREE = National Council for Rehabilitation and Especial Education, Costa Rica

UCR = University of Costa Rica

Date	Activity	People involved
Dec 2006	Meeting with coordinators (CAS) to revise the project	coordinators
Dec 2006	Coordination with the mass media (mostly university media)	Coordinators Volunteers members
Jan 2007 to end of March 2007	Interviews, letters, messages to the media to introduce the PA concept	coordinators
Feb 2007	Coordination with CNREE/UCR about workshop about PA with PWDs	coordinators
April 2007	workshop with PWDs	Coordinators Members CAS volunteers PWDs
April 2007	Monitoring workshop by doing interviews	PWDs Coordinators
Middle May 2007	Second workshop (if interest is high enough)	Coordinators Members CAS volunteers PWDs
June 2007	Recruit PWDs interested in having a PA and select 20 from the workshop(s)	Coordinators
June to August 2007	Recruit volunteers to work as Pas	Coordinators
End of August to Oct 2007	Train the volunteers	Coordinators PWDs
Oct to middle of Nov 2007	PA into practice	Coordinators PWDs Volunteers
Dec 2007 to Jan 2008	Evaluation and results by interviewing PA and PWDs	Coordinators

VIII. Time table

Phase	Activity	Time
1	Education about PA system	Dec 2006 to June 2007
2	Put PA into practice	June 2007 to Nov 2007
3	Evaluation and monitoring	Dec 2007 to Jan 2008

Phase 1: In this stage, CAS coordinates with journalists to get interviews, by sending letters about the important issues I learned in Japan. At starting point, it would be easy to begin with the media at the University of Costa Rica; it has its own newspaper, radio, and television channel and you can get space in the programs for free. Besides, by addressing the media at the university, we can send our message to many young people that may be interested in become a PA for PWDs in the future. It is important to get access to a more popular national media and address more people.

Phase 2: At this stage, we plan to have a workshop or two (depending on the needs and on the budget) in order to explain and inform PWDs about PA system. The workshop will include a theoretical part and a practical part. We will explain concepts, regulations, rules of PA (as used in US and Japan) and then we will demonstrate to the participants how to use a PA (I will trained one trial PA for that purpose). Participants of the workshop will be invited by sending the info to a disability network in the country (that is already created), also we are going to send the invitation to CNREE (National Council for Rehabilitation and Especial Education). After that, we will select 20 adults 20 to 45

years old with physical disabilities from the workshop who want to experience having a PA.

We also are going to recruit 20 volunteers interested in work as personal assistants. We plan to look for the volunteers through the internet (accessing some internet free groups) and asking for volunteers among the university students.

Phase 3: Finally, we need to evaluate results. We will interview the PWDs and volunteers that participated in the project about how they felt doing their respective roles, what they liked or not, highlights what to improve, suggestions, etc.

IX. Budget

Item	Cost (US\$)	# of people	Units\times	TOTAL (US\$)
Telephone bill	7	3	1	21
Internet service	3	3	1	9
Computer paper	2	3	1	6
Printer ink	5	3	1	15
Transportation coordinators for internal meetings	8	3	10	240
Food for coordinators meetings	4	3	10	120
Transportation coordinators for org. work	15	3	5	225
Workshop Transportation	8	50	1	400
Workshop food	3	50	1	150
Workshop materials (set of papers, folders, pen, etc)	3	50 (including volunteers and coordinators)	1	150
Translations	20	1	1	20
Transportation PWDS for training	10	20	1	200
Transportation of volunteers for training	2	20	1	40
Food training	2	40	1	80
Materials training	20	1	1	20
Transportation for volunteers as PAs	3	20	10	600
Others	50	1	1	50
			TOTAL	\$2.346