

Beyond Existing We Should Be!

Alex Garcia – 2014 - Brazil

About the book:

It is a book where I write several thoughts and reflections that gave me and still give me sustenance to my development. I, Alex Garcia, a Deafblind person and person with hydrocephalus and rare disease, graduated and post graduated in Special Education, overturned paradigms and I still do it mainly because I am an extremely fulfilled human being. These thoughts follow me, they are part of me. To me, these ideas were and are a kind of “recipe to success”, built from my daily relations with the people and the environment that surround me. The thoughts and reflections which are in “Beyond Existing We Should Be”, thought me two maxims: to be strong so nothing can defeat me and be myself so no one can forget me.

About the author:

The “gaucho” Alex Garcia, is one of the most famous persons with Rare Disease and Deafblind Persons in the world. Specialist in Special Education by the UFSM/RS. He was the first Deafblind Person and Person with Hydrocephalus and Rare Disease to finish a post-graduation degree at a Brazilian university. He is the founder of the Gaucha Association of Parents and Friends of Deafblind people and people with Multiple Disabilities - AGAPASM. He is the pioneer in Brazil who developed the first research to find Deafblind people all over the state of Rio Grande do Sul. And he had as one of the most important supporters the Swedish Federation of Deafblind persons and the World Federation of Deafblind. He is considered "the father" of Deafblindness in the state of Rio Grande do Sul. Since 2004, as a volunteer, he structured for the first time in Brazil a programme of Home Care with families of Deafblind people to help them with information and educational orientation and also medical and social referrals, training of professionals to attend Deafblind people in their

original places, adapting these places and special programmes in schools. Writer: he is the first Deafblind Person to write a book about education in Latin America. His book "Deafblindness: empirical and scientific" was published in 2008. In 2010, he has published a book for children: "The big revolution". He has never given up of his sovereignty, and so he is registered at the National Library as individual editor - Editorial Prefix 908690. In 2009 he won the "Sentidos" Award, a national award, because of his overcoming story of life chosen as the biggest of the year in Brazil. He is a Honorary Rotarian - Rotary Club of São Luiz Gonzaga in the state of RS. He was the first Deafblind Person to be alumni at the Mobility International Programme in the USA in 27 years of history of this organization. He was the first Deafblind Person in Brazil and Latin America to participate of a training programme for teachers with total liberty and it was held in the city of Cuiabá, in the state of MT. He was also the first Deafblind Person in Brazil and Latin America to work in a training programme for teachers with total liberty and where he had as students two people with disabilities (a young blind educator and a young deaf educator). This was held in the city of Niteroi, in the state of Rio de Janeiro. Alex also writes for the Magazine *Reação*. Alex Garcia was the only Deafblind Person in the world to participate of the High Level Meeting on Disability and Development "The way forward: Disability Inclusive Development Agenda for 2015 and Beyond" held in 2013 at the UN headquarters in New York. He was the proponent in 2013, of the public hearing to treat social inclusion of the people with deafblindness - the first hearing to deal with the issue in the history of Brazil. He is active, participant and collaborator of the IDA Forum - International Disability Alliance (IDA). He is a collaborator of the Secretariat for the Convention on Human Rights of People with Disabilities, Division of Politics and Social Development, United Nations Department of Economic and Social Affairs. Alex Garcia was one of the winners, in the category "Personalities" of the Award Brasil Mais Inclusão 2016.

My Thoughts:

I really believe that all of us, with our differences, are truly and essentially great works of God and that belief is my religion. All our fights keep our balance and support my "incomplete being" so I keep walking.

Deafblindness is the disability which "affects" most the essence of the society because it takes to a distance imposed by the visual and auditory losses as well as the impatience which is generated by the difficulties in communication. So, what concerns to Deafblind persons, the most feared condition lived by us: "being alone" as a synonymous of abandonment, which is different from "loneliness", because this state you can choose and enjoy it when you are not afraid of yourself.

Inclusion to me is rupturing the assumption and shame these powerful social control tools that get and maintain the continuity, the flow. To obtain and maintain the truth and happiness, grounded in the justice of the free man. Inclusion is denying the static, denying the interest that creates opportunities to certain people who are supposed to give something back, in return. Intolerance designs barriers. To deny and subtract men's freedom and autonomy.

To be happy. To have freedom of thoughts and actions. To be human. To support ourselves. and our resemblant. To be strong. To be successful. To be proud of being the way we are. We observe everything using the sense of reason without losing the tenderness. All these and much more is totally possible, with intelligence, faith and determination.

Any organization is born from continuity. It comes from the need of movement. It comes from the desire of the truth and happiness, grounded in the justice of the free man. It denies the statics. The intolerance which designs the frontiers. It denies to subtract the freedom and independence of man.

That the "choices" may be grounded in the historic contribution to the movement and not for the exchange of favors which were born yesterday

and that *The Nothing Over Us Without Us* may truly become, *Real Power* and not false power, as I follow in many occasions.

I refuse to be just “one more brick in the wall”, as Pink Floyd sang, in “Another Brick In The Wall”. In some part of the song, Pink Floyd says: “All in all it was just another brick in the wall”. I am going to fight more and more to further deny in order of not being one more brick in the wall.

I observe in my way, having a deafblindness as my eternal fellow. And if the humankind wants to value me, may it do it while I am still alive, recalling *Nelson Cavaquinho, who used to say “I know that tomorrow /when I die/ my friends will say/ that I had a good heart/ some still will cry/ and they will want to honor me/ making me a gold guitar/ but after the time goes by/ I know that no one is going to remember/ that I am gone/ that is why I think like that/ if someone wants to do something for me/ may it do it now/ give me the flowers while I am alive/ the affection, the friendly hand/ to relieve my ouch/ after I call myself nostalgia/ I don't need vanity/ I want prayers and nothing more”.

Indeed, the victory is the result of persistency. Therefore I love to develop my work for I realize, in the shaking hands and in the hugs I receive from people, the huge respect they have as well as the appreciation they offer me.

We can have an idea about the determination of a deafblind person, through the planning he or she develops exactly for not listening or not seeing, the planning becomes fundamental.

It is a serious and historic mistake to approach the deficiency as a whole. It is as serious as inadmissible. The development is individual, not collective;

Deafblind people have five powerful enemies to defeat: fear, presupposition, shame, distance and impatience.

Having the straight representation, real, respectful and responsible, is important but attention it is not the case of having a deafblind or any other deficient person to represent your mates, that are in equal condition of invisibility because it favors dependency and submission in exchange of favors. I'm straightforward: someone to represent others, must beforehand, be free and independent to face the "normality".

The fear of a deafblind person will disturb your mind, guiding your behavior in such a way that he or she will fail to develop appropriate planning, and without it, everything will collapse.

The presupposition is, actually, an early thought. Our society in general, when reading the word "deafblind", presupposes an identity of the person. It is released upon us, a sea of doubts. Quickly, we are in a position of extreme disadvantage. We start having to prove something to someone.

To a deafblind person, the shame is sneaky. It comes from the cradle, it comes from the religion. The person feels ashamed but doesn't know the reason and the purpose. But it's clear! The person mistakes guilt with shame and vice versa. In this salad called shame, the "tsunami" begins.

The distance for a deafblind person is an enormous challenge, because all the communication ways we use, are of nearness. Without being closer there isn't a chance to establish presential communication with another human being. The impatience is something terrible for a deafblind person. All the communication types we use are slower therefore, we need to be patient. I consider myself a shameless to serve the Inclusion so give up! I have no shame of being the way I am. It is impossible to control me with this "tool" called shame.

Deafblind people should learn how to be strong. Yes, we can more and more strengthen our identity, denying what threaten us, rebelling against the oppression, being unresigned to what they present to us. I learned to

be strong so nothing can defeat me above all, I learned to be myself so no one forgets me.

I refuse to simply exist. I must be. I must be to live intensely the freedom that I have left.

My attitudes follow what taught us Martin Luther King Jr. when he said: “The cowardice asks: is it safe? The convenience asks: is it political? The vanity asks is it popular? However, the consciousness asks: is it right? And the time comes that someone must take a position which is neither safe, nor political, nor popular, but we must take it because it is right.” In this way, I take the right position.

I am completely against the “medical model”. The model and culture of “the normalized body”. I mean, for this model, our bodies, only have social value if they can be “fixed”. Our rights to a worthy life are denied. This model and culture substantially increase our problematic, for they showed us only one door, one way – our cure or nothing.

The life for several times, bashed me with a whip. And in each bash, I have learned different lessons. These moments made me realize I would have to have more attitude. By having attitude, the bashes decreased. Will it be an absolute truth?

It’s clear that the understanding precede the execution. Therefore, it’s necessary to be an inquirer and dreamer Quixote and, then, bang the spirits.

The poverty is the same as being the most invisible of the invisible. A poor person is a strange in your own country. Criating a favorable environment to equal opportunities means as a prior request, having “voice”. Are the “poor” invited to have “voice” ? Of course not! They are invited only to justify, with their physical presence, the decisions that in their name, were taken.

I always ask for forgiveness to people, if my considerations are not important, however, truly, my being does not allow me to make speeches. I must be voracious and straight in order to develop a theme.

Many leaders in the area of People with Disability say when we touch the wound – “Gosh! You seem to have hate in your heart. Your complains are hurting the people. “Apologize yourself!” and you apologize. Then the leader says: ”You are a sweet heart.” Be careful! keep out! This leader is a corrupt.

To me, it’s clear. The main challenge is the unequal power relation that affects directly the development of our full identity.

We should be very careful when someone talks about representation. How a blind person is going to represent a deaf person? How a person with no deficiency can represent a deafblind person?

To reach the full Inclusion and succeed in the public policies, to make them relevant, it is required to have each spokesman in the right place. I talk like this because off all my life, I observed acts which were contraries to logic.

The deafblind people don’t know what really affects them. Therefore, in general terms, the collective of deafblind people don’t reach effective changes to improve their conditions of life.

The Good Samaritan doesn’t exist. The unequal relation of power exists between the people without deficiency and the people with deficiency, although there is also an unequal relation of power among the people with different deficiencies.

I am a deafblind person and I still carry a rare disease and I can tell you, our invisibility is, for sure, a powerful tool that is manipulated to keep our subservience.

Approaching the deficiency as a whole is a party speech and, therefore, it is empty. The maintenance of this speech will produce the unseen of the unseen. This because this speech consigns more power to the inequality of power.

It is necessary to have courage to make ruptures, to rebuild new structures. It is urgent to eliminate all and any representation which was distorted from our identity. A lot of those who say that represent us, keep themselves as such, with the support of the powerful and their money. And for sure not all of them act democratically and neither are part of associative parties, legal or illegal by their basis. It is necessary to rethink the individual identity and capacity of the self-representation.

God, to me, is not in heaven nor in the earth. He is not in any religion nor in an image or book. God, to me, is in our attitudes. And I am absolutely sure about the attitudes I took in my life as I am sure about those I still will take, that God is present in all of them! Where does this certainty come from? I have this certainty because I am alive so far and despite all my difficulties, I wake up each morning saying; "Hi, hi, I woke up to one more day of joy.

I believe that all people with deficiency are Human Being. All of them. The deafblind people too. Because it is too difficult to be the most unseen of the unseen. It is too tough to live an uneven power relation that goes forward day by day without being faced.

The uneven power relation "told" us that we, deafblind people will be eternal apprentices. This "eternal" speech is what we must knock down.

Granting the voice to each person is the essence to an inclusive society. Therefore, it revolts me when the first question is: "Which organization do you represent?" "What organization do you work for?" It is too much representation. It's an excess of "to be part of.... And where are the individual rights?

Diminishing the stigma, does it favor the Inclusion? Yes! Diminishing the stigma, favors the Inclusion, but actually, the best thing to do wouldn't be directly attacking the stigma. We should attack what builds the stigma, in other words, the presupposition and the shame. The presupposition and the shame, are powerful tools of social control. We live in a society that the relation of power is installed and consequently the trend to control is huge and almost a rule. In this relation of power, people need to control other people, precisely to maintain the power and to do that, they use the tools of control, which are presupposition (a forehand thought) and the shame.

This question "Diminishing the stigma, does it favor the Inclusion"? Has the same essence of the question that I answer in several foreign countries: "How we should do, so Inclusion could take place"? I always answer: "The Inclusion is going to happen according as we can rupture with the presupposition and the shame".

The presupposition, to me, after being applied on the identity of a person for long time, solidifies, what we call stigma, like a brand. An example - in general, when people see a blind person on the street, they think: "Poor guy, he can't see"! In general, when people see a person on a wheelchair on the street, they think: "Poor guy, he can't walk!". This is a common reaction that happens with all deficient people. Then, why always "poor"? Then, time goes by. There is always an identity being watered by the "poor". And after several years, what do we have? Well, we have one more poor blind, one more poor person on a wheelchair, one more poor deficient person. I'm going to be a poor guy because all people see me as a poor! That's it! The presupposition won. The tool of control fulfilled your dutie. The Cautious-Power annihilated the possibility of the person to become someone that could "disturb".

We have one billion people with deficiency in the world, we are the biggest minority worldwide, but just a few with autonomy. The overwhelming majority lives your presupposed identity, with no power in their power relations, that is, they live being controlled.

How about the shame? The shame to me, is the most terrible tool of control. It is terrible because it acts in the social ignorance and in the human being by confusing "guilt and shame". And where is this confusion? In general people feel ashamed without being guilty. They are not guilty, but they feel ashamed and here is the power-control of the shame tool. People are not certain about the guilt. The shame as a tool of control acts exactly on the uncertainty. To me, it is clear and proven – after experiencing several cultures and behavior – that people with more developed deficiency, are those who has very clear what is "guilt" and "no guilt". They only feel ashamed if they are guilty. If they are not guilty, they don't feel ashamed.

The presupposition and the shame, as they subordinate deficient people, they also give them power. That's what I call "in the flow of the interest". The Power, in most cases, choose menial people with punctual deficiencies to receive position, status and prestige. But, this choice only serves to maintain the control. Everyone knows that nowadays this practice is very common. Many of our "leaders" are like that. The Power gives the Power to those who will be agents, to those who are not going to "hurt" the power relations, that is, those who are not going to disrupt the chain.

My steps for development!

In "My steps for development" I want to guide persons with disabilities - and perhaps even to guide persons without disabilities on how to achieve development. As usual, in my thoughts I will tell you a truth, it is my own truth. I think there are many truths. Every human being has his truth. "My steps" as you can see, may be similar or very different of other steps , my steps are of a deafblind person, in the belief that deafblindness is the condition that most "affects" the essence of society, because it implies the distance imposed by visual and hearing loss, as well as the impatience that generates communication difficulties . We make references to Deafblindness as the most dreaded condition to human beings: the "staying alone" as synonymous of abandonment, is a very

different situation from "Solitude" choice for enjoyment situation when we have no fear of ourselves. In my life, I try to transmit and exercise "My steps for development". We must never interpret these steps as ready. The steps are in the daily motions of life.

Knowing yourself

The first step, to know yourself, is to be aware of your own needs and abilities - it takes time, so it does not fit at the time of the soap opera. All persons with disabilities, especially deafblind people must realize that nothing is static, so knowing yourself is a constant re-starting and it needs a lot of patience!

Controlling of emotions

Controlling emotions is the second step but you cannot reach it without passing through the first one. Example, it is not possible to control our emotions without self-knowledge. You can only take a new step safely if the last step was solid. Controlling emotions plays an important role in our development. In everyday life I observe often the desperation and fear in persons with disabilities, as well as people who are deafblind, the knowledge of their own emotions are essentially limited.

Planning actions

Here we have the third step. To plan actions we must know ourselves and control our emotions. It's a fact! Planning is the mainspring of development, but, a bad planning can knock you out in a short period of time. A bad planning will bring up the lack of emotional control and we are going to see it clearly: I do not know myself deeply as I imagined. I thought to be able to do that but in fact I have other needs. It's pretty clear: if we know ourselves we will be able to control our emotions and as a consequence of that, we will be able to plan actions that can reach our abilities, not our needs.

Guiding the means

Here we have the fourth step. When you know yourself, you control your emotions. When emotions are under control, it's possible to plan actions and then, finally, guiding the means is possible. Guiding the means is the apex because we live in a society and although we have many abilities, there isn't a perfect human being who doesn't need any kind of support. I must warn you that guiding the means can sometimes be very different from what we expect, it is possible that when we try to guide a person to help us, this person isn't interested. If you face a person who isn't interested, honestly, do not try to change this person. Turn around because you will find another person there who is really interested for sure.

Magnifying life!

God, thank you for leaning over my essence on this land, for giving life to my body and for having this "Beloved Land" as my origin. Thank you for making the blood of *Farrapos and *Guaranis goes through my veins, for making me a son of *Sepé and his eagerness of warrior.

I thank you, my Lord, for this uncontrollable passion for revolutionary freedom, for letting me know in this earthly existence Che Guevara's precepts. We are companions because I tremble with indignation every time an injustice is committed in the world. With you, "Che", I learnt to "grow hard without ever losing tenderness".

Omnipresent God, I thank you for this need of autonomy and independence, for sowing in me "denial", "rebellion" and a "nonconformist mind". From these movements, to my movements of equality. Eternal gratitude.

Thank you, God, for showing me Foucault's "boldness". For making me feel the causality of "power relations" in its full form. For constantly, denying the subordination of my being. Thank you for making me dare to challenge the "observed freedom".

God, keep me as I am forever and ever. Let me always be this little “Dreamer Quijote”.

Allow me, my dear God, to never lose hope. And so, forevermore, thank you for letting me magnifying my life and trying to help others.

Glossary:

* **Gaúcho** – the one who is born in Rio Grande do Sul, the extreme South of Brazil.

* **Farrapos** – This was the name given to the fighters in the ‘Farrapos’ War or Farroupilha Revolution, a regional war or revolution with a republican character against the imperial government of Brazil and which was held in the so called São Pedro do Rio Grande do Sul province and that resulted in the Declaration of the independence of the province as a Republican State, giving rise to the Rio Grandense Republic.

* **Guarani** – the term “guarani” refers to one of the most representative indigenous groups of Americas which has as traditional territories a large region of South America that covers the national territories of Bolivia, Paraguay, Argentina, Uruguay and the south-central part of the Brazilian territory.

* **Sepé** - Sepé Tiaraju (He was born in the Jesuit reduction of São Luíz Gonzaga in 1723 and he died in the Jesuit reduction of São Gabriel in 1756). Today, São Luiz Gonzaga is the city in which Alex Garcia lives. Sepé was an indigenous warrior considered a popular saint and who was declared “national hero by the law nº 12.032. Indigenous chief of the Seven Mission Settlements, he led a rebellion against the Madrid treaty.

* **Nelson Cavaquinho** artistic name of Nelson Antônio da Silva, was Born in Rio de Janeiro, Brazil in October 29, 1911 and died in February 18, 1986. He was an important Brazilian musician.** “ Sambista carioca”, composer and expert in playing a small guitar in his youth. At maturity, he chose to

play the guitar, developing an inimitable way of playing it, where he used only two fingers of his right hand.

The work “Beyond Existing We Should Be”.

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