

Alex Garcia - a deaf-blind educator for inclusion and dialogue

By Milena Rampoldi, ProMosaik.

In the following my interview with Alex Garcia, a deafblind person from Brazil. As you already know, ProMosaik supports the inclusion of people with disabilities in society because they are an enrichment for the so called "normal" people who can learn so much from them. Here you can find the profile of Alex Garcia to get an idea about him. Alex tries to share and or disseminate the job he performs for what concerns inclusion. He won the Prize Brazil More Inclusion in 2016.



Alex is an educator for disabled people. And this is an important point for me. Since I am convinced that disabled people are themselves the best ones who can educate others and promote their self-consciousness. I asked Alex a couple of questions about himself as person with disabilities, and about how to live a positive life. And a positive life for me means inclusion and dialogue. And I also think that as journalists we have the important obligation to help people with disabilities to express themselves and to teach us life in the media.

How did you make of your “problem” a “positive potential”?

Keeping the faith and the unshakeable positions. I always had and still have a position that my fulfillment and positive state are in “being different” and not a “supposed and false” equality. The society must be alert to that. It is impossible in the human scenario, to be equal. All of us are, now, different and so we will always be. Each one of us must love and respect our similar. We must be honest, have high standard of moral and ethics, but everything inserted in our “being different”. I always say: “I have learned to be strong so that no one defeats me and I have learned to be myself so no one forgets me”.

What can people with disabilities learn from you?

They can learn through keeping their positions unwavering. I believe this would be the biggest axiom that I can teach and pass on. Being a deafblind person, experiencing all the communication barriers, it is crucial to keep my positions. The communicative barriers constantly put the deafblind people in the center of the hurricane. Being in this place, the "winds" and the "interests" are strong. In

this gale, we the deafblind people, are in an enormous disadvantage-fragility. It is at this moment that we must have a strong position to refrain the "gale" and above all, to refrain the seductive invitations that the agents of manipulation constantly offer. Keeping my positions, for sure, will give me more consistency to a new learning as in "My steps for development" - www.agapasm.com.br/english_34.asp.

When I was 14, I read Helen Keller and was so impressed, that all my life I have tried to show people that disabled people have one and the same dignity as all the others have. Do you think writing can help to struggle against discrimination?

You are right! Helen Keller was and continues to be the greatest example of a human being's overcoming concerning her condition. Keller was a deafblind person, just like me and thousands all over the world. Keller made writing a powerful tool and so have I. Yes, I believe that words and writing have an infinite power of social transformation. Sometimes we think words and writing are slow or that they seem to have no effect. Yes, it is true for the "impatient" ones, but for the "unshakeable faith" ones words and writing will seed and support hopes.

For me personally, a society is not tolerant and democratic if it does not include disabled people. What does real inclusion mean to you?

Exactly! Society is not tolerant and democratic because it is still far - far away - in issues regarding the inclusion of people with disabilities. Real inclusion for me means: Respected rights and duties that we must respect, primarily in the individual field, and then, in addition to inclusive individualities, the collective inclusion arises. It is in this sense that for me the world is turning to collapse. Society reversed the process. Today there is much talk about groups and collective as if these spheres were made of "ghosts". What is a group or collective that does not know their rights and duties (submissive individuals)? It is a subordinate group or collective. And what is a group or collective that knows its rights and duties (individual active)? It is an independent group or collective.

How do you struggle for disabled people's rights?

Keeping the mind politicized to question the surrounding reality. Writing and publishing reflections on these questions. Developing lectures and participating in national and international congresses on subjects of daily life of people with disabilities in general, and deafblind people in particular.

How can alternative journalism contribute to the struggle for disabled people?

Truly, alternative journalism is central to our struggles, as well as social networks are. I am not going to hide the reality here: Alternative journalism is what most supports us. Alternative journalism is effective. It gives us more visibility and opportunities. Alternative journalism is highly inclusive.

Conventional journalism, on the other hand, does not support us. It is very sad to open a newspaper of great circulation in Brazil and to observe pages, pages and more pages highlighting the notorious corruption, highlighting the daily of the drug dealing and the murders. However, it is rare to find something, a highlight on the overcoming and achievements of a person with a disability. This is discouraging.



Here you can find [My steps for development!](#), a guide written by Alex for other people with disabilities.

In "My steps for development" I want to guide person with disabilities - and perhaps even to guide person without disabilities on how to achieve development. As usual, in my thoughts I will tell you a truth "my 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 do reference 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 - 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, i.e., 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, emotions are essentially limited knowledge of ourselves.

Planning actions

Here we have the third step. To plan actions we must know ourselves and control our emotion. 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 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 that guiding the mean can sometimes be very different from what we expect, it is, 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.

Dreams of a Deafblind Person

I dream that one day... I will be "less" invisible for Humankind.

I dream that one day... Humankind will recover the patience it has lost.

I dream that one day... Humankind will recover its wisdom and will understand my communication.

I dream that one day... Humankind will be close again as in ancient times.

I dream that one day... Humankind will be free of prejudice and will be able to touch me without any fear.

I dream that one day... I won't be "just a brick in the wall" anymore, as Pink Floyd said in the song "Another brick in the wall".

I dream that one day... I won't need to "drink from the same water fountain" as Carl Jung, one of the founders of modern Psychoanalysis, said.

I dream that one day... Humankind will be able to eliminate the label that deafblindness is the most terrifying condition.

I dream that one day... Humankind will assume that "being alone" doesn't mean to be abandoned.

I dream that one day... I will sow the "loneliness" that deafblindness imposes us as a possible aim to be enjoyed because we won't be afraid of ourselves.

I dream that one day... I will change the pre-assumptions concerning my identity and the sentence which is currently repeated "Poor thing, he/she is deafblind" will be left in the past.

I dream that one day... Humankind will see my being and will indeed value my essence as my fight and then will say "Great! He/she is a deafblind person".

I dream that one day... I will erase the shame from Humankind's mind as a tool of controlling.

I dream that one day... Humankind will understand and value that all people are a Divine Creations: alike, however, incomplete.

I dream that one day... I will not just "exist" but actually "be".

I dream that one day... I will learn to be "strong" so that nothing can defeat me.

I dream that one day... I will be "me" so nobody will forget me.

I dream that one day... My dreams will design the future.

I dream that one day... Humankind will be "human".

In 2014 Alex wrote the book, *Beyond Existing We Should Be!*

About this book Alex wrote us: It is a book in which I write several thoughts and reflections that gave me and still give me sustenance to my development. I, Alex Garcia, a deafblind person, 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", taught me two maxims: to be strong so nothing can defeat me and to be myself so no one can forget me.

The "gaucho" Alex Garcia, is one of the most famous persons in the world, he combines three major characteristics: a Rare Disease, Deafness and Blindness. He is the coordinator of the Rio Grande do Sul Regional – a south state in Brazil - for the Baresi Institute. Specialist in Special Education by the UFSM/RS, he was the first Brazilian Deafblind person who attended an 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 to develop the first research to find Deafblind people all over the state of Rio Grande do Sul and he had, as one of his most important supporters, The Association of the Swedish Deafblind, FSDB. He is also 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 Program of Home Care to the families of Deafblind people, to help them with information and educational orientation and also medical and social referrals, the training of professionals to attend Deafblind people in their original places and also, the adaptation of these places to their needs as well as the development of special programs in schools. The 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 published a book for children: "The Big Revolution". He has never given up of his autonomy, 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, due to his overcoming story of life, chosen as the biggest of the year in Brazil. He is also an Honorary Rotarian - Rotary Club of São Luiz Gonzaga in the state of Rio Grande do Sul - RS. He was the first Deafblind Person to be an alumni at the Mobility International Program in the USA, in 27 years of the history of this organization. He was the first Deafblind Person in Brazil and Latin America to participate with total freedom, in a Training Program for teachers who deal with disabled students. It was held in the city of Cuiabá, in the state of Mato Grosso - MT. Another training occurred in Niteroi, in the state of Rio de Janeiro - RJ, the students were two educators with disabilities, a young blind girl and a deaf man. Alex also writes for the Magazine Reação and for the website Planeta Educação. He is a consultant of the Educational network Redem and the Institute Inclusion Brazil. 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 United Nations headquarters in New York.

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 to rupture 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.

The intolerance which designs the frontiers. 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 fellow-creatures. 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.

May all the "choices" be grounded on the historic contribution to the movement and not on the exchanges 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 see 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 will even cry/ and they will want to honor me/ making me a gold guitar/ but after 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 developing my work because I realize, in the handshakes and in the hugs I receive from people, the huge respect they have as well as the appreciation they offer me.

We can measure the strength of a deafblind person, through the planning he or she develops exactly for not listening or nor seeing, the planning becomes fundamental.

It is a serious and historical mistake to address disability as a whole. It is as serious as it is unacceptable. 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 person with disability to represent their peers, that are in equal condition of invisibility because it provides subalternity and submission to exchange of favors. I'm straightforward: a person to have voice and to represent others must, in advance, be free and independent to face the "normality".

Fear in a deafblind person will disturb his/her mind, guiding his/her 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 the identity of a person. A sea of doubts is cast upon us. Quickly, we are in a position of extreme disadvantage. We start having to prove something to someone.

For a deafblind person, 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 confuses guilt with shame and vice versa. In this mess called shame, a "tsunami" is formed.

Distance to a deafblind person is an enormous challenge, because all the means of communication we use are of closeness. Without being closer there isn't a chance to establish presential communication with another human being. Impatience is something terrible for a deafblind person. All the communication models we use are slower. Therefore, we need to be patient. I consider myself a shameless in the service of Inclusion. So give up! I am not ashamed to be as 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 Martin Luther King Jr. taught us when he said: "Cowardice asks the question: is it safe? Expediency asks the question: is it politic? Vanity asks the question: is it popular? But conscience asks the question: is it right? And there comes a time when one must take a position that is neither safe, nor politic, nor popular, but one 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.

Life for several times, beat me up. And in each bashing, I have learned different lessons. These moments made me realize I would have to have more attitude. By having attitude, the bashings decreased. Is it an absolute truth?

It's clear that the understanding precedes the execution. Therefore, it's necessary to be an inquirer and a dreamer Qui jote and, then, bang the spirits.

Poverty is the same as being the most invisible of the invisible. A poor person is a strange in his/her own country. Creating 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.

Historically, I refuse to accept what Carl Jung, one of the founders of Modern Psychoanalysis, used to say to us, that "we all drink from the same source." I refuse to drink from the same source. In this same source where the gags and the "brakes" are to our full development.

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 reflection.

Many leaders in the area of people with disabilities say when we touch the wound "Gosh! You seem to have hate in your heart. Your complains are hurting people. Apologize yourself!" And you apologize. Then the leader says:"You are a sweet heart." Be careful! Keep out! This leader is a corrupt one.

For 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 will a blind person represent a deaf person? How can a person without any disabilities 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 representative in the right place. I speak in this way because throughout my life, I have observed acts contrary to logic.

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 people without disabilities and people with disabilities, although there is also an unequal relation of power among the people with different disabilities.

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

Addressing disability as a whole is a partisan speech and, therefore, it is void. The maintenance of this speech will produce the invisible of the invisible. This is because this speech consigns more power to the inequality of power itself.

I believe that all people with disabilities are Human Beings. All. Deafblind ones, too. For it is very hard to be the most invisible of the invisible. It is very hard to live an uneven relationship of power that advances every day without being confronted.

The unequal power relationship "said" that we, deafblind people will be eternal apprentices. This "eternal" speech is what we must bring down.

Ensuring voice to each person is the essence of an inclusive society. So I get upset when the first question is, "What organization does he/she represent? What organization is he/she part of?" "Too much representation. Excessive "being part of.". And where are the individual rights?

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 claim to 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, legitimized by their bases. It is necessary to rethink the individual identity and capacity to self-representation.

God, to me, is not in Heaven nor in the Earth. He is not in any religion nor in any image or book. God, to me, is in our attitudes. And I am absolutely sure that in all the attitudes I've taken in my life as well as in the ones I will take, God is present in all of them! Where does this certainty come from? I have this certainty because I am alive to this day and despite all my difficulties, I wake up each morning saying; "Hi, hi, I woke up for another day of joy.

Does diminishing the stigma 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 where the relation of power is installed and consequently the tendency 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 (anticipating thinking) 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. Examples of how presupposition affects the identity- 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 persons with disabilities. Then, why always "poor"? Then, time goes by. There is always an identity being watered by the "poor guy". 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 person with disability. I'm going to be a poor guy because everyone sees me as a poor one! This is it! The presupposition won. The tool of control fulfilled its duty. The Cautious-Power annihilated the possibility of the person to become someone that could "disturb".

We have one billion people with disabilities in the world, we are the biggest minority worldwide, but just a few with autonomy. The overwhelming majority lives its 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 sure of the guilt. The shame as a tool of control acts exactly in the uncertainty. To me, it is clear and proven – after experiencing several cultures and behavior – that people with more developed disabilities, are those who are very clear about 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 people with disabilities, empower them. This is what I call "the chain of interest". Power, most of the time, chooses punctual and subordinate people with disabilities to receive jobs, status and prestige. But this choice serves just to keep them in control. Everyone knows that this practice is common today. Many of our "leaders" are like that. Power gives power to those who will be agents, to those who will not "hurt" power relations, that is, those who will not break the chain.

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.

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