working for people with intellectual disabilities
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ABOUT CONFE

Confederación Mexicana de Organizaciones a favor de la Persona con Discapacidad Intelectual, A.C. (CONFE) was founded on September 19, 1978 in Mexico City by a group of parents, professionals and businessmen to achieve a fair and decent way of life for those with intellectual disabilities and their family, promoting their complete integration into society.

Nowadays, we have 160 associate institutions around the country with whom we exchange, generate and promote an INCLUSIVE culture for those with intellectual disabilities and their family.

To achieve this, CONFE offers the following programs and services:

• Evaluation
• Early Intervention
• Parents, Professionals and Associations Counseling
• Labor Integration
• Information and Communication Center
• Counseling
• Associative Movement
• Labor Training
• Sports, Art and Recreation
• Medical, Psychological and Psychiatrist Attention

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FOUNDERS

• Sr. Juan Vidal Graell
• Sra. Luz María Saldaña de Vidal
• Dr. Fernando Quijano Pitman
• Sra. Magdalena Orvañanos de Quijano
• Mtra. Florentina González Ciprés
• Sr. Guillermo Espinosa Iglesias
• Dra. Ana María Latapí de Escobar
• Arq. Ernesto Velasco León

FOUNDER ASSOCIATIONS

• Centro de Integración Social para el Individuo Down, A. C.
• Centro de Terapia Cineciológica para Niños con Disfunción Cerebral, A. C.
• Fundación de Ayuda al Débil Mental, A.C.
• Centro de Terapia Educativa, A. C.
• Patronato del Centro de Educación Especial de Capacitación para el Trabajo, A. C.
• Asociación de Padres de Familia de Industrias Protegidas No. 1 (SEP)
• Comunidad Down, A.C.
The birth of CONFE 30 years ago, was the answer of a series of needs felt by a group of family parents united for a common cause: we had a child with intellectual disability. In that moment, Mexican society was indifferent or didn’t knew this problematic, therefore it was considered a shame an in occasions, was hidden.

We lived in a dark age in concern of the scientific knowledge of the intellectual disability. We lacked information, statistics, leaning institutions, specific treatments, including specialized medicine.

This ignorance excluded our children from society and limited their development; these circumstances motivated us to form a confederation, an association with a relative intension: to bring consciousness and sensibility to society about the needs to guarantee that people with disabilities and their family could practice their right fully and without discrimination.

CONFE was born like an organization that fought for change to modify the perception of “the others”. We have gained fundamental transformation in the society, as the way to interact and with individuals with intellectual disability.

We are clear that the struggle has not finished, therefore the importance for alliances, strengthening of links with other groups of civil society that contribute to develop a social conscience that is manifested in legislative reforms with perspective in inclusions, of equity in the opportunity of education, work scattering, sports and social development.

This anniversary is for us a motive for reflection. A social movement like the one headed by CONFE, impelled changes in human rights, in equity and justice, in changes that have strengthened the democracy in México.

We want to continue being a motor of change, an enriched confederation by a mayor participation of society, permanently transforming without forgetting our reason of being.

Today, 30 years from our creation, CONFE ratifies its vocations through its participation engaged with the Inclusion International movement and the principles of the Convention about the Persons with disabilities’ Rights to achieve the promotion of respect from the society and the government to be recognized in the International Letter of the Human Rights.

This moment is propitious to thank the founding associations, the allied ones, the personnel of our organization and to thousands of people who have lovely participated to achieve an including life.

*Ernesto Velasco León*

*President and Founder of CONFE*
Don Juan Vidal Graell,
When and where, were you born?
The 14th of July of 1934 in Mexico City.

Tell us about your childhood and adolescence.
From 3 to 5, I was in Barcelona, Spain and later, from 5 to 7 in the cities of Toronto and Montreal in Canada, and in New York, USA.

I turned 3 in Spain. As I was an only child, my father decided, something that I will be thankful all my life, to send me away from the maternal sire and to command to Spain; my parents, José and Dolores, were from Catalunya… Spanish. He wanted for me to know the customs, the family, and for that reason he sent me to a boarding school in Barcelona, so I learned to speak Catalan, etc.

My father’s business was a woman shoe factory. First, I was at school in Toronto and later, per variable periods, in shoes factories to learn the shoemaker office. Then, I start working at my father’s factory on November 1st of 1951, after being abroad since the year 47, with a great economic and moral sacrifice to my parents… being only child.

Somehow I am self-taught; for that reason I have a very rare character. All my formation was by myself; I lived alone from very youngster 15, 16, 17 years abroad renting a room, a house, etc. All this fortified my spirit.

On 51, I returned from the foreign, and integrated to the factory founded by my father. The business was growing thanks to God; later, I lost a group of companies in the crisis of ’94 and ’95. Like so many industries in Mexico… especially, the shoemaker business.

Sir, engagement, marriage, family? How did you meet your wife?
I was advisor, president, treasurer of the National Chamber of the Industry of Footwear. Following what it had seen in the US, I decided to organize in Mexico along with two or three companions of the council, who peacefully they rest… we organized in November of the ’57, the First National Fair of the Industry of Footwear. My position in that event went to take care of the governmental authorities and others more than they attended. But also I needed, somebody to be in charge of my own stand: someone with personality and special presentation. A friend recommended a woman. And this is how I met my wife… Lucha. She Afterwards, we saw from time to time and got engaged three years before marrying. That was in the year 57. We got married until 62.

We had four children: the oldest was José Ángel; José after my grandfather, who was his godfather and Ángel because he was born on August 2. And he, as you know, was really a little Ángel. For that reason, we gave him the compound name. Later, Juan Rodolfo was born. At the moment, he is active in CONFE; today he is about 41. Later, we had two girls, who already are family mothers: Montserrat, I named her thus obviously by the Catalan influence; and Lourdes, that is my very small one, who is almost 38 years old.

Is there something you want to stand out before speaking about the beginning of CONFE? Something special?… No. But, speaking of it, I must say that CONFE is equivalent to mental deficiency. Because it was a term used before. For that reason, its first name was Mexican Confederation of Associations...
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for Mental Deficient. I do not like to disguise the things. I understand, but I do not agree with the idea of the name change. A mental deficient, is a mental deficient. Point. There is no sin! I am a visual deficient! The term disability is understood by we the people who are involved; we know what we are talking about… but the gentleman at the corner, has no idea about disability.

What motivated you to create CONFE?
My son José Ángel, Pepe did. We must go to the moment Pepe was born. When one of my best friends, a pediatrician doctor, finds out that our first son had born, went to see us to the Spanish Hospital, where he was born, and had the professional sensitivity of not saying anything to us at that time. It let us enjoy those first moments. But when the nun in charge of the cradle calls me and tells me that we have a son with Down’s syndrome… my first reaction was to speak to Poncho. He arrived with an endocrinologist, Doctor César Chavarría. They checked Pepe for almost an hour. When they finished the revision, I was there in the corridor, alone… outside the cradles’ room. My wife, of course was happy in bed. Standing there the three of us, they told me everything about Down’s syndrome: what to hope and not to hope. For me, it was the personal beginning as a father of a person with Down’s syndrome.

Doctor Chavarría told me three fundamental things: “Look, you are going to pass through certain stages: First, the acceptance. As a man, you will think that it is a consequence of your forays as a single young man. It has nothing to do with it. The lady, on the other hand, is going to think that it is a problem of internal malformation. It doesn’t. Later, you will go through the adaptation stage. Then, you will walk on the street, go to restaurants, to the park, etc., and people, by morbidity or ignorance, are going to turn away or watch your son as if he was a rare animal and you’ll feel victims. Obviously, this offends the parents. It is normal. You must be accustomed to that because it is real. People are not bad. It simply happens because the society ignorance. You will get at a third stage that is the one of acceptance: Acceptance of a reality. And once you accept that reality, you will work automatically with a positive vision”.

For me, it was determinant doctor César Chavarría, and whenever I have the opportunity to talk with a doctor whatever specialty he has, I say: “It is necessary to all things by their name: If they are taking me to chemotherapy, is because I have cancer”.

The doctor also told me: “There will be persons who are going to recommend committing him, because there is nothing to do with them. But your boy is going to grow and is going to learn as much as whatever the education, you give him. He will begin to walk, to speak, and his evolution will depend on the effort of his parents and the affection he receives. Downs require much attention, like any other boy; but especially they require much affection. They are very musical, full of joy; they are the soul of the party”. And thus he was.

“Most probable is that you have more family the doctor said. After many years you are going to live the reality on which your other children form their own homes and they physically move away. However, your son always will need you, and then, if you see it from an egoistic point of view, this child will give you the opportunity of having company and somebody to take care of when you are old.

That same day, speaking with doctor Chavarría, I made my decision, as a good Mexican macho man, I left in his mother’s hands until his puberty. And so it was. My wife took care of him. She took him to CETEDUCA. She crossed 100 kilometers daily to take him to swimming class; to a normal kinder, with a therapist who came from very far away, etc. Later, when Pepe was 13 years old, she coordinated a group of three or four of his partners and took them in the light truck to fold boxes at the shoe factory. Pepe arrived and saluted me very formal. He came down, did his work, when finished, he kissed and went away.
It was at that time when a group of wonderful parents who formed the institution in which Ernesto Velasco was told my wife that it would be a specific congress on Down’s syndrome in Las Vegas; and I told her: “If you want, we go”. And so we did, along with three or four pairs. There I met Doctor Marc Gold, Professor at the University of Illinois, dictating a conference called “Try another way”. It hit me very hard. The gentleman it was hippy times, appeared with metal hoop glasses, cattle tender shirt, jeans and tennis shoes; and bearded. I told my wife before he began: “Hey, this gentleman is going to tell us about mental deficiency? I do not understand why make it so dramatic” (the place was already crowded).

He sat behind a little writing-desk on a secretary chair, those that run. He pushes himself… takes off a shoe and the sock. People could not believe it. He achieves his objective. He catches the attention of the concurrence. And then invites us to clear us and to put the shoes and the socks again. After we did it, he said: “I am certain that no one did it the same way… Find another ways! There are other ways! Every one has theirs”. Then, with slides, he showed how youngsters with cerebral paralysis mounted rays to the bicycle wheels. Obvious, based on the malformations of each one of the boys, there was a teacher who directed the movements of their fingers so they could arm them.

When finishing, I approached him: “Look, I am John Doe, I have a 3 year old son with Down’s syndrome and would love if you give me the opportunity of visiting you in your house, in Chicago”. He accepted and two months later, there I was. I stayed over for a weekend, and there, thrown in the ground like a typical American family, along with his wife who also collaborated with him in the university, we spoke long. I invited him to Mexico to give his conference that was really impressive. He accepted. And he, his wife and another doctor were in the house…

But before this… I left with the idea of granting a scholarship to ten teachers specialized in mental deficiency so that they learned his technique and became qualified by him in the US, with the obligation of enable another ten teachers in our country. Then there would had been a force: people prepared in mental deficiency with the philosophy of Gold’s project. And each one of them, instead of creating an institution or institutionalize the boys, would go knocking doors all over Mexico City, to instruct in the common industries to regular workers, whatever their specialty, in the way to treat a person with deficiency. And the teachers, as well, would teach our boys the technique. I called this idea “Program without Walls”, because instead of institutionalize them, one would leave to look for them in their house. And this is when Marc Gold arrives at Mexico.

I contracted a translator and my wife Lucha, got the Celanese Mexicana auditorium as a loan. I told her: “Invite everyone you know, so many can take good use of the effort of bringing this man to Mexico”. And so it was. There, I met a group of extraordinary people that would be the base and the later birth of Confederación; beginning with teacher Florentina González, Male Quijano and others.

Marc Gold simply act the same play of the shoe. Put it on; take it off; sock and others. When he finished, I told them: “Doctor Gold is going to be provided with accommodations in my house. Whoever wants to come, will be welcome”. During one week, a people river entered and left the house. Among them, Florentina, who obviously, was the first to come.

When Gold left, I kept the idea of going on with the Program without Walls, and mentioned it to Guillermo Espinosa Iglesias, who lent me an office at the Latin American Tower. There we began to join. In the first
session, I told them: “Gentlemen, which day of the week are we going to join? Don Guillermo lends us this office, I have secretary and she could summons us; but she won’t because if someone has to remind us of something, that means we are not interested. Schedule and I will receive you here to continue working on the “Program without Walls”. So we met every Wednesday, at 5 pm, from February to May. On of those days, I said: “I believe that more than another program, what we need is to capitalize the people who comes every week, as much as people with a technical level, and parents and to create an institution that denominates us all. All these changes, these talents that you are all”. So we must not forget to say how Confederation was born. The lawyer José Figueroa, Guillermo Espinosa Iglesias, father of a mental deficient girl and I, made the basic statutes of Confederación. It could only be constituted with people who represented legally instituted organizations and with the capacity of signing a penmanship. Therefore, the incorporation papers were signed by seven associated.

Meanwhile, when this occurred, —it was September of the 78—, My wife and I were on a business trip in Europe. Lucha always had the restlessness of compiling information, so she went to the Information Center of Barcelona. In that one occasion, I invited teacher Florentina González and teacher Gloria Cheek to come to Spain with us. We also went to Vienna, where a congress of what it was called the International League, was going to take place. On the route, we visited many institutions with different characteristics that worked with people with disabilities. All this was coordinated by the founding director of the Information Center of Barcelona.

I made contact with the League —that also changed its name to Inclusion; what does it mean? I still do not know it. I told Mr. Dybward, its President at that time, that I would like the Confederación to be a Member of the League. Then, simultaneous to the foundation of the Officially Confederación we were accepted as members of the League.

Although the League had its office in Brussels, I visited its President in Paris. He was a very important and wealthy French gentleman that told me that as a Confederation, we should use and practice all they had already done and had been beneficial. “It is not necessary to pass through the same road other people did. Use the League, that’s what it is for”.

Your vision of CONFE to medium and long term?
That it keeps on the same line. It goes well; it had his moments of crisis like any other institution. We overcame it. The founders Male Quijano, Ernesto Velasco and others decided to invite our sons to comprise with CONFE so that they would follow the initial spirit, because things are thus and the life is thus: it is neither good, nor bad, it’s just the way it is. The things require of a pursuit and there is so that it must have those feelings that created the CONFE spirit. And who would do it better than our own family? And here they are: Male’s son, Toño Diego’s and mine.

All of them are part of the Council… and obvious, there are going to be changes, the necessary ones; they are indispensable because they are done with the basic spirit which is the flame that caught that one. Then, I see that CONFE goes well.

Those that have had the opportunity to move in the world, can see the inclines, the acceptance. Either people turn around to see people with different characteristics, but with knowledge of what they are seeing, because there is much diffusion in Mexico: the diffusion that has come from CONFE, from the congresses; the contacts with different governmental dependencies, etc. Today it was a conference related to institutions with similar goals that are meeting to create consciousness. Like science itself: I am not doctor, but I am certainly the science in cancer is today very different than 30 years ago. This is a subject that must continue advancing and adapting to the moments. I see it that way, that CONFE must follow those steps, continue growing, and continue adapting itself to each one of the moments of the development of the humanity.

Going back. First of August I gave a letter to President José López Portillo, and on August 2th —the coincidence gives that it was the same day of my son Pepe’s birthday—, his Private Secretary Roberto Casillas, sent a letter to Fernando Solana, Secretary of Education, and the 3 of August to the director of Special Education,
my dear friend Margarita Gómez Palacio, telling her to help us as far as possible. And so she did: from writing-desks, chairs and others; Teacher Florentina arrived with her team that have followed others until today. Margarita made a system so that the personnel of SEP could support CONFE on its programs.

I have so many memories! It was my life.

In 1989, the idea arose to create an Institution of Private Attendance. We thought that we had to especially direct it to the solution of the finances. Such foundation would support the implementation of all type of projects and programs of diffusion, investigation and administration of the center of development for the mental deficient people. It is a foundation that had money, and that is Institución CONFE.

The ramification of a foundation of this type, and all the problems we had to face, would be impossible to number at this moment. It is enough to say that we, as a Confederation, are strongly stimulated to carry it out. That’s why we ask for a joint venture with governmental organisms, indicated through a mechanism to design on both sides, by means of which we shared its administration and necessary the economic contributions for the development of its activities.

Government and society must join and work together, that way, we are going to achieve it.
Transcendental Achievements in 30 Years of Trajectory

Patricia Ramírez Flores y Alin Valenzuela Cabrales

• CONFE, from being an idea, happened to be a reality, and has been expanding during 30 years.
• It is considered a representative Institution of Intellectual Disability in Mexico and worldwide.
• It maintains an associative culture (network) with national representation.
• It is a referring and advisor in matter of qualification and labor integration of people with intellectual disabilities.
• It impelled Law initiatives that concluded in the addition and correction of the Civil and Penal Codes of the Federal District (Mexico City).
• It comprised of the Coordinating National Commission that made the “National Program for the Well-being and the Incorporation to the Development of the People with Disability” that for the first time included the subject of disability in the National Agenda.
• It participated and drove proposals of Law that concluded in the integration of the reference “People with Disabilities” to our Carta Magna.
• It is member of the manufacturing group of experts of the theoretical methodology frame that concluded with the inclusion of the subject of disability in the XII General Census of Population 2000.
• It participated actively during the processes of following the Laws in the Federal District: for People with Disability; Organic Law of Public Administration; Sport; Environment; Transport; Urban Development; Bottom of Support to the Administration of Justice; for the Operation of Mercantile Establishments; of Promotion for the Economic Development, and the Intra-family Violence Prevention.
• It obtained the application, on the part of the Secretariat of Public Education, of the “Manual of Direction for Parents of Children with Special Educative Needs with or without Disability” directed to teachers of regular and special schools of the country made in 1997-1998.
• It participated with the National Program of Integration and Fortification of Special Education of SEP (Secretariat of Public Education), and the Direction of Special Education of the Federal District.
• It participated within the framework of evaluation of the advance of educative integration in Mesoamerica of the Mesoamerican Congress the Inclusive Education, realized in Costa Rica in 2004.
• It collaborates in the Operative Committee of the badge Inclusive Company of Secretaría del Trabajo y Previsión Social (Secretariat of Work and Social Forecast).
• It participates in: the Program of Academic Transformation and Fortification of Normal Schools (Teaching schools), for the creation of the new Curriculum for the Initial formation of Professors of Special Education of the country; in the design of the National Program of Human Rights for presidential term 2007-2012, in coordination with the Secretary of Interior; with the DIF, in the tables of work of the Promotional Council for Integration to the Development of the People with Disability of the Government of the Federal District (year 2000 to the date); with the National Council to Prevent Discrimination (CONAPRED) in proposals in the matter of health, legislation, work and education in order to harmonize the Mexican legislature with the Convention on the Rights of the People with Disability.
• Member of international organisms such as Inclusion International (II); Grupo de Rehabilitación Profesional (GLARP); Instituto Interamericano del Niño (IIN); Asociación Americana sobre Discapacidad Intelectual y del Desarrollo (AAMR); Canadian Association for Community Life (CACL); Confederación Española de Organizaciones en favor de las Personas con Discapacidad Intelectual (FEAPS), among others.
• In Labor matters, it has integrated up to 160 people with intellectual disability in socially responsible companies. Through its congresses, factories, talks and publications, have informed, spread and sensitized on the subject of intellectual disability.
• It has the most complete library of the country on the subject of intellectual disability.
• To the date, and in collaboration with the network of association’s affiliates, it has taken care of and redirected to other institutions more than a million people with intellectual disability.
To talk about the future is to think about so many things, to have a thousand dreams, to set one self on a comfortable armchair and write down the notes of intentions you’d like to make in the month, the year… or in life itself.

Future, is sometimes frightening but also exciting, it cheers up the spirit, mainly when one is sure that the future will be great and prosperous, intense and of much work, surrounded by sacrifices along with satisfactions, no doubt. For this reason, when I ask myself about the future of CONFE I get emotional, I think about my brother Pepe and my father; I think about my other brothers and sister, but above all, about my mother, who gave her life for this cause and this dream which means 30 years of work and achievements. This way, when thinking about the future I see it like way of loosen ideas that will threaded, that will be weaved with the effort and responsibility of many people:
Continuing as an Organization with ethics and firm values, like solidarity, fairness, philanthropy, joint responsibility, tolerance and the common welfare, will turn our Mexican society on to a really including, respectful of the differences, without any discrimination, one.

May fortified CONFE so that it’ll be considered as the guard organization, to guarantee respect of the human, civil and political rights for people with intellectual disability.

May CONFE be an institution that promotes and develops new paradigms by means of scientific, educational, technological and statistical research, to be the avant-garde organization in the subject of intellectual disability, as well as of progress, changes and advances in its field, in order to propose preventive and formative programs.

May CONFE assume the challenges in order to achieve that the Convention about Rights of the Persons with Disabilities becomes a day to day reality; eliminating from our society all forms of discrimination…

a society where the person’s condition is first.

May the Associative Movement be the main and strategic axis of CONFE through which the forces and wills of the affiliated associations work together towards a common aim and coordinated work, nation wide.

Make it possible to form alliances between Government and families to modify policies and structures which hold back the development and full exercise of the rights of people with an intellectual disability.

May CONFE foment and fortify the families, professionals and the people with disability’s gather, to organize at a national level the associative movement in bunds, extending the impact possibilities and support the affiliated associations’ growth and their institutional strengthening.

May CONFE propose strategic actions which translate into public policies to guarantee well-being and improvement of life quality for persons with intellectual disabilities and their families.

May CONFE stimulate the formation of groups of people with intellectual disabilities who constitute themselves as self solicitors to express their ideas and have they listened to.

May CONFE socialize and stimulate between the affiliated associations, with renewed effort, the programs of Early Intervention, Qualification and Labor Integration, the work with families and the programs of Parents Supporting Parents.

May CONFE be an auto sustainable institution with continuity in time and work of fortified, responsible and co responsible associations.

Today is the moment of redoubling efforts, fortifying ties at all levels. Today is urgent to renew enthusiasm and hope, to harden the goals that will turn CONFE into a solid and stronger organization.

A great family founded on the values inherited from the founders who gave CONFE their great spirit of commitment and generosity.
Since the moment I got involved in CONFE’s cause, turning into part of my familiar history, I understood my father’s words defining the birth of this confederation like a moment destiny had prepared to interest us all, for one reason or another, in persons with intellectual disability.

I’ve seen during three decades the concerted effort of many families and friends so that CONFE grows day to day, always adjusting to the different moments which marked the ways they have assisted people with intellectual disabilities, practically throughout the country. The leadership CONFE has today is not a mere accident, we have constructed it, but, without a doubt, there’s still a tall of challenges to fulfill.

Although our institution has promoted the formation of social networks through thirty years, there’s still so much to do; we must develop a new associative culture that responds to the ever changing needs of the population and to the standards of quality, professionalism, innovation and social responsibility that civil associations require at present.

This concept of social responsibility extends to companies, it is necessary to include them in our projects and to entice them so that they practice the concept in their structures and policies, impelling the incorporation of people with disabilities to the communitarian development; thus, we will be promoting the improvement of their life quality.

The new paradigms that we wish to promote demand a greater effort from CONFE, a constant self-evaluation of our actions, processes and, mainly, of our impact. We require developing new knowledge, using technology and the different sources of intelligence and communication in order to stimulate the empowering of associations, families and people with intellectual disabilities.

For this reason, CONFE must renew the commitment, not only as a gratitude gesture towards my parents and other founders, but as a promise towards the people who for thirty years have looked for solutions to their needs.
CONFE, FAMILY AND DISABILITY

*Mtra. Claudia Leticia Peña Testa*

For some parents it is unforgettable the moment when they receive the medical prognosis about the disability of their child. Those words generally go with terrible and hopeless predictions.

Since that moment, the life changes, it becomes a path full of fear, tears, anger, and different emotions that sometimes stay there during all our life.

For some families, it is the beginning of a long search for different diagnosis, extraordinary treatments and promising prognostications, which often wear out the economical, social and spiritual situation of the family.

During this process, some members of the family provide help and support to parents whilst some members do not. So, what happens to the family? How does the family live the fact that a member has a disability?

When we talk about disability we should talk about family. Specially, because that person is part of one, so, it means that it’s a challenge the whole family should face. But the question here is how the family faces this task. As an opportunity to strength ties and develop tolerance? Or as a painful situation that causes the family rupture?

One of the factors that may cause that situation is the way the family lives this process. We refer to an isolated way that increases anxiety and limits the chance to know more about disability and the opportunities that a person with a disability has.

However, when a family has the opportunity to talk about its fears and worries with more families that share the same situation, it might create a healthy environment. This is what I have learned since I have been
I remember the first day I visited CONFE. When I was waiting in the lobby, I saw a group of young people talking and laughing, of course they were happy and it seemed that they got along well with each other. When they saw me, some of them greeted with a smile. In that moment, I realized that I had been suffering about my daughter’s future for no reason. Suddenly, I became aware that she would have the same opportunity that young people have had to be happy and to have a life with friends, a job, and similar activities that most people have.

I also remember that during a meal in a meeting, a young and elegant waiter who was trained at CONFE asked: “Would you like more beans” or the day a group of young people who have different disabilities performed a play. Also, the day a boy from Kadima, gave an exposition about the rights of people with disabilities.

I should also mention, the moments when I have talked to different moms and I have learned from their experiences.

CONFE has had many successful achievements but one I want to emphasize, is that they have joined many families that have shared the strength to fight for a better life condition for the persons who have disabilities.

Congratulations CONFE!
Maria is the youngest of my three children, she’s 10 years old. When I knew I was pregnant I felt very happy, because I always wanted to have three children. But, because of my age, doctors recommended me to take an amniotic liquid test. The exam resulted positive: my baby had Down syndrome. Since I didn’t know what I was facing, at the same time that I felt happy of having the third child we always wanted to have, I felt sad cause the disability they told me she’ll have. This situation made my pregnancy very disconcerting; I felt happy, but at the same time I cried a lot.

However, when I first saw Maria my whole world changed and I promised myself not to cry anymore. Instead of worrying about I needed to take care of her, who actually will need me more than anyone else. I was full of doubts, but the principal one was how I was going to tell my sons that their sister had Down syndrome. I didn’t know how they would react. During the first visit that we made to the pediatrician, he encouraged me, and when I went out from his office I told to my children. I think that I was more afraid than I should be.

Since the pregnancy, when I was told about my daughter’s situation, I began to gather information trying to learn a little about the subject. When Maria was 10 days old I started to look for places where she could take therapy. I visited a school for Down Syndrome children but I wasn’t fully convinced to take her there. Thirteen days after she was born I found CONFE, where I was wonderfully received. I decided that it was the right place for Maria. In CONFE they made her an evaluation and twenty eight days later, she began with early stimulation.

Gloria, her first therapist, told me that my baby needed to make her exercises daily and twice a day, in addition of going to CONFE three times per week. When Maria grew up and was old enough to go to school, the three visits to CONFE diminished to two. Searching a school was not an easy task, since I always thought that Maria needed to integrate into society, but in Mexico schools hardly receive children with disabilities. Although, some people told me Montessori system could result ideal for my case.

Looking for schools with this system I went to NAN Children’s Home (Casa de los Niños NAN), that is near to my house, but Maria was too young to being admitted, so the “Guide” recommended me a Nursery room more suitable for younger children. After two years in the Nursery room, Maria went into the Children’s Home, and when it was time for her to enter to elementary school, I realized that Maria needed little more boundaries and my search began again.

Seeking for a school wasn’t easy: systems in schools where they were willing to accept her were not convincing enough for me, since more than integrating them, they alienate disability children in separate groups and they only include them in some
classes; others are too expensive, and other ones
don’t accept Down Syndrome children but have
great percentage of children with some kind of
disability. My sister, who is a pedagogue, suggested
me to go to the school where I worked as teacher
before my pregnancy.

I arrived to the Escuela Evolutiva Tajín, where I was
welcome by the Founder and Principal, who asked
me about my children, especially about Maria. It was
then when I told her that Maria was the reason of
my visit, since I was looking for a school that would
receive her. Her spontaneous response was: “of
course! You know that in this school we accept every
kid, since our goal is to always get the best from
them, no matter what”.

In Escuela Tajín, Maria began pre-primary and
she has advance through third grade. I can tell that
my daughter is well accustomed to her class mates,
teachers know her and everyone loves her. She
knows very well her school, and she knows how to
move around, despite her speaking language is not
fully developed, she can achieve tasks and make
herself understood in her own way. It’s true that
academically, she’s a bit slower than the others, but
thanks to her teachers’ dedication and other kids’
support, she’s learning, little by little, how to read,
write and about the subjects of primary program.

Her tests and exams are oral, and according to
her knowledge. At home, she works on especial
homework for her and she receives extra reading
and writing support.

Furthermore, she has always received all sort
of therapy: visual, psychomotor, language and
academic. During some time, she also attended
swimming lessons, because this is as important for
her safety and her parents, and it’s something she
enjoys quite much.

Since two years ago, Maria attends catechism,
getting ready for her First Communion ceremony.

For the family, Maria represents something
marvelous. She awoke a
very especial family union
making us participate with
her on everything she does. We have learned a lot;
day by day we have new
experiences and learn to
value many things life has.

Our patience has
grown and every day we
have more love to give.
It’s all thanks to María.
RODRIGO

Liliana Escobar Córdova

Rodrigo was born 27 years ago and that was the beginning of this story.

Rock, as we lovely name him, was eagerly expected with love and illusion by his mom and dad.

I remember his face when I held him in my arms for the first time, his eyes closed, his little hand opened to life and the best of all, his well-formed little nose. I hugged him, filled his face with kisses and thanked God for the blessing of becoming a mother. I didn’t realize at that moment that this hug will join us together to share the amazing adventure of this life.

Rock grew up as a “normal” baby, and I didn’t know that since he was born he was suffering a disease called ITP Idiopathic Thrombocytopenic Purpure which was the main cause of a deep intellectual disability when he reached two and a half years. I think that the diagnosis is not important by now, what really matters, is what comes after… this is when the story begins to take shape.

It was very hard for my husband to accept that his first-born had a disability; this fact was the origin of many differences on his education, but fortunately with love, we have overcome to it. It was hard from the beginning: first the diagnosis, then from one specialist to another. This made me realize that persons with disabilities in Mexico are put apart, even though our efforts, there is a lack of coordination between the multidisciplinary teams to follow the case. At the beginning of the stimulation of my son I was very lucky to meet a Paidopsiquiatrist who gave me the opportunity to work as volunteer in the project, which nowadays is an option for persons with intellectual disabilities. That was the beginning of being part of the intellectual disability world. I spent endless hours learning language and physical therapies. Finally, when Rock was three, he was accepted in a Montessori kindergarten with the support of a therapist who weekly supervised his evolution in school. We had a lot of joys and sorrows, because our son was rejected from parties and certain events, but with enthusiasm and tenacity we have created a different world.

It was very important for me that Rock could have the same opportunities as the other kids, so we took him to swimming classes, to the Scouts where I found greathearted people; all afternoons I invited some children from our neighborhood to play with him, we went to the park, played in the playground, made parties for his birthday, Halloween, “posadas”, etc, so he turned to be a very sociable and lovely little person.

My husband and I were very happy to see how our little kid was growing. Five years later his brother Bernardo was born. He used to say that he wanted to learn a lot to be able to teach his brother. Two years later a beautiful baby girl was born and we named her Natalia, and she also became a “teacher” to his brother Rock for good and for mischievous tricks too.

When Rodrigo was 11 years old, we decided to leave Mexico City due to the polution and we settled in Querétaro, where we started to suffer because we couldn’t find a proper school for him. We found two choices which were pretty small schools that finally disappeared. Painfully my son had to go back to his previous school in Mexico for nine more months together with his father, in order to have his stimulation therapy. I stayed in Querétaro with the difficult task of starting a new option for him in a city where I was a complete stranger.

It was so hard to knock at doors and be rejected; I had no idea how to start the project taking shape in my mind: I wanted a place where my kid and many others could have an option, a chance of living with dignity,
lo normal es un trato normal

looking for a solution to discrimination... where could I find it? God is so great that he made the way. On February 6th 1996, in a garage that somebody lent me, with my son’s didactic material, started the activities of a Civil Association called “Nuevo Mundo en Educación Especial, Qro. IAP” and on May we became “Institución de Asistencia Privada” (Private Assistance Association). Rock came back from Mexico. Up to now, we have had a lot of successful stories to tell, a lot of smiles inside our heart from our 92 beneficiaries.

We have worked really hard and here are some of the goals we have reached:

The acquisition of a state category in Tae Kwan Do for people with disabilities.

The donation of a plot of land of 4000 m2 on which we’re now starting the construction of a building which will include: Training Center, Gym, Swimming pool, a mall and a shelter for 30 persons.

We also are studying CONFE’s proposal to become a Job Integration Agency in the state of Querétaro.

We are trying to attain the necessary support from the Ministry of Employment to be able to accept CONFE’s proposal of getting scholarships for our beneficiaries to train them in the first “Piñatas Workshop” in order to become, along with DIF (the government office that aids less favored families), furnishers of this item.

We have evening workshops with the support of SEDESOL (Ministry of Social Development) from Mon. through Fri. from 4 to 6 pm.

We assist our beneficiaries all week days from 8 am to 4 pm with a personalized program for each student.

We are working with a population between the ranges of 12 to 60 years old.

There have been rough moments as a Founder and General Director of this Institution, but I wouldn’t change it because I have also had a lot of satisfaction smiles from my son and from our students as everyday they can feel they have a choice for a dignifying life.

Since the beginning of “Nuevo Mundo”, we have faced a lot of different challenges but the founders have not given up to the dream of having a place for these boys and girls where they can keep on growing in all aspects of life.

Many people involved in this dream, specialists and professionals, have offered their support, knowledge and enthusiasm being and important part of this team.

Nowadays, “Nuevo Mundo” keeps walking, looking forward to get to more beneficiaries who require a suitable shelter and space, That is why our challenge, in 12 years, is to build definitive facilities with big rooms and workshops to allow them to learn a job; rooms for social activities and recreation; areas as a second home, they can take charge of themselves. This and many other aspects are the result of pedagogic studies in which the Academic Model of Nuevo Mundo is based on, to look for a fair treatment for persons with disabilities.

In Nuevo Mundo, we are certain on breaking the social paradigms established about the “different” people, and we are starting a new culture of acceptance and social involvement to people with any kind of disability, through education, love and comprehension so they can become part of the society and of the productive system, too.

“Nuevo Mundo” is the place where young people and adults with intellectual disabilities are taken as accepted and loved persons.

We created a space for development, interaction and belonging among the persons with disabilities, their relatives, professors and specialists where they can find choices of a life full of dignity for those whose special circumstances can be integrated to the world of formal education and job.

1 Founder and General Director of Asociación Mundo Nuevo en Educación Especial Querétaro, I.A.P.
A MOTHER’S TESTIMONY

Leticia Álvarez García

30 years ago, we gratefully celebrated CONFE’s foundation, as an authentically, rights and dignity of persons with intellectual disabilities, defender institution.

Although it had the globalized world pressure-lacked of the pressure of old values, such as: dignity, honesty and helping others-. It turns out to be a heroic act to dare for and continue a social work such as CONFE has done until now. Of course CONFE’s members of the board are not heroines or heroes in the romantic style. No! But, they certainly are dedicated and brave people with a great sense of responsibility for work. They don’t only go on believing in the persons with disabilities’ potentialities, but are convinced about them and are convincing others –as me- to fight for this cause, too.

In recent years all of Mexican society had some dire moments, but those were particularly difficult, for our dear CONFE, while representing us proudly nationally.

The first of these events was the International Inclusion Congress’ synthesized document “Listen to our voices” in which, CONFE performed a very important roll, hosting all the assisting countries representations.

Personally, I had never participated on such an important congress before, so, thanks to CONFE, I shared experiences with a lot of persons with disabilities from around the world, who bravely climbed up to the tribunes to defend their existence, seeking for respect and job opportunities, just as worthy as any other human being.

If my conviction was already clear and firm and I showed proudly the equality flag for all persons with disabilities, ever since this encounter, my compromise is now personal. From my working place, in the community where I live in, and every time I get a chance elsewhere, disability will be an objective to fructify.

The second event was, with no doubt, the approval of the Persons with Disabilities Rights Convention, in march 2007 (promoted by Mr. Gilberto Rincon Gallardo, who just passed away), a document that requires all our working, enthusiasm and willpower to learn about it, spread its knowledge and above all defend it and make others respect it. May it be a reality for millions of people with disabilities and their families.

The third one, to end with a flourish, is the CONFE’s 30th anniversary of permanent and fructifying work as an authentic defender of rights and dignity of people with intellectual disabilities.

We couldn’t have a better panorama! As Chilean singer Violeta Parra would say: “gracias a la vida, que me ha dado tanto” (thanks to life, that has given me so much)

I would add: “thank God for allowing me to be part of this great locomotive that CONFE is. Thank you for giving to families with a child with disabilities, a different sense of life”. We have learnt to see opportunities to pull out the best of ourselves, of difficulties, we’re many times surprised, because we didn’t believe ourselves so strong and that we could survive trying.

I’ve been in contact with CONFE for about 5 years now, during which I’ve worked and shared with different associations; all of them, enthusiastic institutions we shared experiences with. Until now, all meetings with these associations have had a lesson, of humanistic and professional nature. We always finish them with new experiences, and, above everything, with recharged will and enthusiasm to improve the life of those we work for, including my own daughter.

Congratulations along with my gratitude are for CONFE, for the trust they put on me. One of the most valuable supports in this institution is their personnel and board members: honest and brave professionals who will always encourage us with hope, backed on serious and supportive work.

My gratitude also for all the fellow team members with whom I have enjoyed work and experiences. Thanks for sharing without selfishness your professional knowhow. Thanks for your supportive will at our members work.

How fortunate I am, because God placed in my hands my daughter Daniela’s life! Despite all pessimist and obnoxious prognosis of some doctors, my
daughter not only went on, but, along with her, the entire family learnt to have a different vision of disabilty, not the “bad luck” or “disadvantage” one, but the opportunity to be better human beings. How fortunate I am, because I accepted the reality life posed to me, because, despite my fear and sadness, faith was stronger and I was able to look out and find the support my daughter needed.

Thank you Lord, for placing in my way, such sensible and generous people, with whom I have shared 30 years of so many life stories.

Thank you Lord, for making me stronger, even without knowing. For being sensible to others’ pain, for knowing how to cheer us up, and for the fact that you work with rejected or scorned children and youth.

Thank you Lord, because on hard and dark times I have learnt how to invoke your name and try to follow your example: give part of our lives for those who need it.

If there’s something I learnt in CONFE is that giving makes you stronger; sharing renovates; and working for others, creates new friends.

CONGRATULATIONS CONFE FOR THESE FIRST 30 YEARS!
Jesús

Emilio Álvarez Icaza

My wife Raquel and I are parents of two girls and a boy: Guadalupe, 12, Luisa, 10 and Jesús, 5 years old.

Jesús case is an emblematic case of love: according to doctors, psychologists and therapists, he has a generalized disorder of autistic spectrum development that has meant discovering a very impressive world.

The bases of our relationship are love and affection, and have not only got deeper, but have also made us learn. Jesús is a child who with his smile, his affection, and his daily life has challenged us to build new understanding codes.

During the first two years, we saw several features that called out our attention, we didn’t know what was happening. In evolution terms, we found out that when compared with his sisters he had another rhythm, ways of doing things, when he sat up, crawled, when we taught him how to climb the stairs down backwards. At some moment we were dubious if that was because he couldn’t hear us and we went to specialists that made him tests. A part of the challenge was that we didn’t know what we were confronting. Fortunately, nowadays there are better conditions, treatments, professionals in Mexico that help parents. Denying things never solves problems. We took promptly and timely action.

We started working along with other parents, we were able to learn from their experience how to educate our son with affection, but also how to communicate it. Jesús had ADHD, he had trouble imitating, it was really hard for him to look into our eyes and generate an interpersonal relationship. We had to learn how to connect with him, for example, with soap through the glass or making games to paint our faces.

It’s a matter that involves the entire family. Therapists have given us elements not to generate conditions for underdevelopment, not to spoil him but to help him to evolve with his own capacities and conditions. He has friends at school, he draws, learns, he talks more and more and interacts. He learns every day how to hold his impulses, because he was pestering his sisters when they cuddled their mother.

Every day he learns more and more how to contain his violent impulses. For Jesús the physical contact is different, for him hugs and kisses are different. They are magical experiences of love. The presence of Jesús in our lives has been a great blessing, big joy. We wouldn’t have been able to stand all of these moments without the magical reserve that love is, without tolerance, without learning. Who despairs and gets angry looses.

A family becomes actor for the change of persons with a disability whatever his/her condition may be. This is what has to be accomplished: that we all include persons with disabilities, whichever it may be: auditory, motor, mental, visual, or other type, we all need to aspire to everyone to have mobility freedom and dignity.
My name is María Cruz Díaz, I’m José Andrés Morales Domínguez’ mother. In my son and my family’s life, CONFE has been and still is very important, because for my son, it’s home. He feels understood and supported in CONFE, do you know why? Just for being part of this institution; he has grown as a person, and goes on, being an active part of the working process in which he participates right now. We, as his family, are proud of him, because he is adjusted and accepted by our society.

CONFE has provided Andrés with the tools he needed for his adjustment. My family has also contributed actively, giving him instruments of basic support such as comprehension and respect on whatever he wants to do.

We thank each and every person that has contributed with CONFE, and had the vision of constant growth in every aspect of life, all of these to benefit persons with disabilities.

I am proud to have Andrés as my son, a person with intellectual disability, who has given me the opportunity to grow as a person, as a mother and, through him, to meet a lot of people.

Thank you CONFE holeheartedly… With you all through.

1 José Andrés Morales Domínguez started his capacitization at CONFE in 1988. He actually works in our gardeners team.
IN SEARCH OF OUR BOY…

Margarita Orta

This is the narration of what has been a very arduous, heavy, painful, and expensive path; but also full of love, satisfactions and frustrations. It is a path of three years and a couple of months between the scientific and the mystic, between dreams and nightmares; a trail full of surprises, trying to find an answer that explains us why our boy “Is not the same as the others”.

Everything began at home, when Maury turned three years old—who in his first years was an apparently normal boy, but that did not behave like the others nor develop the same way in certain activities. This was a matter of preoccupation for our family, but his dad encouraged himself saying: “Anytime now this small one is going to wake up…” But the truth came afloat in school, when they gave us his first reports, and realized something was wrong with our boy. Maury couldn’t pay attention and was most of the time isolated from the group; he didn’t tell when he wanted to go to the bathroom and generally he presented an impediment in his development.

Maury from July 2005 to August 2008
1. San Juan del Rio. A presentation about Indigo and Cristal children takes place. They evaluate Maury. Diagnosis: he’s the most Cristal boy she has ever seen, but it will be difficult to control his energy at this age.
2. UNIR (therapeutic center). Diagnosis: Spoiled and overprotected. They suggest therapies; after three months the therapist does not know how to handle Maury and very annoyed yells to me: “If you don’t put limits this will not work…” The result is not reliable.
3. Center of Therapy and Ozawa Language. Diagnosis: Probable Asperger. The neurologist diagnoses Maury autism because of the way he grabs a ball. He suggests an electroencephalogram to identify the level of brain damage.
4. Cuban neurologist. Diagnosis: DDAH. He suggests daily color therapy for an hour, with a cost of $300 each session. After a month, Maury is blocked and doesn’t want to go to therapy anymore.
5. Reiki. Diagnosis: Extra-sensorial faculties. She suggests Reiki sessions for the whole family.
6. Center of Tonatíco Attention. Unable to diagnose, since they hadn’t had a similar case. She suggests different learning strategies.
8. Neurologist. Without diagnose because there are no specific signs of a specific disturbance. He says that he will interrupt therapy, without asking for an electroencephalogram. He orders an X-Fragile study in search of a genetic cause.
9. Bach Flowers Remedy. Diagnosis: Worries about his new life. She prescribes Bach remedy to relax him, avoid fear and help him to pay more attention.
10. Medium. Diagnosis: He is a spiritual Master. She suggests to consciously go through every event the family has gone through in the past months.
11. Equine Assisted Activity. Diagnosis: Lack of vestibular coordination. The exercises will help him to pay more attention, to diminish the anxiety and to improve coordination. He advanced favorably, but they stopped providing these sessions to us.
12. Dianetics School for DDAH (Cuban psychologist). Diagnosis: Maury does not live in real time. His emotional area is the most affected, this is the reason he is such a sensible boy. He does not have DDAH and it’s necessary to handle it with special therapies as well as orthomolecular treatments.

13. ILCE (his dad enters with Maury). Diagnosis: Intellectual disability. They make the diagnose before running any tests; they order psychometric examinations, and asks us to come back with the results. They ask Maury three questions, which he does not answer, and they determine that they can’t treat him.

14. Spiritual visit. Diagnosis: A spirit wants to hurt Maury and our family –in individual ways. He suggests us to go with a chaman.

15. Limpia Sessions. Maury absorbs all the negative energy, and he fears the dark because of what he sees. We went to some sessions, but it was difficult to maintain Maury calm.

16. Neurologist. Without specific diagnose; there are no specific symptoms of any syndrome. He suggests game therapy to regulate his anxiety and obsession, besides electroencephalogram. Normal results come back.

17. Paidopsychiatrist. Without diagnose. He only says that Maury lives in a different reality. He prescribes Prozac. Maury gets worse and we suspend it. Prescription drops for the hallucinations and some therapy. No results.

18. Information of Indigo and Cristal children. I send an e-mail, she answers that she is not qualified for spiritual effects. She recommends someone else.

19. Chaman in Argentina. I contact him by e-mail and he answers with a complete description of our situation. He requires some photos of the family and tells me that the process will be very slow and difficult. It is necessary that Maury settles on this earth so he does feel comfortable in it. He suggests some changes at home and school.

20. Kinesiology. Diagnosis: Blocked. Maury lived a very hard situation when he was two, and because he couldn’t express it, he is still stuck in it. He carries problems of somebody whose name begins with “J”.

21. Center of Sensorial Integration. Without safe diagnosis: It can be Perkins syndrome. They suggest that Maury goes to a normal school three days a week and two days with them. There was not much advance, because he copied behaviors of other children with various disabilities.

22. Circle of emotions. Visual and corporal contact. At the moment, Ivonne is our family therapist, but the main character of this story can’t be included yet because the dynamics are too complex for him. Even so, her support has been transcendental in our familiar process.

23. Association for children with DDAH. Diagnosis: DDAH. Without knowing Maury, and only by an interview with us, the psychologist says that there are things that he will not be able to do; that there is no need to keep searching, that we have to accept Maury’s situation. She recommended a Paidopsychiatrist, one that never gave us an appointment.

24. Kinesiology. Diagnosis: Emotional and Karmic Barrier. Maury is blocked by an event that he lived when he was three years old, from which he has not been able to move on; he catches the emotional state of his mother and that his emotions were stuck in his stomach. He suggests Chakra alignment; Maury did not feel much confidence and the therapies were painful, since the doctor “had to accommodate his stomach that was all scrambled”.

25. Domus. Diagnosis: Generalized upheaval of Development (TDG) in “the nonspecific” heading. This was the closest to our reality at the moment. It means that he presents immaturity only in some areas. They suggest working with a Shade in his regular kinder and that he takes therapies at home, which resulted to be very expensive and therefore, nonviable.

26. Congress of Autism and TDG. These boys present heavy metals in their brain and urine, as well as candid in the stomach. This is the reason that these organs don’t work properly; they can also be allergic to gluten (wheat) and casein (derived from milk). Probable causes: mercury in amalgams and vaccines.

27. LINCA. The specialist, certified as DAN (very few in Mexico), recommends a combo (urine, serum of the blood, excrement, hair). Normal and very expensive results.

28. SCOPRIRE. Diagnosis: Maury is slightly immature. This school is focused to children in recovery. Something very important for us was a diet “without gluten or casein”. We decided to change Maury there, besides we followed the diet at home to be “sharing in common”. After three months of tests the same director recommended us to work in the behavioral and structural part, since Maury does not have allergies to the derivatives of the gluten and the casein, nor candid in the stomach.
29. Angel Channel (Crayon of the magnetic system). When talking with the swimming teacher about Maury’s perceptions, he gave us information about what Maury told him in class and suggested this option. Crayon is an organization that works in balancing the world, chooses some persons to do it and has the faculty to enlight those who need it. We took it for a time but he decided to quit.

30. Magnet Therapy. They proxy Maury and by spiritual magnets they implant them to me and to his grandma. There was no change.

31. Paidopsychiatrist. Diagnosis: TDG. He only treats adolescents. He suggests an excellent doctor (the first one we saw), because Maury gives signals of different characteristics that don’t fit in a single diagnosis, and he says he will send us information of another excellent doctor.

32. Fundacion Pasos. Diagnosis: Insufficient sensorial and behavioral integration in certain areas. It was based in Domus results; It is not justifiable to make another evaluation.

33. Neurologist. Diagnosis: TGD. She orders a magnetic resonance to discard any deformation of the bones of the brain (we are still in that, §). He identifies an upheaval of strong anxiety and suggests a very light medicine, as well as familiar integration, school support, exercise and therapy. The most important thing is the structure, while he understands the changes in his surroundings. She comments that the hospitals in Mexico do not have a structure support to children with this upheaval.

34. Study of the X-Fragile syndrome. Fundacion Pasos decides to run the test. After two weeks of anguish, the result is positive. We feel sadness, but simultaneously tranquility to have a diagnosis and the possibility of following a line of precise work. My daughter and I agreed to take the test to know if we were carriers. I turned out positive, my daughter didn’t take it. Something within me is not comfortable: my son does not cover some characteristics. A medical friend suggests we look for a second opinion since these studies have an allowable error.

35. Another geneticist suggests a different technique to confirm the diagnose: saliva sample.

36. Meanwhile, when consulting it with his neurologist and informing her of Maury’s possible X-Fragile, she says that he would be the first X-Fragile boy without intellectual disability she knew.

37. After two weeks, the result comes back negative. In order to confirm which result is the most reliable one, we must take the “Southern Blot” technique; two or three times more expensive than the previous, but very certain. This study takes place in Mayo Clinic in the USA.

38. They run the “Southern Blot” exam to Maury. Result: NEGATIVE. We are calm. Now we keep searching what causes Maury to have different and so special conditions.

39. Magnetic resonance and cariotype; two studies that are suggested to provide more information to find the root of Maury’s immaturity, in order to help him. We are still doing these tests.

At the moment, Maury is six and a half. He attends a regular school with a support teacher; he also takes sensorial and behavioral therapy in Fundacion Pasos, and swimming lessons. He is very charming, sensible, loving and handsome boy (this is how he identifies himself). Maury has advanced favorably at his own pace.

On the other hand our family is affected by these situations and from time to time we feel desperate and helpless; these feelings seem endless and unbearable; but we also feel calm when we see our little one go to sleep with his little angel face. When we see his conduct and the way he speaks, it makes us think we still have a long way to go.

Everyday we ask God to guide our way, provide us with patience, to give us strength to support us, to place us in the proper place to continue with the aid for this special being that surely will teach us many lessons in our lives and whom we love with the same intensity as his sister, who endorses and fortifies us in this process.

Finally, we want to finish this narration being thankful to everyone that has helped us in this journey: grandmas, uncles, friends, doctors, spiritual advisors, etc. A thousand thanks to all. And Maury, for being here.
It has been 30 years since CONFE was born; and when I think about these words, my daughter Edith comes to my mind at the age of three.

In those days, I received the information of a national encounter of parents of children with intellectual disabilities, that would take place in Mexico City.

It was then, that I was sailing on a sea of uncertainty; barely something was known about intellectual disability. The centers that offered their services to our kids, where in the worse conditions and forgotten by the Ministry of Public Education. The most part of the teachers were improvised and our kids had to wait until they turned 6 years old, to be accepted in one of them.

During this time I had no approach to any other parent in a similar situation, so, besides of feeling lost, I also felt alone.

Coming back to the first encounter of parents. I took my guía Roji (Mexico City Map), I got over my country woman fears and headed to Mexico City and got there. I can’t describe with words –because I think they’re not enough- what finding thousands of parents resorting to, looking for, wishing for a light in the dark, meant to me.

From that encounter and on, a star illuminated my soul and those of thousands of other parents. Mrs.Latapi, Mrs. Aurora Cárdenas and other whose names I don’t remember, along with a team of parents and professionals, that understand our sorrow, holding hand one with another, felt the warmth of identity that would give us strength, that challenged us, that exhorted us to fight for our children, and that, at the same time gave love and comprehension to each one of us.

I’m certain that after being there, our life would never be the same. I’m sure that no one came back with empty hands; personally I received an incomparable gift: I never felt alone again.

Some of the founders are gone, and I raise my eyes to God telling him: you have taken those who you had sent us to guide our steps; they accomplished the mission you gave them, and we know they are with you, satisfied, watching that the seed they planted has germinated, giving plentiful fruits.

CONFE, I’m thankful with God for Your existence. You are the star that I saw to be born and now you became a comet that with its flow covers all the associations of the country and therefore for our children and all the persons with intellectual disability.

Happy birthday CONFE!
And may you live for other three thousand years!

1 Attends The Hellen Keller School in Oaxaca, Oax.
Analyzing the "Seven Reasons Against the Interpretative Declaration of the Mexican Senate to Article 12 of the Convention About Persons with Disabilities Rights".

Carlos Ríos

Article 12. Equal recognition as a person before the law:
1. The States Parties confirm that persons with disabilities have the right everywhere to the recognition of their legal personality.
2. The States Parties will recognize that persons with disabilities have legal capacity in equal conditions as others on every aspect of life.
3. The States Parties will adopt pertinent measures to provide access to persons with disabilities to the support they may need on the exercise of their legal capacity.
4. The States Parties will ensure that in all the measures related to the exercise of legal capacity adequate and effective safeguards are provided to prevent abuse complying with international law related to human rights. These safeguards will make sure that every measure regarding to the exercise of legal capacity respects the rights, will, and preferences of the person, that there may not be any interest conflict, nor improper influence, that may be proportional and adapted to the circumstances of the person, that may be applied shortly and that may be subjected to periodical tests, made by an authority or a competent, independent and impartial legal organ. The safeguards will be proportional to the level these measures affect those rights and interests of such persons.
5. Not damaging what disposed on this article, the States Parties will take all the pertinent and effective measures to guarantee the right of persons with disabilities, in equal conditions as others, to own and inherit goods, to control their own economic matters and to have access in equal conditions to bank loans, mortgages and other financial credit modalities, and will watch over for the persons with disability, so that they don’t become deprived of their goods in an arbitrary way.

Article 12 content:
The contents of article 12 (Equal recognition as a person before the law) are directly related with the subject of equality and no discrimination.

Equal recognition before the law means that persons with disability may be part of different legal acts such as receiving a heritage, participating in goods transference acts, request bank credits, establish a marriage, etc.

This text represents one of the biggest advances on the treaty and was product of a long struggle of persons with disabilities organizations to convince the States to its inclusion.

Many persons with disabilities, in different countries, are deprived of their rights and goods, when declared "incompetent", "unable", "insane", etc. This way, different kinds of abuse are committed, when other person assumes full representation of the person with disability.

For many of these persons (especially with intellectual or psychosocial disability), have been deprived of inheritances and goods that, in a legitimate way, would belong to them.

Article 12 reflects a change of a substitution of the person with disability model, to a support of this person one, in relation with their condition and needs. This substitutive model is associated in many legislations...
with legal mechanisms such as the one named curatela (process through which the goods of adults with disabilities, considered “unable”, are submitted to the protection and guard of a representative namely curator) and interdiction (to the legal process through which a judicial authority declares the absolute incapacity related to certain persons, considered “disabled” to take charge of themselves and their patrimony).

A big part of the advance reflected on article 12, is expressed in the safeguards that take place to prevent abuses against persons with disabilities, who require, effectively, a representative’s intervention, in case such a person has difficulties or limitations to take his/her own decisions and this is proven. This measure’s porpoise is to protect the person with disability and to guarantee, there are no interest conflicts and the rights, preferences and will of the person are fulfilled, should a representative is used.

**Interpretative Senate Statement:**

The United States of Mexico formulated this interpretative statement, when ratifying The Convention on the Rights of Persons with Disabilities:

The United States of Mexico’s Constitution, in its 1ᵉʳ article, establishes that: “(...) It is forbidden all discrimination motivated by ethnical or national origin, gender, age, disabilities, social condition, health condition, religion, opinions, preferences, marital status, or any other that may attempt against human dignity and which objective is to cancel or diminish the person’s rights and liberties.”

When the United States of Mexico ratified this Convention, they countersigned their compromise in favor of Mexicans with any incapacity’s rights promotion and protection, for both, those in national territory and those beyond.

The Mexican State reiterates its firm compromise of generating the conditions that allow every person, to develop integrally, and to exercise fully their rights and liberties without discrimination.

Consequently, with absolute determination to protect persons with disabilities’ rights and dignity, The United States of Mexico interpret article 12’s paragraph 2 of the Convention, in the sense that in case of a conflict between the mentioned paragraph and national legislation – in strict compliance with the pro homine principle – the norm that confers more legal protection, safeguards the persons dignity and ensures physical, psychological, emotional and patrimonial integrity of the persons will be the one applied.”

**What is an interpretative declaration?**

It is a statement a State can make, while signing, ratifying, accepting or approving a treaty or when adhering to it, through which the interpreting way of a text or a concept is set, the treaty included. In human rights conventions, interpretative declarations not affecting recognized rights may be presented, but there may be others which would limit their enjoyment or scope.

A concrete example in the convention is an interpretative declaration presented by Spain, when approving the treaty. In this European country, the expression: “lengua de signos” (signs language), to name what Latin Americans call: “lengua de señas”. According to the fact in which the convention the second name was taken, Spain fixed an interpretative declaration that points out that it will be read “lengua de signos”, there. As may be seen, the declaration does not affect the contents. It is therefore, an inoffensive interpretative declaration.
Another entirely different case would be if an interpretative declaration about legal capacity is included, indicating, for example: the expression "legal capacity" referring to the "legal capacity to flaunt rights", and not to the "capacity of acting or doing". This declaration inclusion would be dangerous, because it may have practical consequences concerned to rights limitation. In this sense the Mexican senate interpretative declaration is dangerous because it is incompatible with the object and purpose of the present Convention.

So, it has to be considered as illegal and consequently invalid.

**Analysis of the seven reasons against the Mexican senate of article 12 interpretative declaration:**

**First.** The lack of democratic legitimacy has to be denounced, because the Mexican state modifies discretionary and unilaterally the Convention’s nature through this statement.

**Second.** Mexico’s attitude is contradictory because it promoted the Convention in 2001, and at the moment of adopting this Convention, makes an interpretative declaration that limits its range and its projection sphere.

If Mexico supports the worldwide biggest minority formed by the persons with disabilities it can not open the door so that other States also restrict persons with disabilities rights in other parts of the world.

**Third.** The legal capacity is the aptitude to be the rights and obligations holder. It’s a *conditio sine qua non* for the rest of these rights because it is the base for the exercise of all civil and politic rights.

If the legal capacity is denied, the rights consecrated in the Convention are denied as well. This is why the declaration is incompatible with the nature and essence of the Convention which objective is, on the contrary, to promote and protect the human rights of the persons with disabilities.

According to the article 4 of the Convention, “none of the human rights and fundamental recognized or existent liberties is restricted or revoked”.

**Fourth.** Article 46 of the present Convention declares that: “no incompatible with the object and the purpose of this Convention reserves will be allowed”.

When the treaty forbids the reserves to the total dispositions or part of them, such unilateral declaration formulated about these dispositions constitutes an interpretative declaration and not a reserve. But, if the interpretative declaration excludes or modifies the legal effect of some dispositions of the treaty in its application for the author, it should be considered as an illicit reserve.

Article 19 C) of Vienna Convention indicates about the rights of the treaties that: “a State can formulate a reserve at the moment of signing, ratifying, accepting or approving a treaty or in addition to it, unless the reserve is incompatible with the object and aim of the treaty”.

Hence, the Senate’s interpretative declaration should be considered as an illicit reserve and thus legally invalid because it affects the object and essence of the Convention.

**Fifth.** The Convention only indicates that persons with disabilities have the right to legal capacity. The article says that persons with disabilities have the right to legal capacity – not distinguishing between enjoyment capacity and exercise capacity. Where the law (the Convention) does not distinguish, there should not be distinguished.

According to the declaration, “the United States of Mexico interpretation for paragraph 2 of article 12 of the Convention, is in the sense that in case of a conflict between the paragraph and national legislation – in strict compliance with the pro homine principle – the norm that confers major legal protection, safeguards dignity and assures physical, psychological, emotional and patrimonial integrity, should apply”.

That is why it is incompatible with the Convention’s objective, because national legislation makes difference between enjoying capacity and exercise capacity.

**Enjoyment capacity:** to be the holder, the titular of certain, determined and concrete acts. The capacity of a person to do something. Regards the determined act and regards who is the person allowed by the law to do it.

**Exercise capacity:** Competency to carry out by one’s own the enjoyment capacity. Meaning: that it is an aptitude to be able to perform an act personally and directly.

The code (art.2) establishes that if you don’t have the right or enjoyment capacity for something, you simply
don’t have the capacity, in a general sense. Meaning that if you don’t have the capacity for what the law stipulates, that right simply doesn’t exist. The code takes the capacity as an attribute.

**Sixth.** Article 12’s paragraph 3 adds that measures should be taken to provide persons with disabilities access to the support they may need in their juridical capacity exercise.

Even though the Convention, doesn’t expressly exclude tutelage, meaning, the total will of the person with disabilities substitution, for certain cases; it privileges the autonomy and independent life exercise, as autonomy for normative design of the juridical capacity support model. It gives priority to a model that maximizes capacities by means of the intervention of assistants that help the persons with disabilities to take their own decisions, and not one that substitutes those decisions for the “dignity, physical, psychological, emotional and patrimonial integrity of the persons safeguard.”

But, through this declaration, the Senate chose a tutelary and protectionist model, which is a paternalistic schema that confers “better legal protection” to the person with disabilities, and consequently limits the full exercise of the juridical personality and the juridical capacity. It is, then, incompatible with article 12 and with the rest of the Convention because their rights and liberties can be contradicted.

The mexican tutelarismo is legally unpresentable because it contradicts precisely the object and purpose of the Convention.

For example, according to the interpretative declaration, it will continue being legal to take away the children from a mother or father with a severe motor disability, invoking their “incapacity to obligate themselves” (article 450, fraction II, of Distrito Federal Civil Code) And it permits that the capacity to be lost. But, according to the Convention, the State is obligated to establish the needed measures to provide access to the support that persons with disabilities may require for their juridical capacity exercise, and this way the Mexican State would have to support this person for the exercise of the parental custody, not declaring their “incapacity to obligate themselves”.

**Seventh.** According to the Mexican State the persons with disabilities can’t be guilty (because they’re not legally capable) and will not be submitted to a penalty. Nowadays, the immune to persecution subjected to security measures may spend years in the prison’s psychiatric block.

But, it’s false because the penal imputableness is different from the civil capacity. Rights can’t be conditioned to the obligations. In fact, otherwise than what today happens, the Convention will obligate the executing authorities through security measures to do periodically revisions to leave with no effect the imposed measures that varied the motives that helped to decree them.

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1 Criminal lawyer and Member of the Comisión de Derechos Humanos del D.F. (Human Rights Commission)
In intellectual disability cases, support should not only come from an institution, professional or the State through public services or philanthropy. The kind of support I mention, are the every day kind, from the family, school, authorities and the community, they are more often not provided, mainly, for ignorance and lack of will to dwell in this responsibility; as a society, in fulfilling an inclusive environment with the necessary support with no limits or discrimination to the disabled person.

Therefore, we reiterate the need to educate and create a conscience that the disability problem is not the person enduring it, but the social surroundings.

- Develop values by caring for others, such as solidarity, respect, good will, tolerance and compassion.
- Create public policies center in widening capabilities and generate opportunities.
- Facilitate integral human development.
- Sign liaisons with State Governments promoting co responsibility.

THE PEOPLE WITH DISABILITIES’ RIGHTS CONVENTION, promoted by our country, signed by the United Nations Assembly on December 13th 2006, countersigned by the Republican Senate on September 23th 2007, entering in action from May 3th 2008 as a part of our legislation, is an international instrument which confirms and widens the rights of people with disabilities in judicial grounds.
Mexico signed this convention formulating an interpretative statement due its rights, just after specialists in the matter (constitution experts) read the document and the mentioned statement, determining their approval with this reserve.

The constitution for the United States of Mexico—Our Major Chart—, in its first article stands over the rights and obligations of the Mexicans with no lack of their condition.

The people with disabilities needs differ from one another by being unique and non repeating persons. Therefore, the needs will always be different, same as are the solutions. So the needs for protection Trial for the persons with intellectual disabilities, has been solved by our laws, deriving from the conscience taking of our congressmen and people of great sense of humanism, aware of their defenselessness and how vulnerated their rights have been.

To promote the interdiction trial for those over 18 years of age to the end of designate a tutor or legal representative; redact a will even though there are not goods, and to name a testamentary tutor when our children are minors and also endure intellectual disability, even when they already are under tutelary care; name curators – in charge of watching the tutor performance along with the familiar judge, who also legally declares the interdiction estate, and of the Local Tutelar Counsel; just as foresee the possibility to form a budget to allow the fulfillment of their basic needs,

1 Asociacion Tutelar, I.A.P.
THE VOICE OF SELF ADVOCATES REGARDING THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Robert Martin1

The Convention on the Rights of Persons with Disabilities talks about living in the community. I attended every session of the Ad-Hoc Committee that wrote the Convention. I spoke out time and time again about the abuse that was happening to children and my friends in the institutions. Few really wanted to know – they put what I said in the too hard basket. Some thought I was overstating my case.

The film “Bulgaria’s Abandoned Children” is a wakeup call to all those who doubt that abuse happen in institutions. Who was not moved to tears as the horror of life in this institution unfolded on our screen?

Those who justify institutions will always tell you this is an isolated case –that the institutions they know are not like that. In my experience abuse happens in every institution. I have been castigated by both parents and professionals in the past for saying this.

I was almost run out of town in one of our cities when I said this about their institution that was closing. It took many years for the truth to come out and this was followed by some large payments to people for the abuse they suffered in the institution.

I want to read you something I have written for the Taskforce over the past few days.

“How can we talk about children being valued in our families and communities when we still force some children with intellectual disabilities to live in institutions?”

Many children in institutions continue to be treated in the most inhuman way. Their lives have become the topic of prime time news. I am really sad when I see what is being done to them in the name of so called care.

We have made little real progress and it is tragic that our fellow human beings are being treated in this way.

We do not need to be locked away in institutions, we have committed no crime –our only crime is that we were born with a disability. If others without an intellectual disability were treated in this way society would demand that their human rights were protected.

However because it is happening to those of us with an intellectual disability everyone turns a blind eye and lets the abuse continue.

Our families need support so they can care for us when we are children with an intellectual disability. It is this lack of support that forces too many families to abandon us to the institutions. If our family cannot support us then we should be placed with another family who is willing and able to help us.

Our right to speak for ourselves is all too often denied to us. Some say only our family can speak on our behalf. This must change as given the right support, particularly from our family; we can all learn to make our own choices and decisions.

If we do not have a family then others with an intellectual disability can help us to be heard. As people with an intellectual disability we understand our world best. It is this understanding that gives us a unique perspective as to the needs and wishes of our friends with an intellectual disability who are still to gain their voice”.

“I believe Inclusion International is about advocating for the rights and welfare of all people with an intellectual disability and their families. When I see what children are expected to endure –lying on a bed with hardly any clothes– no one to talk too– not being able to feel love or give love– I...
lo normal es un trato normal

ask what is the world coming too?
The children looked so malnourished; one girl who was 16 looked like a 6 year old. We do not treat animals in this way.
It is time for us to talk to each other about how we can move forward. How we can work together to stop the abuse and prevent children still to be born from being abused in this way”.

Our Message to Inclusion International
When we are segregated from society by being placed in an institution we are institutionalised for life. We may leave the institution but the institution never leaves us. It will remain as part of our life forever

It will affect the way we see our family and how they see us. It will shape the way we see our community and how our community sees us. Our experience will never go away, our bad memories will never go away —our feelings of rejection will never leave us. We will always be afraid.

We want Inclusion International to become our champions. We want every person who is part of Inclusion International to join us in our fight. We want you to use your influence and power to:

1. Stop any child from being placed in an institution —children have the right to grow up in families, not be locked away where they can be abused and deprived of their most basic human rights.

2. Help those who are in institutions to leave. This includes both children and adults who have been forced to live in an institution through the decisions of others.

3. Ensure that governments understand the meaning of the Convention on the Rights of Persons with Disabilities.
In particular:

• Article 12.- Equal recognition before law. This article guarantees that every person has the capacity to have rights and to exercise those rights. In effect it denies others the right to force a person to live in a particular way. It takes away the right of professionals and families to decide a person is to live in an institution.

• Article 19.- Living Independently and being included in the community. This article guarantees a person the right to live in the community. It also means that a person cannot be forced to live in a particular way to obtain the support and services they need.

• Article 24.- Education. This article promises that all children will have the right to an education in an inclusive setting. Inclusive education leads to inclusive communities. Children placed in institutions lose this right even though it is protected by the Convention.

On behalf of the Taskforce I ask that the Council of Inclusion International considers this paper and our request for support.

1 Council member, Inclusion International, Self Advocate
LABOR LIFE: INTERVIEW WITH DANIEL QUIROZ, FROM THE PROGRAM “LA PRIRINOLA GIRA EN LA RADIO” (THE PRIRINOLA SPINS IN THE RADIO)

Interview realized by Sandra Escañero Granados

ABOUT YOU
Complete name, date and place of birth?
My name is Daniel Alonso Quiroz Dufau. I was born on April 1st, 1981 in Mexico City.

Your parents name?
Miguel Quiroz Patiño and Maria Eugenia Dufau Alvarez.

Tell us about you relationships: friends, family, couple?
Well, I don’t have a couple now; I had one few years ago but not any more. About my family, I think it’s pretty good they have always tried that I am more independent and not to see my disability as one bounding, as a… no, you are a disabled person and you can’t do this. No. On the contrary. I have always been supported by them, and when I’ve had stumbles, my parents have always been there for me to give a little push and to tell me I can.

I have a brother and two sisters: the oldest and my brother have their own homes. The youngest, my sister Karina, lives here with me and my parents.

What studies do you have?
I finished Elementary School. I don’t know if I am going to study High School in an open system.

LABOUR LIFE
When did you want to start working?
Well, since the beginning my family has wanted me to be independent, that I can do things for myself; with a little bit more of problems, a little bit more of work, of course, but to be able to do everything by myself.

How old were you when you had your first job?
Well, that started when I was 18, 20 years old. One day my dad told me: “You know? I am going to teach you how to look out for yourself on the streets”; and I started that day, thanks to a man who worked with my father as messenger. We went together everywhere: walking, by subway, bus, and that’s how I learned to manage on the streets.

Do you have problems getting a job?
Yes. Businessmen and companies in general, put barriers because they do not know how to work with intellectual disabled people.

I went knocking doors to get a job, I was interviewed, everything was perfect; but when I asked them if they were ready to work with a person with intellectual disability, things changed: “Look let us think about it and we’ll call you in a week —they said”. But it never happened, I went several times to look for the person I had talked to, to see what was happening and I found out that they weren’t there, or had gone to a meeting, or went for lunch.

The thing is that they were never there and they never answered my calls. But I have not stopped knocking doors.
What kind of work have you done?
I’ve worked as messenger, sold car batteries, I was at a Cinemark, at a laundry: Nowadays I work at La Pirinola and at a place where they sell credit cards; not as a salesman, but supervising that the sales are well done.

How did you get this job?
One of my father’s friends knows Jorge, one of the telemarketing enterprise associates. Told him about me, so we had an interview and decided to hire me. The first day I got to work, I wore a suit. When he saw me, he said: “Hey, what’s with that suit? Formalities out. I don’t want you to come here wearing a suit; dress as you always do and that’s it”. He also told me “Don’t let anyone offend you. Not even me”.

How did you get to be a supervisor?
I started filling documents for the Counter Department. As they discovered I could do more, I got promoted.

What about La Pirinola program?
I got to La Pirinola radio program, the place where I work now, eight or ten years ago, by a video workshop that was near Coyoacan. This workshop was organized by La Pirinola, a civil association that has worked with art and disabilities for 13 years.

What did they do at this workshop?
We were kids with intellectual disability and were given a video camera for us to record whatever we wanted. We made a little story; we recorded and created it. Then, on February 14th, we went to Coyoacan Center asking people what people celebrate on that day; if they knew who San Valentine was and start playing with the camera.

Who invited you to join the radio program team?
Lourdes Silva, who is the program producer. I met her at the workshop eight years ago.

Look, when quit the laundry, operated of a hernia in the spine. As soon as I was Ok, I went to Cancun with a group of partners from CONFE. When we came back, I started looking for a job.

One day, my mother said: “Hey, they called you from La Pirinola, they said if you are interested, there might be a job for you”. I went to see Lourdes, who told me all about the radio, and that’s how I started on May of the 2006. So I’ve been here for two years. The program will be four on November or December.

What do you like the most at work?
I conduct right next to my friend Zitlali, and make the script. I am scripter. What I like the most about La Pirinola, is to sit in front of the microphone and think that although I am not been watched, there’s a lot of people listening. In the marketing business, I have lots of friends who like me, and I can relate to other people. I like to be able to do my job.

How do you manage being in two jobs?
I attend La Pirinola on Fridays; Saturdays and Sundays only for a little while; and at marketing, full time, 9 to 6 from Monday to Friday.

What do you want to communicate the people who listen to you?
I want to talk loud to the parents, to teach their children to be independent, not to keep them in a glass box and leave them there; on the contraire, they must tell them “Come on, go” and help them to be independent”. Because they don’t know how nice it feels being a person with intellectual disability, to work, to manage oneself on the streets, interacting with other persons, and, the day there is a party somewhere, not to depend on my parent’s or my brothers to see if they want to take to me there.
Is there any section for parents or you just say what you want to communicate?
There is not a special section and I haven’t said it, but it is one of my purposes on radio: to communicate the parents to help their kids to be independent and help them to have an independent life.

What sections are there?
There’s the News made by Javier Estrada. He has breed Autism; he records and edits the news, and sets the music. In fact, he runs all the news by himself. There’s another section called the Gyroscope, where they invite persons with intellectual disability to talk about their daily life. For example, now that we are in the Paralympics, Zitlali, my partner in the program, went to CONADE (National Sports Council) to interview some of the kids that went to Beijing to the Paralympics. So we have been interviewing kids in Paralympics.

On this section, we always have a guest with or without disabilities, but always related to it. For example, today we had people from the National Polytechnic Institute that work in the biomechanics and prosthetic area. The appliances are made for persons who lack a part of their body.

Which one of the sections do you like the best?
The Gyroscope, because I meet new people, I see what they live, their daily life, what happens to them, what worries them. I like having a lot of chats, to meet people, I seek chats with anyone.

How does the people you relate with, inside and outside of work, treat you?
Good, very good, they treat me like anybody else; I think that’s the way it should be in any enterprise. Bosses, working partners, everybody should not treat persons with disabilities, as an invalid or a disabled. They should think and say “We are all equal here, and you are going to work. Of course that depending on your capacity, depending on the faculties you have, is the way you will perform. But anyway, you are going to work here with us too and you are going to be one of us. You are not going to be the person with disability that works with us”.

Were you in the 2007 social development contest?
Yes. It is a contest organized since two years ago, by the Universidad del Valle de México (UVM); this is the second year I participate. They convene young people from 19 to 29 years old that have innovating projects to help society. So my boss Lourdes tells me: “Look Daniel, I got this from the UVM. What’s up, are we in?” And I said “Ok, let’s do it”. But we accepted because we wanted to know what was all about. There were 400
and some applications and 15 were going to win 25 thousand pesos and I was one of the lucky winners.

I introduced myself to people, and explained what La Pirinola Spins on the Radio is. During a week, very important people gave conferences about money. They said “…yes, we are going to support you on your project, but I need you to work harder on it” and they had ideas. It was very interesting.

**What were the subjects on the conferences?**

There were a lot of associations, like the one from the Bank of Mexico. As there were projects on disability, they took specialized persons in disability projects or field projects, hygiene projects. There was a journalist who coped very well with the media.

The Contest result was on February 21st, 2008 at the Anthropology Museum.

**An anecdote from Daniel’s father**

At this contest, Danni represented La Pirinola program; they only chose 200 participants. Most of them were senior students from different universities and the rest had already finished. One week before the awards, there was a very emotive detail: The 15 finalists were got together with the purpose of giving them some help with their projects. In one of those a very important Conference man started asking the boys if they had finished College, or if they were University graduates; there was Danni’s turn, so the gentleman asked: “and what about you? And Danni said: “No, I haven’t”. The man insisted: “But you are almost finishing College, right? At this moment, he had realized that Danni gave in conferences, etc. And Danni answered: “Not really”. And there he went again: “What do you need to finish it? And Danni said: “Well, I have to do Secondary and High School…” The man was astonished by the fact that Danni had only studied Elementary School. It was a very eloquent detail, a very emotional one. And after all, the prize awards were very good.

At short and long term, which are your goals? What do you want to accomplish as an individual?

I want to be more independent. Depending on my capacity, I am going to set more goals, and although I lack of economical independence I will not to be afraid of being alone.

**What are your labor aims? Which is your goal?**

Stay in journalism. I want to be a journalist and to communicate. To communicate what I feel and to support parents in whereabouts childhood, because childhood is a very difficult stage, because parents say before the kid is born: “My son is going to be these or that”, and they think he is going to be the best, and when the day they realize their son has a disability, that day the family sinks, and many times in that sinking, the father ends up walking away from his family, which luckily is not my case.

For example, my mother talks to me about what they told her: that I wasn’t going to walk. Or I’ve had cases in which somebody tells the parents: “Do you know your son is not going to live for a long time?” These are the cases of Down children and I know some of them that live 40 to 50 years and they are still there and the parents didn’t pay attention to the doctors that said “you know what? Your son is going to die”.

**So your principal concern or interest is parents?**

First of all, parents. They need a lot of support in the childhood stage of their sons. I also want to talk to adolescents so they try harder and be motivated.

**What institution do you stand for?**

I was almost eight years in Mariposa Blanca, a civil association that works with intellectual disabled persons. Light or hard, they also work with persons with physic disability. What we see here are workshops, and they teach you to be independent. There are cooking and sawing workshops.
What did you do at Mariposa Blanca?
First, I was a student. On Monday, I had pastry and on Friday cooking. After some time, SEDESOL gives Butterfly a place outside a subway station and I start working for Mariposa selling pastries, donuts, etc.
I also taught kids how to be a money collector and everything about selling. I was paid 300 pesos and I had a scholarship, it was another benefit I had at Mariposa. Unfortunately, there is no Labor Agency at Mariposa; there was a day when I said this is it. It’s all I can give in here.
Danni was ahead from his group so they made him a professor —his father says.

Do you know what self-advocator means?
No, they don’t do that at Mariposa Blanca.

ABOUT CONFE
Do you know CONFE?
Yes, I know it. Well, I don’t know it as a worker, but I know it because of the camps.
How did you get to the camps?
Mariposa Blanca is an associate. In 1999 was my first camping, there I found out that going without my parents was different and fun.

Do you think camping is of any use?
It helps the kids, because if your parents don’t come, what are you going to do without them? You have to do things for yourself; they teach you daily hygiene, to keep your place clean. They are very fun.

ABOUT THE CONVENTION
What do you think of the Interpretative Declaration?
I think that in some cases is good, depending on the disability. For example, for an autistic or a boy that finds difficult to speak, like a Down, could be good. In other persons I think not, depending on the disability and the disability level they have.

What do you think about the Interdiction Trial?
Yes, I know it. I think the same: it depends on the disability level. For example, a kid with severe cerebral paralysis is never going to be 100% independent.

CONGRESS
Have you ever been to a congress?
Yes, to the World Congress of Inclusion International that CONFE made in Acapulco. I went there as a reporter from La Pirinola. I got in. In fact, I remember a girl with Down syndrome from Pakistan. They didn’t let her study in her country, and his parents had the opportunity of sending her to study in the US because she had disability; this girl surprised me.
I also met, the President of Mexico —Vicente Fox Quesada at that time. I went as a reporter of La Pirinola, I had my recorder, I get close to him and I tell him: “Hey Fox, an interview”. And he answers: “No, I can’t now because I have another commitment, but I can salute your program” and I tell him “Ok” I take out my recorder and I have Fox’s voice in my recorder! It was cool!
I also interviewed the Acapulco’s DIF Director, a physic disabled person. That man was something! I remember he defended disabled persons’ rights in his entity.

Do you think congresses help People with Disabilities?
To tell you the truth, yes. Because you get to know new things that they do in other countries and we don’t. And there’s when we start struggling to bring that goal to our country. For example, in Spain they do a lot to support disability, they worry a lot, but in the other hand, Pakistan they don’t give anything.

And how do you think Mexico is doing?
We are not very good, but we are not bad either.

Do you want to say something else you regard as important?
Well, the parents must let their sons fly. That’s the principal subject in a disabled person’s life; that they help them open their wings and let them fly.
The signing of the Convention on the Rights of Person with Disabilities (CRPD) on March 30, 2007, and its coming into force on May 30, 2008 were cause for great pride and happiness for persons with a disability and their families, but not yet cause for a huge celebration.

The formation of the broad consensus that created the Convention on the Rights of Persons with Disabilities – between governments, disabled persons' organizations, organizations of families of persons with disabilities, development Non-Government Organizations, and multi-lateral institutions - was marked by heated debate and compromise on all sides. The Convention is a landmark document because it marks a paradigm shift, from seeing persons with disability as “object” of charity, medical treatment and social protection to seeing them as “subjects” with rights, capable of making decisions about their own lives. For Inclusion International, it marked a huge success in our lobbying efforts.

Inclusion International had several priorities during the negotiation of the Convention, and was successful in having all recognized in the final text: the recognition of the role of families; the right to inclusive education; the right to live and be included in the community; and the right to legal capacity. Self-advocates from all over the world helped to convince governments and other disability advocates of the Inclusion International perspective.

While most of the debate on these issues was with governments, the question of whether the Convention should recognize the role of families led to heated debate within other disability organizations as well. In its simplest form, the debate was between advocates of families of persons who have an intellectual disability, especially those with the greatest needs for support – who argued that families need to be there to represent those who do not speak for themselves, and persons with disabilities whose experience had been that their families had tried to make decisions for them, often against their will.

The compromise was to include the following text in the preamble: “Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.

This text is consistent with the overall Convention in having as its goal the “full and equal enjoyment of the rights of persons with disabilities”, but it also recognizes that families can have a role in promoting those rights, and may need assistance in order to do so.

What is the role of the family? And what support do they need to play that role?

In the case of children, the role of the family is paramount. The Convention embraces a social model of disability, and certainly the family is the social bridge for the child with a disability to the world. But the family of a child with a disability is more than that. In most countries, most support to individuals with a disability comes from the family. In the case of children, parents, especially mothers or often sisters or grandmothers provide most support. In the case of adults who have an intellectual disability, the need for such family support may continue lifelong. In the case of adults with other disabilities, that support role may shift from parents to spouses, partners, or their own children. In Mexico, research shows that 80% of all support received by persons with an intellectual disability comes from family members (Inclusion International, 2006).

Families also band together to create supports in their communities, such as education, vocational, and recreation activities. Family–based organizations also play an important role in advocacy for the rights of their disabled family members.

However, the impact of having a family member with a
disability can be great, usually not because of the nature of the disability, but because of poverty; the unavailability of needed services for their children; the stigma associated with disability; and rejection from health care professionals, educators, and community members (Inclusion International, 2006).

In Kazakhstan, 80% of fathers are reported to abandon their wife and family on the birth of a child with a disability (Asian Development Bank, 1998). The situation is similar elsewhere. Often a family member must give up the opportunity to earn income in order to provide needed care for their child, and families also must cover the additional disability-related costs such as extra medical care, technical aids, transportation, etc. This is especially true in poorer countries, but families in wealthier countries feel the economic impact as well. The economic pressures coupled with the time pressures of caring for the family member with a disability means that it is often very difficult for families to engage in the organizations that can advocate on their behalf or work to improve supports and services.

So families need support to compensate for the additional costs of having a disabled family member, and they need supports so that they can be good advocates, and support their disabled family members to advocate on their own behalves.

Sometimes, it may be more important to provide financial support to a family than it is to provide a direct service to an individual with a disability. For example, the government of Panama is making subsidies available to families of persons with a disability so that the family can start a small business and thus escape from poverty. A World Bank supported initiative in Ethiopia provides employment to family members of persons with disabilities with the same objective. Many families have had to abandon their children to institutions because of lack of support. The Convention calls for a refocus of resources so that instead of building up services that break families apart, support can be given to make families stronger.

The commitment in the Convention to the right to inclusive education and the right to live in the community can help to make families stronger. When a child does not participate in an inclusive setting, there is more risk that he or she will not develop the relationships in the community that will lead to life of full community participation. In addition, when parents must spend countless hours fighting for supports for their child, there is an emotional, social and even impact on the family, as such advocacy efforts often come at the expense of hours contributing to the family income. Similarly, the right to live in the community requires that supports be given to families in order that they can in turn support their family member.

One issue that Inclusion International thought had been won in the negotiation of the CRPD was the right to legal capacity – that is the right to make decisions, with the necessary supports. However, ironically, Mexico, the country that first proposed the Convention at the United Nations and which played an active and positive role throughout the negotiations, has ratified the CRPD with a limitation on the right to legal capacity. Confé and others are working hard to reverse this decision, but until that happens, and as long as other governments limit the rights outlined in the CRPD, we cannot truly celebrate.

1 President of Inclusion International
Latin America and the Caribbean countries, the sub region of the Americas, have a great debt with Canada, especially with Canadian Association for Community Living. A moral debt that has its origin in 1993 with the Partnerships in Community Living Project which took place in several countries of the Americas, and which was sponsored by CACL, the Canadian Government, and the Interamericana Institute for the Child.

This event gave us the first context and opportunity in our countries for reflecting together and placing goals and actions in the context of human rights for persons with a disability and their families.

With this experience we learned also the importance of having inclusive practices in partnership among people with intellectual disabilities, families, professionals and government representatives in order to build a better world for all, to build societies that recognizes and accepts diversity as a fundamental part of social coexistence. This represented a fundamental basis for many people with a disability, for many families, professionals and organizations in our region in order to promote and defend human rights.

How could we forget the Seminar that took place in Guatemala, when we were reflecting together about the recognition and respect of human rights for persons with a disability while outdoors the soldiers were standing with their guns waiting? That day we showed our strength and cohesion as civil society, as people with a vision, with an ideal: to build a society based on equity, justice, equality and interdependence. A society that ensures a better living standard for everyone, without discrimination of any kind.

In the contrary of what it has been usually interpreted, Latin America is not a poor region. If we just overview its natural resources, we may confirm its enormous richness; if we analyze the economical resources that are being used to pay the external debts, we may be surprised; if we look at the list of the world’s richest people —men in fact— in Forbes magazine, you might be astonished to find that
most of them are Latin-Americans.

No, ours is not a poor region. Poor are the majority of the people that lives there. Ours is a rich region with poor people.

We live in a world characterized by huge inequities; and our countries in Latin America are the best examples of it. Poor and rich people live apart, in very different universes within the same cities. We can not forget that these inequalities are getting more and more profound every day, and those poor countries, due to differences among levels of education; professional training and investments have very few opportunities to participate in the global economy.

Hunger, illnesses, violence, wars and constant violations to human rights are the worst diseases of humanity; these are having great negative impact in huge sectors of the global population.

Only in speeches and Treaties we celebrate diversity in our countries. In every day life we must be conscious of the perversity of this reality, the one which feeds and generates inequalities of access to opportunities and development. This reality is fed in many countries in our region by corruption, and violence is increasingly the consequence.

In this context, in a region plagued of great contrasts and inequities, it is essential that we look at the situation that people with intellectual disabilities and their families are facing. It is in this social group that poverty has the greatest negative impacts. With all these images, many questions came into my mind:

How can it be possible that, while the world is approving and celebrating a Treaty as important as the UN Convention for the Human Rights for People with Disabilities, 80% of the 650 millions of people with disabilities of the whole world are living in developing countries? Don’t these numbers show poverty and inequality consequences as causes of disabilities? Between 10 and 14% of the poor countries population has some type of disability. And, what can we say about the responsibility of public policies to address this situation?

At least one of every 10 children in the world has a disability, and in poorer countries, the rate is even higher. Knowing that 98% of the causes of disability result from humans’ actions—the inequities, injustices and poverty that result— we must ask ourselves, what kind of future are we building?

My close friend from Argentina, Maria del Carmen Malbran, told me with sadness that in her country the unemployment rate for people with disabilities is about 9%. So are we to see this impact as a benefit of globalization? Why can’t we globalize solidarity?

Can you imagine how countries like Nicaragua are facing natural disasters in the context of their poverty? The peace they live with is just a post war state that has institutionalized poverty. And undoubtedly it is people with intellectual disabilities and their families who are among those who suffer the most in this context.

Antonio Cárdenas, President of the Parents Federation in Honduras, told me that the rate of illiteracy for people with disabilities in his country is over 50%, while the rate for people without disabilities is only 19%. In the face of such numbers,
where do we find equality of opportunities?

In Mexico, 58% of children younger than 5 years old have physical and intellectual developmental delays as a result of poor nutrition, for no other reason but poverty. What kind of future is waiting for my country? There are nearly 2.5 million children with disabilities in Mexico, and for this number the main responsibility must lie with the inequitable distribution of resources.

In my country, only 24% of people with disabilities have a job or an income, and the other 76% have no dignifying occupation or opportunity for social and economic participation. Of the more than 10 million people with disabilities in Mexico, 82% depend partially or totally on their families and friends for care, and 2% survive by charity or begging in the streets.

In Latin America and Caribbean countries, between 90 and 100 million people with disabilities and their families are still waiting the see the UN Convention become a reality. Many countries have already approved and ratified the Convention, yet our social reality is still colored by inequality, inequity and lack of opportunities for most of the people.

In Mexico, just as in the majority of countries of our region, people with disabilities are still an invisible population. Still today in the 21st century, our societies have a great socio-cultural and political problem in recognizing the existence of disability. Some recognize and declare disability with no problem. Others recognize it, but don’t want to declare it. Still others don’t recognize it at all, and many people, mainly in rural areas, hide it all together.

We do not yet have a serious and joint effort to generate systematic information about the population of people with disabilities in Mexico. An example of this is that in 1996 our national Social Security agency reported 4 million people with some type of disability accessed government services, but our country’s census of 2000 reported that we only have a total of 1.8 million people with disabilities in the entire country.

Does this mean that the economic crisis that Mexico experienced in the late 1990s erased over 2 million people with disabilities? And what of the official estimates of the World Health Organization that 10% of the population has some type of disability, and in Mexico estimates almost 15% have a disability. On what basis are our governments developing plans to address issues facing people with disabilities, and other marginalized groups, when the estimates of the size of the population vary so dramatically?

Mexico is just one of many countries facing a similar situation, as we found in our Inter-American Forum on Poverty and Disability, held in Managua in August 2004.
What then can civil society and the international communities contribute to eradicate poverty and exclusion of people with disabilities? As a first step, I think we must focus our efforts to promote solidarity across our borders in the face of the negative impacts of economic globalization in our region. We must establish an agenda that reinforces the role of civil society to work together and with governments and other institutions. Given our essential role in development and our potential to bring about change, civil society organizations must insist on resources to strengthen our capacity. We need resources so that people with disabilities and their families can work alongside professionals, other sectors and governments in the Americas in confronting poverty and exclusion.

At this point in our shared history in the Americas and across the world, we also need strong and coordinated action to develop policies and programs that advance the implementation of the UN Convention in our own countries, region, and globally.

As I think about our challenges ahead, I am inspired by the words of Robert Kennedy in a speech he gave in South Africa in 1966:

Few will have the greatness to bend history itself, but each of us can work to change a small portion of events, and in the total of all those acts will be written the history of this generation. Thousands of unknown men and women in Europe resisted the occupation of the Nazis and many died, but all added to the ultimate strength and freedom of their countries. It is from numberless diverse acts of courage and belief that human history is shaped. Each time a man stands up for an ideal, or acts to improve the loss of others, or strikes out against injustice, he sends forth a tiny ripple of hope, and crossing each other from a million different centers of energy and daring those ripples build a current which can sweep down the mightiest walls of oppression and resistance.

(1) Director, CISEE-UNAM  
Vice President, CONFE  
President, Inclusion Inter Americana
I have news for you. More than the early stimulation and the inclusion work in all aspects, I want to convince you that we also have to do another job, to educate our Mexican communication media. Also our authorities, the legislators, the municipal presidents, the governors… and if I am urged, the president and his wife, Margarita Zavala, but we must say she is interested in disability problems.

I think we all realize. The media are not mirrors of what we are living like society. They don’t know, we don’t know. I add myself those intellectual disabled persons in all society and with data from OMS, is the 10 percent of population, one third of this have intellectual disability. The 25 percent of them has the Down syndrome, the most frequent disability. It is a shame that INEG (Instituto Nacional de Estadística y Geografía), known before as INEGI, recognizes only .8 percent of population in its census for the year 2000. We also have to work on that for the year 2010. Why do I say we have? Well, for different reasons: because although the responsible associative movement, the families, NGOs and the teachers who work for disabled people, we cannot transform this country for it to include our sons and pupils completely with Down syndrome unless we make them see the importance of this people.

We have to demand from the government enough national budget for education. Unless we demand from the government jobs for disabled people and bigger efforts to be contemplated, and that they are not to be discriminated in any ways. We have to be the first ones to know the rights of our pupils and sons. And ours as families. If we don’t show that we are a lot and we are decided, there will be no adequate public politics.

For that we need in a big measure, the communication media as allies, and as co helpers for the hit and run episodes we are all exposed. We also need to be talked about, of the associations we create, of the labor the congress does, of the persons with any disability. We need for them to create an adequate image of the persons with disability and particularly the ones with intellectual disability and this is very important strengthening old stereotypes.

We need the media to adopt another language to refer to disabled people, starting by telling them that they are persons before all, and the disability comes after, for us to help build what we want and what they deserve, to be seen as citizens and not like “poor ones” or “disabled ones” to assist the vision that remains in our reality.

We need to sensitize a big part of the population that still remains distant with persons with disability, for them to start seeing them everywhere and to start seeing families like us everywhere. We are part of the world, of Mexico, we deserve to be seen and heard by the media.
Educational Inclusion and exclusion. A shared perspective

During the time it takes to read this article, in multiple places of the “impoverished south”, thousands of boys and girls will die as a result of contracting curable diseases or they may simply die of starvation or thirst. Among those with more “luck” millions survive in social contexts of poverty and marginalization, and, if they get to attend a school, they will be equally poor in resources, with poorly trained and paid teachers; for all that, they will only have access to fragile, weak an poor education, which will not allow them to avoid the circle of inequality reproduction. Mean while, in many places of the “rich north” that keeps this state of things, the harrow for many other kids, or young people of school age will not stop, although their situations and the social context is quantitatively different from those in the south. In rates sometimes exceeding 25% of the school population... many students will leave early or end no formal education precariously, stigmatized and without the basic and essential power to fit in socially active life without some warranty as not to fall into the same scheme play list of disability and inequality of the south we see in the news. In their career through school they will go through various centers, classrooms or special devices created for their sake, with the intention of compensating for their limitations and difficulties on account of their school days or personal social disability. In both cases, the north and the south, share and are subject -in my and other authors and organizations point of view- a common process now called “educational exclusion”.

…I do not intend to fall into the naive thought that education is the most important gateway to ease the processes of social exclusivity, even in cases of extreme poverty, nor in other less dramatic, but it is certainly one of them, and our responsibility as educators is that whatever we do inside the school becomes part. Studying in depth what is called educational inclusion, the first thing that has to be pointed at that, talking about “as its antonym” makes reference to and concept as a polyhedral practice, meaning that, it has many facets, each of which has something of the essence of its meaning but they don’t exhaust it entirely... In the first place, it refers to an aspiration and a value equally important for all pupils or students around the world, -children, youth, adults should feel included-, therefore recognized, valued and considered at their reference groups (family, school, friends, work), but there are individuals and groups at a higher risk than others when it comes to live fully this feeling of belonging as the boys and girls, in many countries, or children with disabilities in others, or those belonging to certain ethinical minorities in other cases, or those who are immigrants or children of immigrants in other countries with different languages than theirs. ...school life in which all students must feel included passes through teaching and learning activities with their equals, not apart of them. In this sense working for an educational inclusion is to think of the conditions and processes that promote learning with meaning and direction for all. Also you could say that it’s about thinking and checking if the scholar curriculum, in all its breadth of meanings, is set or not, as a facilitator of the learning process and achievement for all students,
and if the major projects of assessment of school performance, as they are designed and specified at present, contribute to or undermine efforts to build a system where quality and equity are not perceived as antagonistic factors... We are highlighting another criticism facet of the educational inclusion exposing precisely the different types and conditions of barriers set by the school tradition and reinforced by certain school cultures, limit the presence, learning process or participation of some students on an equal footing with their peers in schools to attend or not to turn students considered to be vulnerable. The barriers often masked and far away from critical analysis accounting for policies focused on “the students with an intellectual disability”. One might ask whether talking about inclusive education does not become a synonym for “quality education for all” or simply “good education” and whether, therefore, we need a new label that also might suggest to some people that this is a simple upgrading of old labels and other practices, such as those concerning the “special education” or “compensatory education”... In any case, we believe that we have to go on fighting for a common reference framework for all students at a disadvantage situation, without euphemisms when referring to “all”. This enterprise of trying to be more inclusive in school life is not, should not be viewed as a movie of “good and bad” of “being or not being”, but as of singular and honest searchers of commitments with democratic values and depending on their own circumstances. It’s not either a hassle-free alternative to “live them alone” (the educators) in these deliberative processes.

Since the beginning of this text I am insisting again and again that the inclusion must be seen as a process of scholar restructuring related to the implementation of innovation and improvement processes that bring the centers closer to the goal of promoting the presence, participation and the performance of all students in their locality, including the more vulnerable to the processes of exclusion, thereby learning how to live with difference and to improve thanks precisely to these same differences among students…

Indeed, nobody can slip that the aspiration for a more inclusive education is not simple at all... adaptations of the curriculum that might be beneficial for some, might also affect, in a certain some degree, others who do not need them...

... In any case, the best way to deal with these dilemmatic situations at school is to create the scholar conditions (of time, space and counseling) in which the teacher can feel relaxed and not threatened to be able to say “I do not know how to resolve these dilemmas,” but also eager to explore alternatives for action that could help overcome them. The role of managers and local government, through their advisory services and oversight pedagogic psychology, are crucial for this purpose...

I would like to emphasize that it is essential to enrich the dialogue with the voice of the weakest, the least popular and most marginalized, -the vulnerable children and young people themselves-, and for that reason and for this it is necessary to collect and amplify their voice, not only because they have the right for their own opinion and perspective to be considered (a right guaranteed by the way, by the Convention on the Rights of the Children), but also because it is a powerful strategy for change that is very useful given the growing
recognition of Children and young people as active and competent to participate and learn about everything that affects their lives. It is a formula not only necessary but also challenging to imagine creating ways to reach the life experience and emotions that affect certain pupils or students at risk of marginalization... Thinking about what that voice tells us, brings up to the surface implicit conceptions towards inclusive education in the practices of many teachers; listening to what the students feel, generates emotions that help to change; and as Ballard says, something important happens when a person is identified with a "wounded" individual like the ones who now occupy us; emotion, including grief and anger, makes it more feasible for people to disagree with oppressive and harmful policies.

A research project is always an ideological choice, an educational commitment. If we need to highlight what is the condition that summarizes what is needed to pursue these initiatives grouped under the term "hear the voice of children and young people," it would not be other than a school culture that values their opinion and mobilizes to keep it in mind and that is committed to the most basic cycle of what a professional activity that really deserves the name is: action, reflection on the action, action, reflection... We are also learning from the experts, that those skills for reflection and improving sustained education need to be accompanied by positive emotions and hope, an emotion indispensable face to the obvious lost cause that involves the inclusion of education and, that –careful!- "is not a simple and naïve vision of an unlighted life, but the ability not to panic in rough situations and finding ways and means to tackle difficult problems" And the best way to nurture that hope and to find ways and means to cope it is to establish broad and strong networks of collaboration, interdependence, mutual help and support inside the centers and among them and their educational community and local level. I am very concerned about the issue of the dilemmas inherent in the task we have set ourselves (moving towards more inclusive education systems), get solved, but with a kind of regression toward limiting prospects in an unacceptable manner the inalienable right of some students to that “equality (educational) quality,” mentioned by Bonal, Escombra and Ferrer. In fact, the principle of inclusive education is continuously subjected to “restrictions”, “nuances” or “exceptions”, sometimes depending on the unique (in)abilities of certain students, others to do with the inefficient education of the “normal students” because they have an “unreasonable” cost for the public treasuries. Therefore I fully share the position of Parrillas: "Perhaps the politically correct speech, -but so far ineffective in our practices of inclusion, must open the way to exclusion discussions as a tool for change."

A good way to modify the hardly naïve developments or critical events under the concept of really weak inclusion, could be the analysis of the internal forces and processes of exclusion in the education system and in schools. This could allow the analysis of the meanings and implications behind some educational practices described as inclusive, that although, serve only to perpetuate the status quo of the system and that open new doors to marginalization..."(Parrillas,2007:15)

Therefore we must literate in moral values, find out how they are learnt, taught or reinforced among with our professional ethics. 

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2 "Voice and loss" are verses of a song of Caesarea Evora and Pedro Guerra "Time and Silence" in the disc of Caesarea Evora "Sao Vicente di Longe".
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Information and Communication Center

Bonded Assembly Workshop
Services and Support

Garden Workshop

Cellar Workshop

Cleaning Team and Workshop

Breadmaking Workshop

Volunteers Team

Workshop Chief
lo normal es un trato normal