

APRENDICES - DESGRABACIÓN EN INGLÉS

Episodio especial: Inés Enciso

INTRO

I believe that culture is a place of confrontation, of showing other realities, of opening the mind.

A stage is a very powerful speaker, for better and for worse.

I didn't associate with anyone with a disability when I was little, so I was terribly afraid of the unknown.

I believe that if you give yourself the opportunity to approach them with an open mind and discover everything that is out there, I believe that the reward is so powerful that it is worth it.

PREVIA

I love it because he looks and stops to think.

Yeah.

What is missing here?

I'm thinking about that.

I think we're set.

Welcome, a pleasure.

How are you?

Grateful, the word is gratitude.

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I am grateful, I am very excited to share this time with you.

We have to confess something to you, it is the first time that we are going to record a special episode.

The series is already in its third season, and we filmed all the interviews together.

And we were saving this as a wild card, to see which visit merited a different sort of episode.

This has only added pressure to this moment, as I have been saying, but hey, I am very excited,

and I am very excited that it is here, in the Cultural Center of Spain, which always welcomes me with such affection.

And I love coming to Uruguay. Maybe one of these days I'll stay indefinitely, so be prepared.

And on top of that we are lucky to have Tatiana.

Tatiana has a lot of qualities. She is our colleague at Ceibal and she works with a really nice team, important within the organization, dedicated to accessibility and inclusion issues.

So I hope you enjoy the wickedness of bringing them together one afternoon in the cafeteria as much as we do.

More pressure too.

More still.

Thank you, Ramón.

They had been talking fifteen minutes before.

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Yes, yes.

They count as old acquaintances.

Yeah.

We've already taken pressure off. That's done.

There is good chemistry here, so everything is going to be fine.

Inés, take 1.

CHARLA

Professionally, I define myself as a cultural manager. I dedicate myself to launching and promoting projects that are linked to the field of culture. And if I had to define myself personally, I think I am a person who has been very lucky, and it is something that I like to be very aware of because it is not so common. I have felt that throughout my life I have had many incredible opportunities and that luck has always been close at hand. And I like, as I say, to be very aware of that and not lose it because it is also a way to ground yourself and be aware that life is a fragile thing, that in a minute it changes and the tortilla is turned upside down and darkness appears. So, I am thankful for being able to travel through all these spaces of light and having the opportunity to be in places that make me happy and that fulfill me. Well, I like to be grateful for that.

You just mentioned that at some point your life was one way and then the tortilla turned upside down.

Can you tell me a little more about inhabiting that place and how did you get through it?

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Well, yes, I guess the most difficult moment of my life was the birth of my son Mateo. Well, not exactly the birth, but an ultrasound, already at the end of the pregnancy, in which I was diagnosed that the child had a series of malformations that were going to greatly complicate his development. And so, I had entered that room as a happy mother, with my full belly and thinking: "Now when I get out I'm going to go buy bodysuits for the baby when he's born", and suddenly, I came out of there in complete shock, not knowing what was coming, you know?

Sure, it's a very long transition journey, not just because you have to adjust to that new reality. A month and a half later Mateo was born. Indeed, the worst forecasts were confirmed. Well, not the worst, because he survived the birth and is here today. He is 14 years old. But well, it is true that you always cling to that hope of: "Oh, maybe it was a diagnostic error and then when he is born...". But no, it was not the case.

So, well, suddenly I had to go through all this medical journey that involves all the cares and that is very complex. But then there is another part of resignation that has to do with motherhood, with what you expected, with how you started that journey. Suddenly, you have to give up all that you dreamed of, like seeing your child walk, having your child call you mom, being able to teach them the language, watch him relate with other people. It is a moment in which that darkness that we were talking about inevitably appears, and you sink as in a well, where you have to gradually find footholds to get you out of there. It is not an easy path, at all.

How did you manage to transform that into something else?

How were you able to leave that place?

Well, it was a very natural transition process, that is, I don't have the feeling of having made a clear effort. Things begin to settle. In the end, one has to accept the circumstances that life has given you in order to live happily because otherwise we would be locked in that pain all day. So, well, little by little things began to settle.

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Once again the luck factor appeared. Mateo is a wonderful child, very good, affectionate, who makes our day to day very easy. And that has also played in favor. And then, well, also having the possibility of being able to combine my entire professional life with professional development because it has also made the push faster and, above all, a very important learning process because when Mateo was born my whole family thought: "What a pity that this happened to Inés", because I was a hypochondriac, very impressionable, very sensitive, you know? So it was like... well, it could have happened to someone else, someone with more tools to handle it, right?

And well, you also discover yourself in that other place, thinking: "Come on, then, I'll load my backpack and push forward because I have no other option," you know? And discovering that you are much more resilient, much stronger than you thought, with more tools than you thought, puts you in another place regarding the image you had of yourself. So I discovered a world that I had not seen before, surely out of fear.

Inés, when I asked you to define yourself, you told me you're a cultural manager.

How did you become a cultural manager?

Well, in my youth, I wanted to be an artist, I studied Fine Arts. I also thought about becoming an actress. I mean, it's like art had always been a very essential part of me. But then over time you begin to be aware of the level of talent you have. And then I began to discover this other side that exists in culture and in creativity and in art, that has to do with the organization, with the management, with the promotion of creators or new projects, which I also found exciting and very creative as well.

So, I began to occupy that role in a natural way. I was the person on the other end helping ideas to land, looking for the funds, creating the infrastructure so things could happen. And it is a place where I feel very comfortable in and it seems to me that it is also a way of being able to push and to open doors that artists or creators often cannot do on their own.

And also, I think that culture is a place of confrontation, of showing other realities, of opening the mind. Very interesting too. So, trying to mix all that part with a social component to it and channeling it through culture, I find it very exciting, really.

How did you start your work in art with people with disabilities?

How did you begin that road?

Well, after Mateo was born, many questions of a general matter appeared, but also linked to my profession because that lack of visibility that we discussed before, I suddenly realized that it also happened in culture. For my part, I didn't see them, I didn't count on them, so to speak, and I didn't see others paying attention either. I did not see people with disabilities on top of the stages, on the screens. And of course, it couldn't be a question of talent, because talent has to do with transmitting emotions, with communicating. And that is in the essence of the human being, regardless of what his form is, right? So I started asking questions. What's happening? Why isn't there a higher level of participation?

At that time I was doing an internship at the National Dramatic Center, and together with a companion, Miguel Cuerdo, with more daring than anything else, and without any expectations, we went up to the office of Ernesto Caballero, who was at that time the director of the National Dramatic Center, with a rather commanding tone: "It cannot be that the National Dramatic Center is not including this other reality, and such...". And he said: "Yes, you're right, totally agree. You do it.". And then we left that office saying: "And now, what do we do?". So, well, we thought a lot about what we could do. It was a golden opportunity, having the team from the National Dramatic Center, which is the most important theater in Spain, willing to explore this new path and to hear how we thought it should be done.

So, well, after thinking about it a lot, we decided to create a festival format called A Different Look, which we doubted very much if it was the best

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formula because you never know if a festival is also a ghetto, a space of exclusion. It's like: "Yes, we open the doors for you, but you are going to be on this specific programming this month". But we also thought, if the NDC dedicates all its communication and production resources to talking about this topic, in a city like Madrid, with a very high level of cultural activity, where it is very easy to dilute yourself and for people to miss out on your project, well, it seemed to us that having that space as a specific noise could work for us, because of course, it was something very unusual at that time. And you also have to do a process of accompaniment with the public, but also with all the staff of the National Dramatic Center. They didn't quite understand what it was that we wanted to do. The moment you put the word "disability" in the context of culture, they think "amateur", like art therapy. "Oh, poor people", right? So, of course, you had to accompany the project so that it could sink in and settle.

So, we did this festival format for nine years, and in 2020, when the direction of the National Dramatic Center changed, with Alfredo Sanzol, we decided to lead by example. It is true that when we presented the festival the first thing we said was: "We want it to end as soon as possible", which is a very strange request when you start a project. "We start today, but we hope it ends as soon as possible, when it is no longer necessary". So, I think that now, fortunately, within that institution, they have assimilated that this is a right and that they, as a public institution, cannot do anything but guarantee it and fight for it to be established. So, now all the programming and all the activities of the National Drama Center are inclusive, and I believe that it has become a model in that sense.

What about the general public when they go to see those plays?

Sometimes it's hard to entice the public.

It's very difficult. The first year of the festival no one came. It was an absolute public failure, but we could afford to do a second edition since we are a public institution. If we had been a private institution, surely the festival would have died right there. And it was something I did not expect. Look, I thought that people were going to come to discover this new

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reality, probably because I was so fascinated with what I had discovered that I took it for granted that everyone would react the same way. But nobody came. So, we had to do a one-on-one job, almost going door-to-door saying: "Hey...". And it is true that once they came, they'd come back the following year. "Hey, what are you doing this year? What's going to happen?".

Of course, a stage is a very powerful speaker, for better or for worse. That is why we were very careful with what we put on the stage because it can change your outlook, make you understand the capability that exists within disability, break prejudices, paradigms or, vice versa, if you put on stage something that lacks the quality of the rest of the programming throughout the year, then you are reinforcing the idea of: "Ah, they are not capable. This is the best they can do".

So, we did have to be very careful with the programming, but I believe there's been a transformation of the public, which also has to do with the social transformation that has taken place in Spain in recent years, and the level of visibility, inclusion, and respect for people with disabilities. But it has been very nice to experience it firsthand, to see those stalls became more and more crowded. More and more disabled people came in, who did not at first attend either, and the discourse has set in, and this year we have released specific shows that talk about disability. Three shows, and all three have been full all year, you know?

That's also it. Not just for people with disabilities to have a place to work as artists, but to open up the access to culture for people with disabilities, which are generally closed spaces.

Can we say that in this theater there is real inclusion?

Well, we are improving, but it's been a real learning curve because from the first year we made a great effort so that all the shows had accessibility measures: audio description, magnetic induction loop, subtitles, and you think that's enough. You go: "That's it, I apply the measures and this show is officially accessible," and people with disabilities will come. But people

with disabilities do not go to the National Drama Center because they have never felt that it was a space for them. So, it's not enough for me to set accessibility measures and announce it through my channels and say: "Hey there!". They are not listening to you because they are not looking there. Because you are not part of their leisure, you are not part of their lives.

So, we had to work a lot, go look for them and say: "Hey, you can come, we're dying for you to come, we want to share this with you". And little by little, we were able to generate a regular audience. Of course, you also have to see what each group needs, very much in collaboration with them. You think that a deaf person needs subtitles and that's it. No, there are many deaf people who don't find subtitles useful.

So, we have to see what we can do, and that's without mentioning people with intellectual disabilities, who need someone to support them, and specific exhibition schedules, a lot of things, and then there's the economic barrier. We've had to make an analysis little by little, looking at all the barriers that they faced from the moment they opened the door of their house. I mean, it's not just going into the theater, it's from the time they leave their house, all the barriers that they have to face to be able to go see the show, and the effort involved for them to participate. So, we take it little by little, adapting ourselves specifically to each viewer.

Of course. What is your opinion on the educational system?

Is there real inclusion in education?

Well, in education and in general, I wish we were capable of creating a system in which all boys and girls could be educated equally and could live together. You are in school for many years. So, having that space to live with people who are different should enrich you in a powerful way, right? It is true that in Spain there is now a very strong internal debate about inclusive schools, which is something that even the European Union is demanding from us. What we have currently are special education schools, and it is true that with a lot of effort and vindication on the part of people with disabilities, especially people with intellectual disability in Spain, they really are centers that exhibit a very strong general state.

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So, there is an internal debate that is very painful, especially for families and parents of children with disabilities because we don't all agree. It is true that in an ideal world we all want to have an inclusive school, but in the real world, if in a regular school my son is not going to have the support and commitment that he has in the special education school, well, I don't know if that is the school I want, you know? But then, I believe this is something that should be sought, especially by the fathers and mothers of children without disabilities, who in the long run are going to benefit from being able to share their days with a child like Mateo. Because my son is fine where he is and right now my son has all the resources and everything he needs on a daily basis, all the time he spends at school.

But the child who is being raised in this society that we have spawned, where you always have to be first, where you have to show you are happy all day, for him to suddenly being able to share his days, and I see this in my nephews, with someone like Mateo, whom they treat as an equal despite his difference, and how they adapt their games so that he can participate in his way, you know? The joy with which they receive him every time they get together. I mean, how extraordinary! Because this didn't happen to me. I didn't associate with anyone with a disability when I was little. So it scared me to death, you know?

Yes. The unknown.

The unknown. And yet I look at them... for them it's completely normal.

You just mentioned that this fight for inclusive education is not so much yours, but a fight for the moms and dads with children without disabilities.

Do you think that these families are aware that they have to put up that fight?

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No, no, I believe that fear and ignorance are widespread in society, and in fact, some very painful cases have occurred in Spain as well, in those early stages of training, in which it is easier for children with and without disabilities to coexist because the training is still very focused on playing and experimenting, and there were many parents who asked for children with disabilities to not be in the classroom because they slowed things down, and if they are children with a complex pathology, difficult to manage, they worry that something is going to happen and then their son has to see it, you know? These things put me in a place where I think: "I can't understand you having that thought".

It is true that it's not the majority, and Mateo was in regular school until he was four, you know? And well, somehow I also felt welcomed by the rest of the families. But there isn't that push that there should be. True, I don't want to place all the responsibility there either because the educational system, I don't know here, but in Spain it's very complex, it has many blind spots, many things to improve. The student ratio is very high and so in the end you are also thinking about the well-being of your child, and that those years are going to be decisive for his development and for the person he will become in the future. So they are fighting their own battles that have to do with other things. And this is, let's say, another fight. But I don't have the feeling that they have internalized the struggle. They expect the parents of children with disabilities to be the ones who give their opinion. So, as I told you, right now this is a painful moment for us because in the end we can't hope to agree. And sometimes we have unpleasant discussions, that we have enough every day, with all the adversities that we have to face, and this would only add fuel to the fire, you know? So, I don't know, we'll go down that path and see where it leads us.

Inés, if you had to give a message to society or ask society something, what would it be?

Well, I would ask them to come closer, and I understand that it is difficult because that backpack of prejudices and stereotypes weighs a lot. But I believe that if you give yourself the opportunity to come closer with an

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open mind and discover everything that is out there, I believe that the reward is so powerful that it is worth it.

Maybe it's a feeling I've had in the last few years, but I understand that what we've done about everything to do with the correct use of language, political correctness, not doing anything that could be offensive, has also created a new relational barrier with people with disabilities. And many times we're stuck thinking: "Do I have to say it this way? Do I bend down to say hello, take him by the arm?". So, for fear of doing it wrong, you say: "I won't get close, to avoid putting myself at risk". And that makes me sad because I think that, in the end, if you approach the person with respect and the desire to know him, then it's all good and no one is going to feel offended, you know? And that very nice things happen when that barrier is broken and you let yourself go. In other words, they should try it. I think they are going to discover a wonderful world.

Thank you. Now we are going to give way to questions.

If anyone has a question to ask Inés.

Hi Inés. Well, thank you very much.

I wanted to ask you if you could give us some strategy, some tip, to allow for more inclusion in the educational field.

I believe that each territory is so different and has such a different reality and such different needs. I think that there is something that we have to keep in front of us all the time, the educational system, but also the people who dedicate themselves to culture and society in general, and it has to do with the fact that this is a right, which is something that we often forget, and we talk as if it was an act of charity. And how benevolent we are, thinking "Oh, look how nice I am because I've done this and I'm so open to that". No, the reality is that there has been exclusion for many years, and a lack of guarantee of those basic rights for any person, and it has been so intolerable that we can no longer turn our backs on it. So, I believe that in whatever action we take or whatever decision we make, that has to be on

the first page. I am doing what I have to do. It's not something I do because I'm a good person.

Thank you.

You're welcome.

If anyone else has any other questions to ask...

Well, thank you very much.

Working with people, with families, with people with disabilities and, above all, in those first moments where they're just finding out, it always happens to me that I don't know what to tell them.

So, my question is: Looking back with Monday's newspaper, what do you wish they had told you in those initial instances?

What word? If you could say something to yourself back then, what would it be?

There are so many things that I would have liked to have been told at that time. I'm going to get emotional. The first is that nobody brought me flowers when my son was born, and I felt like saying: "My son has been born". It is an exciting and beautiful day for everyone, even if it is hard, and not being able to live it as the other mothers had. And then I would have liked someone to tell me: "Don't search online", because it is a mistake we all make and on the internet there is no way out, there is no room for hope. Everything is worse, the worst diagnoses, the worst prognoses. So, you go in there in the tough moment you are living and all you get is: "This is going to be horrible". So if I had to tell you something, with conviction, though I would never give any advice to anyone, if I had to say something with conviction to a mother who was in that situation, I would say: "Don't look online, because life is something different". I don't know.

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Now, as you say, with Monday's newspaper, which is a phrase that I loved, I wish I could have peeked a little at myself today, even for a second, and see what's there, because that would have freed me from a lot of fear and anguish that inevitably accompanied me during those first years. And then, at the end, light always comes. So, I also believe that each family and each mother, in this case, if it is them that I am addressing, they have to be able to make their way in their time and in their freedom. Because there is another phrase that I thought of a lot: "You have to be well, otherwise the child will not be well". Well, I'm not well. And that's that. It's alright. I'm going to assume this and I will go through my own process and I will be by my son's side in the way that I can be.

But without the added pressure of having to be fine and on top of things... each one gets there when they can. It's something that I have questioned a lot in the last year, in the last two years, which has to do with worrying about giving an image that could become a burden for other moms who have not yet reached that place of light. It is something that I would not want to happen in any way. I have been, as I said at the beginning of the interview, very lucky. Many wonderful things have happened to me by Mateo's side, but also in my professional and personal life. Not everyone is that lucky and not everyone gets there at the same speed.

I would not like for my tender sort of activism to become a burden for someone with a much more complex life situation, or someone having trouble to internalize, assume and walk that path. Each person needs their own time and we must accompany them according to their needs, you know? Hopefully, it can serve as inspiration for someone to think: "I'll get there someday" or "There are things I can do to help me get there faster". But yes, above all that, don't go online and allow yourself the time to be able to go through the whole process, what is called the mourning of the healthy child, which has been studied, typified and which requires accompaniment. Allow yourself the time to live it and get to where you need to go when the time is right for you.