



Perspectives

Intellectual Disabilities Through the Eyes of Others

A Newsletter from *Wildflower Caterers*

Source: El Pais
April 30, 2017
Uruguay

As they get comfortable for the next picture, Sabrina (28) and Pablo (29) hold hands and say they are thinking about getting married. “We are just thinking about it because it’s not the right moment yet,” he explains as he looks at his girlfriend in the eye, tugging lightly on his arm as if there was a secret plan between the two that she could reveal in a slip. “This is ours,” he continues, “our families have nothing to do with it.” Pablo says that when they get married, they are going to live with his in-laws because he would like to live in a house different from the one he grew up in. He wants to move, just like his co-workers do.

Next to Sabrina, Carolina (25) smiles and timidly looks down. She feels embarrassed, although she

spent all last year promoting a movie in which she stars (*Carolina's World*, by Mariana Viñoles) and is one of the models advertising the latest commercial from the Ministry of Tourism. The two friends work in a perfume store. Following the directions received in their biweekly inclusion workshop, they wear makeup and jewelry like the rest of the female vendors do.

Next to Pablo, Matias (33) puts his hands in his waist. He is the oldest of the group and smiles as he observes his friends. Matias does not mind repeating a picture or changing his pose, although he is still agitated from running from the bus stop to try and make it on time. These workers hate being late and it is not uncommon for their bosses to call them out for being thirty minutes early. His cell phone rings, he answers quickly and annoyed. "Yes, I'm here. Bye." It was his mother. Like most adults, Matias does not like talking to her in public.



15.9 % of the population in Uruguay is disabled.

-Why do you like working?

To be independent. To have my own money. To have co-workers and a boss- says Matias.

-How do you spend your money?

I bought stuff for my bedroom. A bed, a desk, a dresser and a laptop. I also go to the salon- says Sabrina.

I bought a new radio to listen to music- says Pablo.

I am saving to buy carpenter tools because I have a pallet business; I make tables- says Matias.

-Matias, you've been working at a gas station for 11 years. Have you thought about quitting?

I'm waiting to hear about an interview. I would be organizing documents and delivering the mail.

-Carolina, what do you do with your money?

I save because I like surprises. I want to have a baby with my boyfriend.

-Have you told your mom?

I haven't found the right moment yet. I'm going to



tell her when I'm already in the hospital and she's not going to have any other option than to want it.

The mothers who founded the Uruguayan Association of Down Syndrome (ADDU) in 1986 met by word of mouth in halls, clinics and schools, sharing advice on how to deal with the news that their

child had Down syndrome. In most cases, it was told as a tragedy or a stroke of bad luck.

Childhood for children with Down syndrome tends to be slow. "It's almost like a different language that only these parents understand," says Nidia Viña, president of the association and mother of Ezekiel, who is now 35 years old. Maria Luisa Tarán, member of the education commission added, "All children are born with a potential that we have to discover. We have to pull that potential with a corkscrew, so the difference is made by the early stimulation. My son Felipe began going to physical and speech therapy when he was 14 days old."

Pablo, Matías, Sabrina, Carolina, Ezequiel and Felipe (among others) are the result of a group of parents determined to have their children be out in the open. They had to first change their mentality, then their children's mentality and then try to accomplish the same with business owner's. There is still growth to be made in the fields of medicine and education.

Andrea Pesce, mother of Matías and a member of the board, says, "The other day I was asked if there were more people with Down syndrome and I said, 'It's not that there are more now, it's just that now they are no longer invisible, you see them on the streets and in offices.' This generation is changing everything."

According to the ADDU, for every 700 births, one child is born with Down syndrome. There are about 7 million people with Down syndrome in the

world, which makes them the largest minority. New medical technology has tripled their life expectancy to 65. In 1929, a child with Down syndrome lived until 9, now, almost a century later, they often survive their parents. Therefore, jobs are essential to guarantee them a place in society, especially when they are alone.

Though inclusion has improved in part due to employment, the mothers are saddened by some recent news. Medical advances have generated prenatal studies that allow for early diagnosis of this genetic alteration. According to Spaniard specialist Jesús Flórez, 8 out of 10 women in the world decide to have an abortion. Down syndrome births have decreased 100% in Iceland, 95% in Spain and China, 90% in the United Kingdom and 65% in the United States.

Amid this contradiction, parents are seeing their children mature like never before. Entering the labor market brings a wave of changes. From an increase in self-esteem and confidence, to the demand for more independence and the projection of a life with home ownership, marriage and children. “Everything they do is to try and be like everyone else, they guide and encourage us,” says Tarán.



Due to the care they need since they are babies, people with Down syndrome are the center of family routines. According to ADDU psychologist Laura Cortés, becoming employees, receiving orders and keeping a schedule removes them from the place of spectators. "For the first time they are feeling useful in our society, which poses a lot of challenges for them and their families. Work became a shortcut from eternal childhood to adulthood.

Daniele Restano received the news a few hours after delivery. No one wanted to tell her that her daughter had Down syndrome. She became depressed. Once she got better, she took advantage of her profession as a psychologist and specialized in communicating bad news: "You have AIDS, you have cancer, you have a child with Down syndrome." He says the secret to eliminating that weight of tragedy is to have all the information. Every time there is a birth, the maternity units notify ADDU and a group of mothers visit them. The association began to normalize these actions that were previously a gesture of generosity among strangers.

Restano also recounts his bad memories. When her daughter was a few months old, a doctor told her she was deaf. "It was stupid because these kids have a slower neurological development and he did not know it," he says now nine years later. "He listens better than I do, but who gives me back those days of anguish?" Despite the number of people with Down syndrome, Uruguay does not

have specialized doctors. Specialists who usually treat them have made mistakes in diagnoses.

The picture gets worse as they age. Virginia Kanopa, a neuropsychiatrist, says she accompanies such patients up to age 15. There are several pathologies associated with the syndrome, although not all of them suffer from them. The most common are congenital heart disease, leukemia, ear problems, speech, sight, thyroid and digestive complications. Adulthood for those with Down syndrome happens at full speed because they age 20 years faster.

Magdalena Prado, Matías' sister and ADDU's communication officer, believes that the reason for this indifference is evident, "It is not profitable, because the syndrome is not associated with a medication, so there is no interest on the part of the labs." Tarán interrupts, "In Uruguay we are ignored.

When they want to know about medical advances, these families look to Spain, Italy, Brazil or Argentina. Spain, above all, is a benchmark with hospitals in Barcelona and Madrid that have an entire floor for patients with Down syndrome.

A child with Down syndrome can attend elementary school without the company of a personal or therapeutic assistant. The condition is that the teacher adapts the curriculum and understands what the child can learn and can motivate him. The most ambitious teachers want to create inclusive schools, which would bring together students

with different levels of intellectuality into the same classroom.

At the end of 2016, the association succeeded in ensuring that the government recognized a Protocol of Acting in Education, which only ratified the right to study and the obligation of institutions to receive them, which had been in forced since 2008. "Whenever they say no, they do it subtly," says Restano. "I was a psychologist in a Catholic school and they told me, very kindly, that my daughter was not going to be accepted because she would delay her classmates. That day, with the same subtlety, I resigned."

Although the association has provided advice to public and private schools, principals and teachers, they believe inclusive education is still a utopia. "Every year facing a new teacher is a headache. Imagine multiplying it by 10," says Restano.

Cortés explains that many parents prefer to send their children to special schools to avoid the stress of not being properly contemplated. When kids become teenagers, that's when the intellectual and social differences appear. However, at work it is easier to see yourself as a pair of someone doing the same task, no longer seeking a reaffirmation of identity but adulthood.

All respondents agree that, oddly enough, job inclusion is much easier than education. María Jesús Tobler is about to get a degree in Human Resources with a thesis on this subject. "Hiring begins when they reach the age of 22 and they are linked mainly to corporate social

responsibility." What many companies do not know is how beneficial these workers are. They perform at the same time as the rest, they are effective, loyal and agents of change in the environments. Their concern for their coworkers improves communication, eliminates friction and makes teamwork grow.

Although 55 years ago, Law 18.651 obliges the State to have 4% of the disabled among public sector workers, this percentage is not met. According to the Down Association of Uruguay, the actual figure does not reach even 1%. Óscar Andrade, executive secretary of the Sunca, presented a bill for the employment insertion of people with disabilities in the private sector. Andrade makes a mea culpa and acknowledges that part of the responsibility for non-compliance with the current law is of the unions, because they never claimed the rights of these workers. "The percentage seems coherent to be representative, but let us be frank, if no one cared that the law was fulfilled before, we cannot think that this change will be radical. The fact is that we have 130,000 people with disabilities and it is time for them to enter working market".

Though they support the project, the association believes that once again a distinction has not been made between intellectual and physical disabilities, whose differences are fundamental. "For example, hiring an employee with Down syndrome does not require any building investment," says psychologist Laura Cortés. She added that rather than focusing on the private sector, they would like to push for the government to meet the share of participation in public offices. People with

Down syndrome often have a work load that does not exceed five hours because premature aging is part of their condition. The physical and mental deterioration happens 20 years before than for the rest of the people. "For them to work eight hours would be as if we did 16," explains Cortes. The would like to see higher salaries though.