WE THE PEOPLE

Inclusion of People with Disabilities

in Latin America and the Caribbean

IDB

ACCESSIBLE AND INTERACTIVE **PDF**

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This is Us

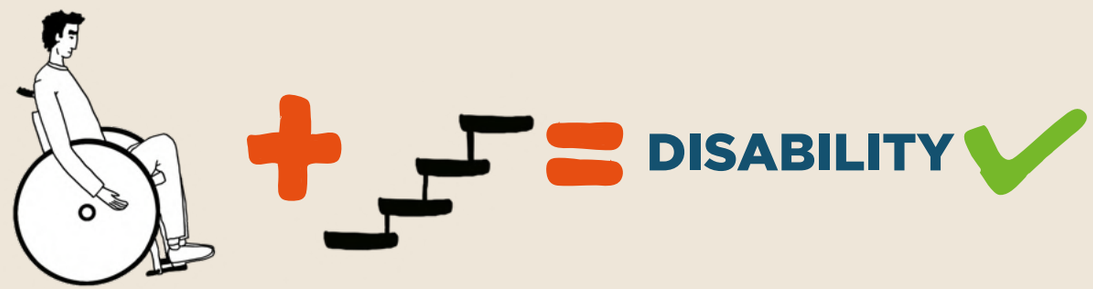
Who are people with disabilities? For far too long the obvious answer to this question has been to point at blind or deaf people, a person in a wheelchair, or a child with Down syndrome. It's "them." It's something within their bodies. But what if this is wrong? What if that way of understanding disabilities makes the inclusion of this social collective far more difficult?

Over a decade ago, civil society organizations started a conversation asking those very same questions and the result was a UN Convention ratified by 179 countries that would forever change the way disabilities are defined and perceived. The Convention presented a "cure," if you will, but not in the sense that popular culture ever since the Bible has imagined this cure to be. More than a miracle solution to "fix" damaged bodies, it aimed at tracing a path by which an excluding society can fulfill the human rights of all of its diverse citizens.

What was so disruptive and liberating about this new definition? It extracted disabilities from within the individual and conceptually placed them in the relationship between an individual's impairment and a barrier in the environment. For example, being in a wheelchair is not a disability in and of itself. You need the staircase with no ramp or elevator to understand that situation as the disability.

MEDICAL MODEL

Impairment = Disability



SOCIAL MODEL

Impairment + Contextual Barriers = Disability

It's a game-changer! By placing disabilities outside the individual and in a context full of barriers, we set a goal for society in general and governments in particular to remove those barriers and build a future that is truly possible for all. We transition from a medical model that placed the blame on health conditions to a social model that demands access to equal opportunities. In this updated model, enshrined in the UN Convention, the emphasis is on the long-term status of the impairment, since someone with a temporary impairment such as a broken arm is not considered to have a disability. At the same time, it recognizes that disability status can evolve over time and be influenced positively by rehabilitation or negatively by a deterioration in contextual or underlying health conditions.

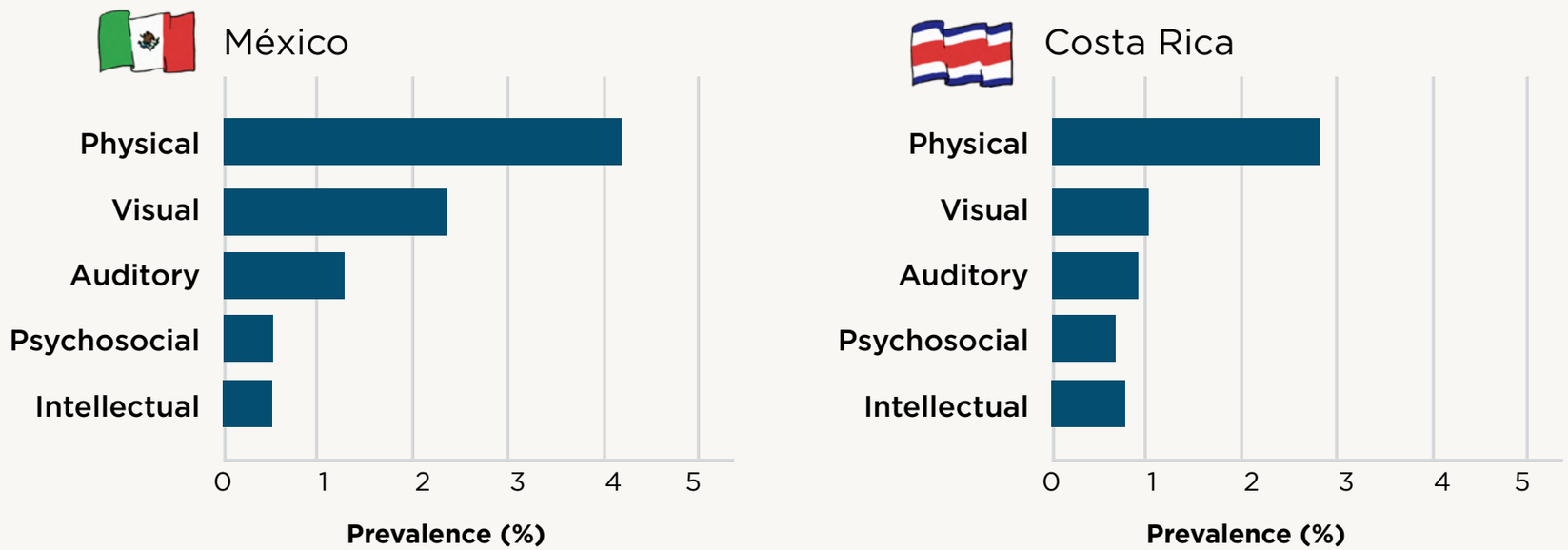
In the wheelchair-plus-staircase example, it's fairly easy to identify the barrier. But many attitudinal barriers also generate disabilities that, sadly, are deeply rooted in the common culture. Perceiving people with intellectual disabilities as eternal children or prejudging people with psychosocial disabilities during a job interview can seriously hinder their participation in society.

Examples of interactions between impairments and contextual factors that determine disability

(A) **Domain**	(B) **Contextual Barriers**
Sensorial (hearing,seeing)	• No provision of screen readers, other adaptive software, or materials in alternative format such as Braille • Non-captioned films, webpages, podcasts, videos • No sign language interpreter available, nor real time captioning
Mobility	• Inaccessible transport services, buildings and public spaces • Non-adaptive keyboards • Non-adjustable height tables/workstations
Intellectual	• No consideration for the need of a less distracting environment to study/work • No provision of extra time for learning or additional support
Psychosocial	• Employers not providing opportunities for job interviews or career advancement if condition disclosed • Schools blocking enrollment based on stigma

Worldwide, one in eight adults live with a disability. That's more than a billion people! In Latin America and the Caribbean, the proportion is similar; people with disabilities make up about 13% of the population. How we think about and measure disability has changed in recent decades on the basis of the social model. Measuring the prevalence of disability implies including questions in surveys that are representative of the overall population. Countries have moved away from asking "Do you have a disability?" to implementing the recommendations of the Washington Group on Disability Statistics in which individuals are asked about difficulties performing basic activities such as walking, climbing stairs, hearing, seeing, cognition, communication, and self-care. It is common to measure different types of disabilities. While prevalence varies across countries, higher rates are generally measured for physical and visual disabilities as shown in **Figure 1** for household surveys as well as measured in the 2010 census rounds.[1]

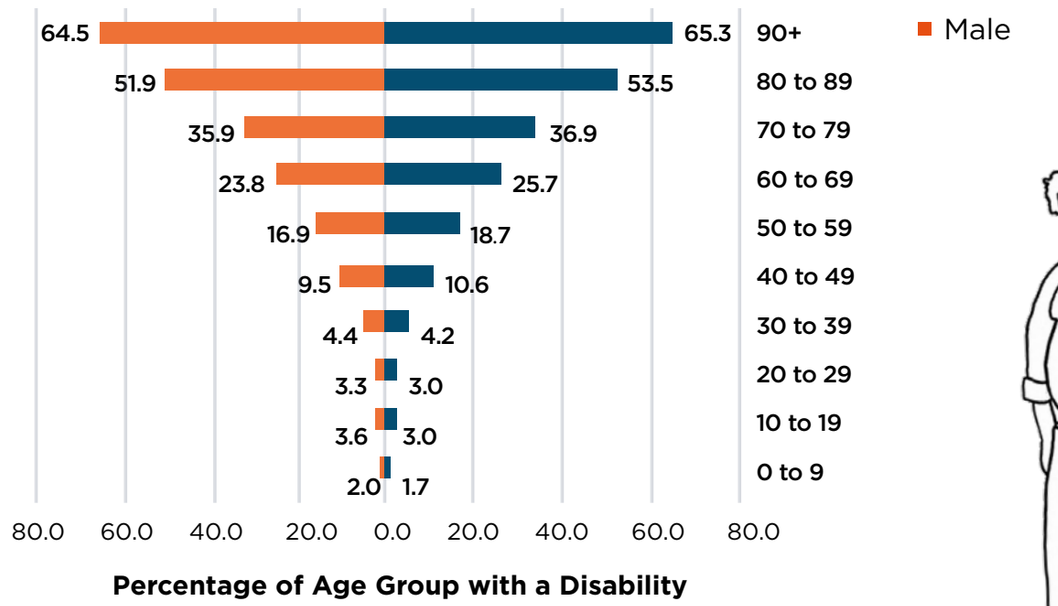
Figure 1: The Prevalence of Different Types of Disabilities in Mexico and Costa Rica



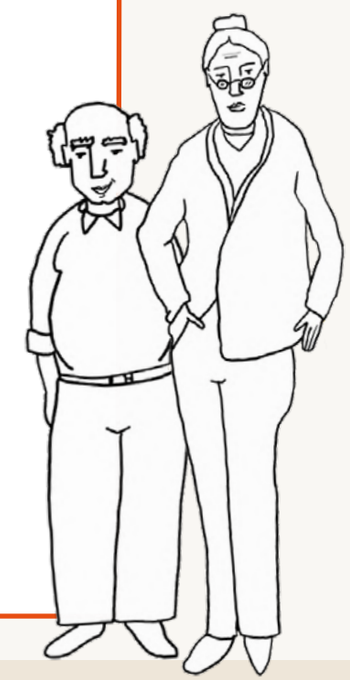
Source: Huete 2019 using IDB Harmonized Household Surveys for Mexico (2016) and Costa Rica (2017).

But where are people with disabilities? The naked eye is unreliable as many disabilities are invisible. Nonetheless, people with disabilities are represented in all age groups, genders, ethnicities, and socioeconomic groups. Not surprisingly, people with disabilities are disproportionately older as seen in **Figure 2** using the 2010 Census data for Panama. Across the region, the prevalence of disabilities is 4 to 6 times higher for people aged 60 to 69 as for people in their 20s; the prevalence rate in the population over 60 years old is upwards of 40% in many countries. The aging of the population in the region will swell the ranks further, as 1 in 5 persons is projected to be over 65 by 2050. While the age gradient reflects a functional decline associated with aging, the very low prevalence rates measured for children younger than 18 may reflect parents' unwillingness to stigmatize children or unawareness of difficulties given their age. A new set of child-specific questions has been piloted to improve measurement among children.[2]

Figure 2: Disability by Age and Sex, Panama 2010 Census



Source: Berlinski et al (2019) using 2010 Census for Panama.



In the region, more women than men live with a disability, reflecting the higher prevalence rates for women at older ages. Regression analysis finds that for the population aged 64 or older, prevalence rates are higher for women than for men in 7 of 8 countries with available data for the 2010 round of the census. Higher life expectancy for women means that the population in these older age groups is heavily female, which further influences the numbers toward women in the overall statistic. In general, the gender differences at younger ages tend to be less pronounced, as illustrated in the Figure showing prevalence by age and gender for Panama.[3]

Indigenous peoples have a higher prevalence of disability, as do people from lower income groups. In a vicious Catch 22, poor people are more at risk of a disability and people with a disability are more likely to be poor. Poor people are more likely to live in areas where infrastructure and services are less likely to be accessible and they are less likely to have the personal resources to be able to self-finance equipment, technology, and assistants to reduce barriers. For people with disabilities, the avenues to escape poverty narrow; quality education, decent jobs, and public services—the vehicles that could lift people from poverty—are often closed off by attitudinal and environmental barriers. Additionally, since people with disabilities face high costs for treatment and personal assistance, the impact of catastrophic health expenditures on family incomes is even greater.

The irony is clear. The most vulnerable groups in society—the elderly, women, indigenous peoples, and the poor—who are already some of the most excluded segments of the population, are also the populations with the largest proportion of people with disabilities. In many ways, their exclusion is magnified by having a disability.

Putting a face to the statistics is important. This large segment of the population includes our mothers, brothers, friends, neighbors, and ourselves if not now, then in the future. Disability, in short, is not a rarity; it's a basic color in the palette of human diversity.

Eureka

"The persons with disabilities are not pitiful nor incapable – we are unstoppable", **Julián Acosta**, athlete from Colombia

Key Tools:
Reasonable Accommodation and Universal Design

For far too long, the way governments approached people with disabilities was with paternalistic policies that, although implemented with good intentions, ended up segregating this community even more. Concepts such as special schools and segregated infrastructures such as separate entrances were the norm; and the cultural impact of these policies on the perceptions of persons with disabilities still casts a shadow today.

What is the proper approach to design and implement accessible and inclusive policy? There are two main tools: reasonable accommodations and universal design. These two concepts should be the new norm moving forward for understanding how to truly include people with disabilities.

A **reasonable accommodation** refers to a change made to an environment—typically work, school, or living area—to enable a person with a disability to enjoy the same access and participation as others. Adjustments are made in response to case-by-case requests to employers/schools/landlords and are considered "reasonable" if they do not create an undue hardship. This, of course, is contextual and varies by the level of income.

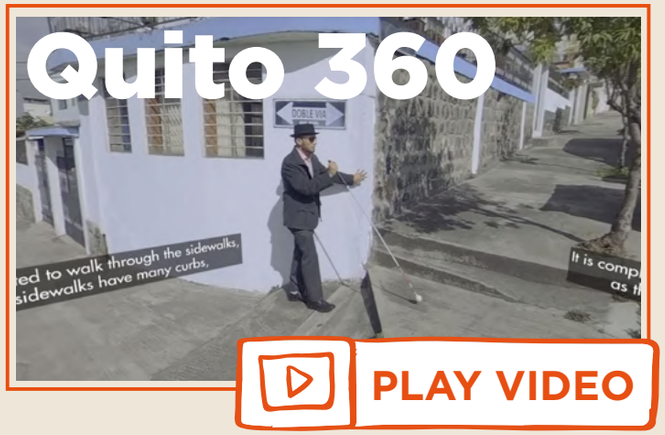
For example, an employee in a medium-sized firm in a city may request a type of equipment that accommodates their impairment, such as software that magnifies a computer screen for individuals with low vision or sign interpretation during audio meetings for individuals with auditory disabilities. Individuals may request reasonable accommodations to be able to participate in a job application process for positions for which they are qualified. For example, someone with autism or an auditory processing disorder may request that interview questions be written down or sent to them in advance. A renter with a physical disability may request the apartment provide grab-bars in the shower or toilet. Accommodations go beyond equipment and technology to include the waiving of policies, for example, the request to bring a service animal into establishments where animals are prohibited or permission to take a break or telework to recuperate after a seizure. While most accommodations

Decorative image

do not involve a monetary expense or cost very little, some requests may in fact not be reasonable or feasible because they are too costly for the employer/school/landlord to provide. That brings us to universal design.

Rather than making ex-post adjustments to a program or structure, the **universal design** approach implies planning for the needs of a diverse population from the initial phases of the project, such that the final project/environment will be accessible and user-friendly to a diverse population, including people with disabilities. While well-designed projects engage with people with disabilities from the initial planning stage to consider their needs, no project will perfectly anticipate the needs of all users. Thus, employing universal design principles in planning infrastructure and programming does not eliminate the need for reasonable accommodations. However, both the need for adjustments and the overall costs for accommodation are likely to be lower when inclusion happens from the outset. As anyone who has ever remodeled a kitchen would know, fixing anything that is already done ends up being more expensive than building it as it should be from scratch.

One example is the accessibility and inclusion that has been embedded through universal design in the Ciudad Mujer Project **(Women's City Project)** supported by the IDB in the Dominican Republic. Not only is the physical infrastructure designed to be accessible for people with physical and sensorial disabilities, but training protocols for addressing



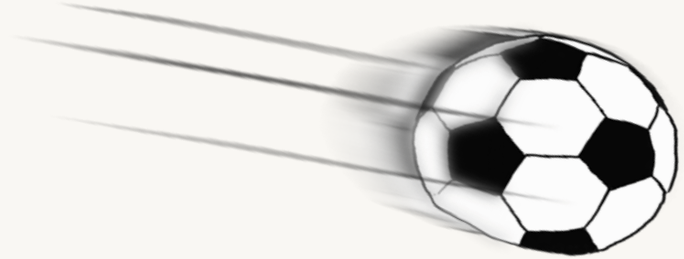
Quito 360

"We would need to get off the sidewalk and walk on the street, exposing ourselves to be hit by a car", **Pablo Vargas**, a pedestrian in Quito

health screenings, job placement, violence against women, and other modules have been designed to address the population of women and children with disabilities. Videos with closed captioning can also be considered a type of universal design in contrast to accommodations such as real-time captioning or simultaneous sign-language interpretation. For widely distributed videos it is much more cost-effective to include the captions than to make adjustments time and time again; in addition these features are useful for a broader audience. By properly implementing reasonable accommodations and universal design, impairments will be purely anecdotal.

The Moral, Legal and Economic Rationale:

The Hat Trick to Inclusion



People count...and they all add up. Everyone, including people with disabilities, has the right and responsibility to contribute to their families, communities, and countries. Morally, it is simply the right thing to do. Legally, it is a right sanctioned by international law. And economically, the math makes sense. This, in a nutshell, explains why it is important to give people living with disabilities every opportunity to live happy, productive, and fulfilling lives.

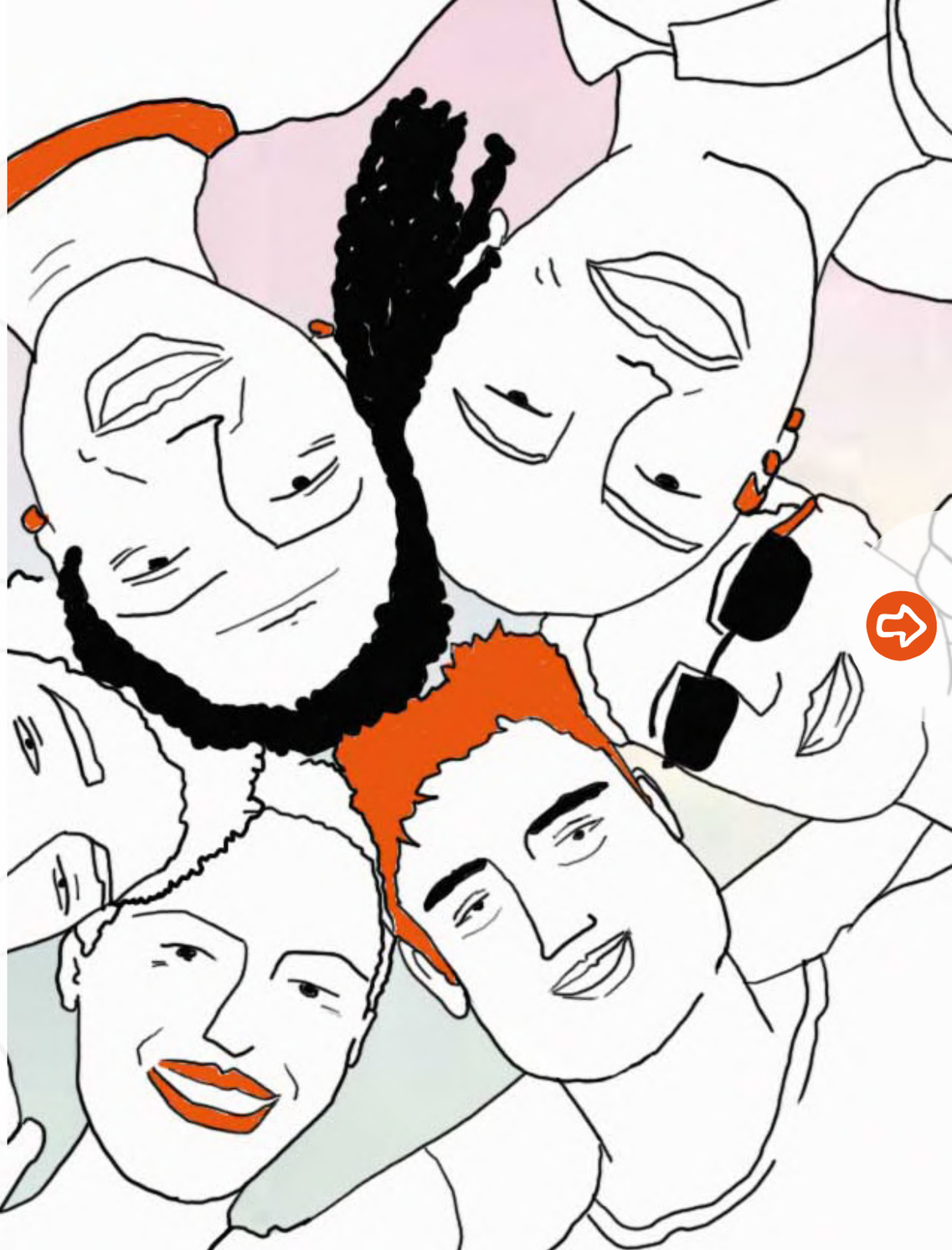
The Moral Case

Shouldn't empathy, understood as the ability to feel what others feel, be a good enough reason to have inclusion by default in everything we do? In a perfect world, the legal and economic arguments to include persons with disabilities shouldn't be necessary. It's just the right thing to do. But we are far from perfect and the mor- al justification, although overshadowed by the other more pragmatic reasons, must be stated as the first and driving force behind everything done for inclusion´s sake. From a human angle, why should any society make the slightest effort to include this community? Why should anyone care?

Whether over race, gender, ethnicity, age, or sexual orientation, people have fought for equal treatment and opportunity throughout the ages. People with disabilities haven't been apart from that struggle. Rather than being valued for adding diversity, these out-groups have been historically been subject to discrimination and exclusion by an in-group. By force of fear, hate, or plain and simple ignorance, this discriminative pattern of behavior used towards "the other" is deeply rooted in the human psyche and has sadly and repeatedly summoned scandalous displays of brutality, exclusion, and neglect. As Tzevan Todorov pointed out, "the fear of barbarians is what risks making us barbarians."

But, to be fair, humanistic values such as the equality, fraternity, and liberty preached during the French revolution have also had a good run throughout history and, at least on paper, seem to be where the international treaties are looking to drive the way we behave towards each other. The belief in dignity as an inalienable right for all humans is considered paramount to build better societies. All constitutions throughout the American continent refer to equal rights for all people and the United States Constitution even starts with the phrase "**we** the people," which is powerful proof of the relevance of that principle to this day. Even more so, it's a reminder of the constant need to update the definition of "we", as it has evolved to include more social collectives that have stood up for their dignity. The protests led by civil society, including the Civil Rights and Anti-War movements of the 1960s, opened the way for disability activists to make the Americans with Disabilities Act (ADA) become a reality, paving the way for more disability-rights-based activism in Latin America and the Caribbean and throughout the world.

Societies are composed of individuals, but individuals have a shared nature and destiny, a collective consciousness, and a spiritual dimension that inherently understands the demeaning of the dignity of one of its parts as a jeopardy for all. Along these lines, the UN Sustainable Development Goals motto prays for a world where no one is left behind. It is from this perspective that cancelling altogether the "otherness" of disabilities is a challenge we as a society need to achieve fast.

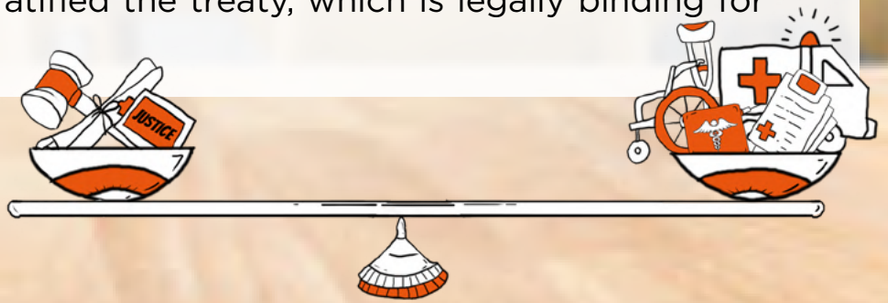


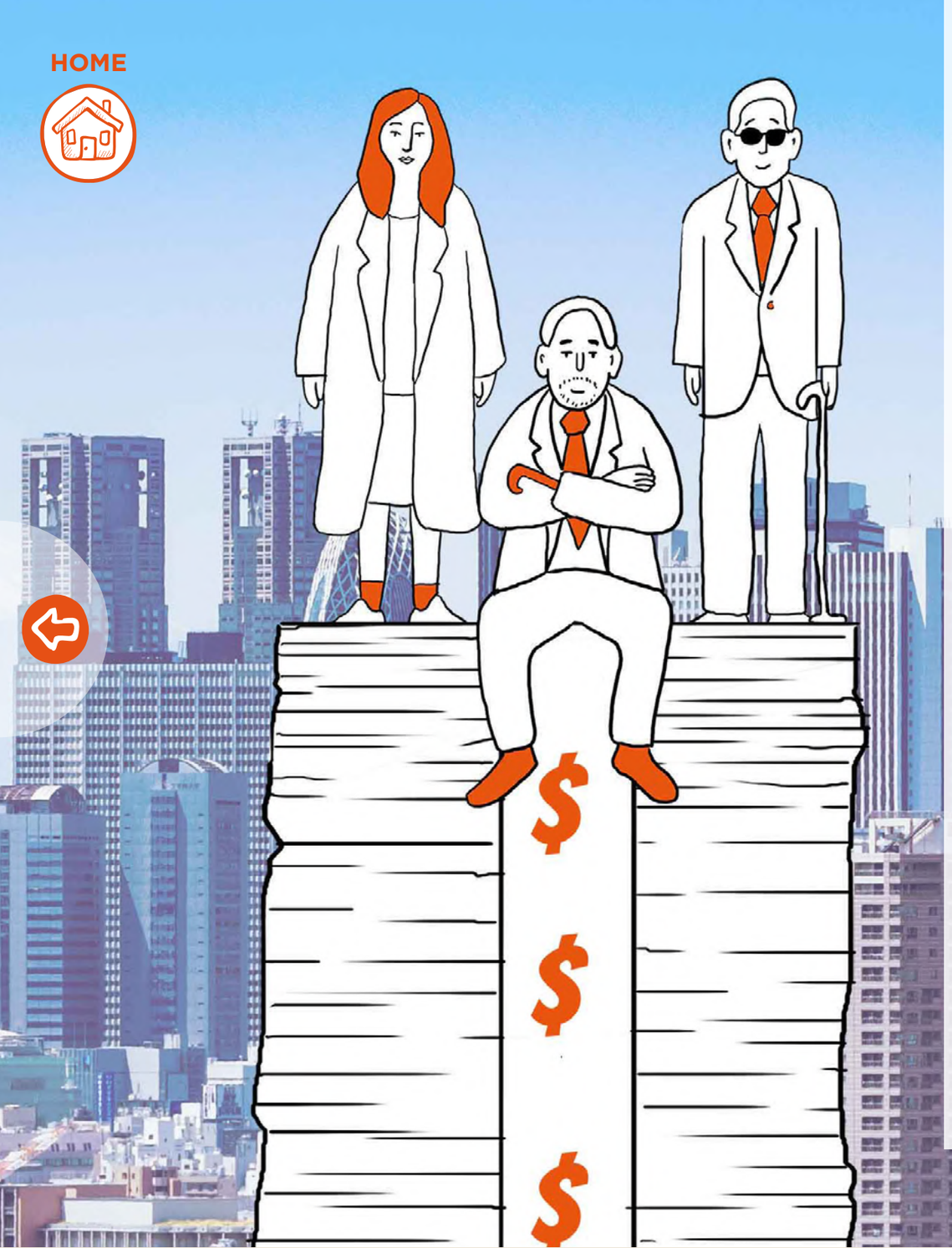
The Legal Case

We see it in social media and at the dinner table. People love to talk about how the world should work. But without legal frameworks all of these opinions are just that: opinions. Legal frameworks are roadmaps that mark the steps a society **must** follow in order to better itself. It's the difference between a nice to do and a must do. A mandate. Luckily, when it comes to the inclusion of persons with disabilities, it's not just an opinion.

The paradigm regarding disability has shifted and is enshrined in international protocols. Both the Organization of American States (OAS) and the United Nations (UN) have designed legal frameworks that embrace the social model of disability, which defines disability not as a static medical condition but an interactive relationship between people with impairments and the external barriers that limit their effective participation in society. The UN Convention on the Rights of Persons with Disabilities (CRPD) was introduced in December 2006 and is the most important international instrument to hold countries accountable for ensuring that people with disabilities are afforded all rights and basic freedoms. Its stated purpose is "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity."

The CRPD consists of 50 articles that cover the purpose and principles of the treaty as well as specific issues such as education and health in the context of disability. Importantly, Article 4 lists the obligations of States that have ratified the CRPD. These obligations include adopting policies and legislation to comply with the CRPD and abolishing existing legislation that violates its principles or that in any way conspires against the human rights of people with disabilities. To date, 179 countries have ratified the CRPD, and in Latin America and the Caribbean all 26 member countries of the IDB have ratified the treaty, which is legally binding for both public and private entities.





The legal case for inclusion is sound and clearly defined. The continued plight of people with disabilities in the region and worldwide speaks to the need for better enforcement.

The Economic Case

Given that people with disabilities make up about 13 percent of the population in Latin America and the Caribbean, it's easy to understand the economic cost of not taking full advantage of the production, consumption, and tax paying potential of this group. Just as the costs of exclusion are anything but negligible, so too are the benefits of including people with disabilities in economic activities. An IDB study examining Costa Rica, Chile, and Mexico estimates that including people with disabilities in the labor market would boost GDP by 2% to 3%.[4]

At its core, the economic problem for people with disabilities is that they are less likely to be employed than their peers. Among 24 to 35 year-olds in Latin America and the Caribbean, the employment rate for men with disabilities is 24 percentage points lower than for men without disabilities and for women, 12 percentage points lower.[5] Even among employed people with disabilities, salary levels are far lower reflecting different potential sources of exclusion. The lower skill levels observed on average for people with disabilities results in part from

previous exclusion in education, lower promotion rates, and unemployment spells. When employed, the jobs are more likely to be low-paying and in the informal sector. In Costa Rica, for example, 44% of employed 25 to 34 year-olds with a disability held formal sector jobs and, therefore, contributed to social security compared to 76% of employed people without disabilities in the same age group. Across the region this pattern of employment takes its toll down the road as social security contributions tend to be tied to formal sector jobs. People with disabilities are thus likely to have lower—or no—pensions in old age.

The challenges to including people with disabilities in the labor market are complex and intertwined. On the demand side, employer ignorance of the talent pool and reasonable accommodations can be addressed with training in what is entailed in providing these accommodations, training of co-workers and front-line staff, and public employment services. At the same time, environmental issues such as inaccessible transportation must be addressed to facilitate access to the workplace. Among potential workers on the "supply side" of this ecosystem, lower levels of education and technical skills or limited work experience can be addressed with vocational and occupational training. Inclusive training programs that simulate interaction in a context as close as possible to a real job experience are also critical, with many programs including soft skills components to encourage confidence and knowledge about the job seeking process.

While the challenges are great, they are not insurmountable and are best addressed by intermediating between supply and demand (that is, **connecting the talent of people with disabilities to the needs of employers**) as well as investing in both sides of the supply-demand equation (training both potential workers and the firms that could employ them). Examples of the first type of program are digital platforms designed to link jobseekers with employers without having to travel. Incluyeme.com is such a program that operates in six Latin American countries (Argentina, Chile, Colombia, Mexico, Paraguay, and Peru). The program has over 200,000 registered users and has found jobs for more than 1,300 people with disabilities, 92% of whom were previously unemployed. **Solutions should have inclusion at their core**, i.e., segregated training programs and segregated job search platforms are difficult to justify unless they are contributing to an inclusive ecosystem in the longer run. An employment portal for persons with disabilities should serve as a plug-in to a broader array of jobs openings

as well as training that may be provided through public employment services or other sources. Employers should never get the message that it is ok to send "bad jobs" to a digital jobs platform for people with disabilities while sending their "good jobs" to a general job bank.

Is It Possible to "Nudge" Inclusion?

Within the Latin American and Caribbean region, 15 countries have legislated employment quotas that require private sector firms above a certain size to employ persons with disabilities as a certain percentage of their workforce. Despite strong legal frameworks, compliance with quotas is extremely low across the region. In Peru, for example, a recent study found that only approximately 8% of firms hired at least one hour of work by a person with disabilities.[6] The study found that just sending a letter that reminded firms about the quota— independent of whether the letter mentioned a punitive fine or had a positive tone — increased the probability of the firm hiring work by people with disabilities by 2 percentage points with the punitive letters having the strongest impact (2.9 percentage points). The study also found an increase in the percentage of the workforce registered with a disability at firms in which the quota applied, suggesting that a very low-cost intervention — sending a letter — may make an existing policy —quotas—more effective, and boost the hiring of persons with disabilities.

So, do the quotas themselves work? Is it possible to "mandate" inclusion? Rigorous studies have found mixed results. Studies in Austria, Japan, and Spain have found firms with sizes just above the binding threshold of the quota, employ a greater share of workers with disabilities. However, the studies in Austria and Spain found that the direct effects were attenuated by firms poaching workers with disabilities from other firms and reclassifying longstanding workers as having a disability as opposed to hiring new workers. In the Austrian study, 64% of workers were already employed before certifying their disability status. Worse yet, firms may create menial jobs with low salaries simply to comply with the law. More research is needed, particularly in Latin America and the Caribbean, to examine whether these policies are effective at promoting labor market inclusion. Stay tuned!

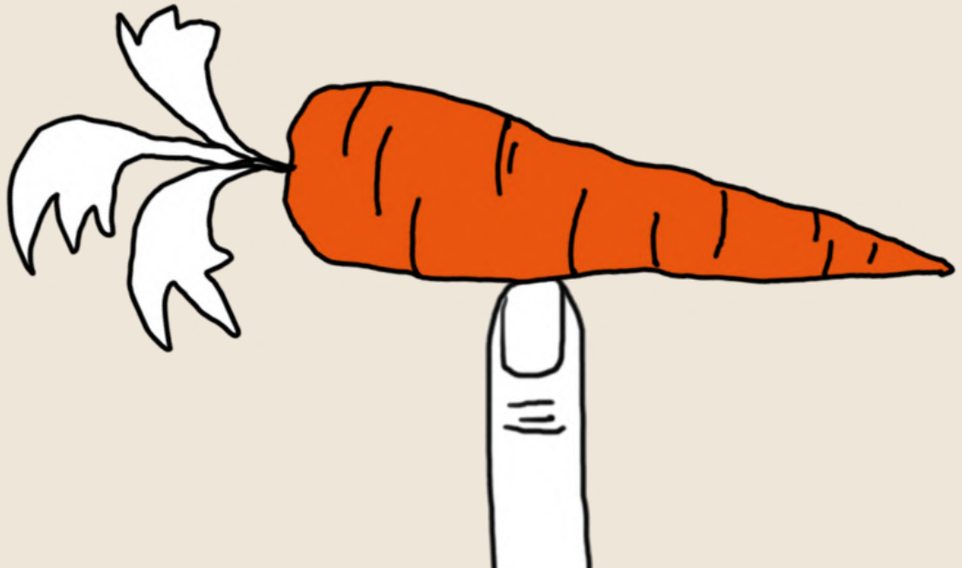
Carrots and Sticks

Governments have the power to set the tone for inclusion by balancing the threat of penalties with the promise of rewards. Rather than sanctioning firms for failing to meet quotas, programs like Chile's **Sello Inclusivo** (Inclusion Award) certify and publicly recognize firms for outstanding performance in disability inclusion. The publicity that accompanies these rewards can help motivate other firms to follow suit and step up their efforts to be more inclusive employers.

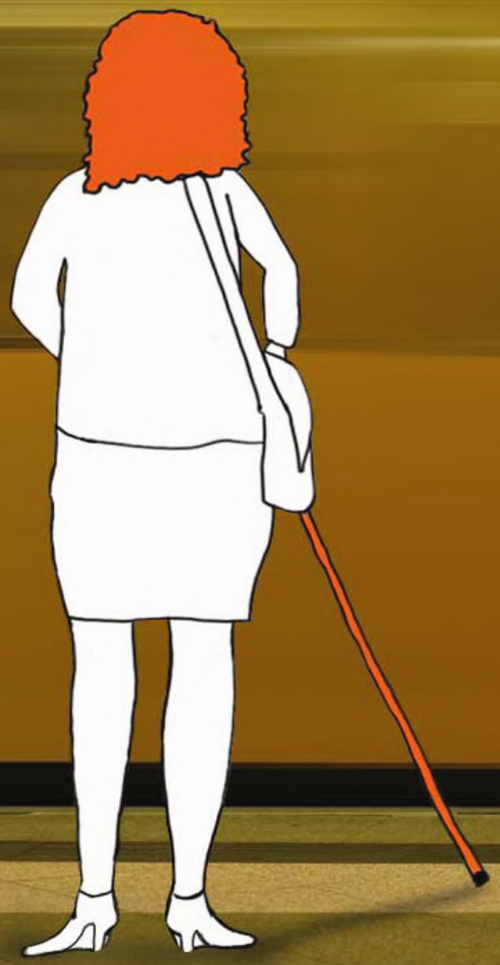
Among public employment services, Colombia's Pacto de Productividad is an interesting model. A public-private partnership, it works with both potential workers and potential employers. The program provides employment guidance in 11 employment centers to people with disabilities and technical advice to firms on how to interact and support people with disabilities. Companies learn to view workers with disabilities not as a challenge but as an asset to their organizations.

The most promising programs contribute to a better functioning overall ecosystem, which includes a private sector equipped to recruit, hire, and support the employment of persons with disabilities, accessible public transportation, and labor market intermediation systems.

"If we were included in the labor market with more and better jobs, with good wages ... we could contribute to economic growth"



Breaking Bad Health Myths



Living with a disability is not synonymous with sickness and weakness. This was clear to the record-breaking number of spectators of the approximately 2,000 para athletes competing in the 2019 Parapanamerican games in Lima this August, as they exemplified physical capacity and steadfast tenacity. However, like all other citizens, people with disabilities do get sick, and, like all other citizens, need affordable, high-quality health care to live productive, socially engaged, and happy lives. And people with disabilities are subjects with rights that struggle with barriers that prevent access to these rights, which is the fundamental point of the CRPD.

Many impairments associated with disabilities do not necessarily imply poor health—for example being blind, deaf, having autism, or missing a limb. These impairments become disabilities after interacting with barriers, including those in the health sector. At the same time, other impairments may be associated with greater health needs over the course of one's lifetime. In fact, evidence from around the world shows that people with disabilities have less access to health services and poorer health outcomes.[7] The barriers to health and rehabilitation services that people with disabilities confront are still daunting in most countries, including those in Latin America and the Caribbean. But, what and where do those barriers exist? What is being done now and what can be better done in the future to overcome them?

In order to understand this, we must first separate the obstacles that exist around the health sector—in society at large—from the obstacles that exist within health systems.

Barriers around the Health Sector

Human rights are interdependent. They affect each other for better and for worse. It´s fair to say, for example, that lower levels of education and/or inaccessible transportation contribute to lower labor market participation among people living with disabilities which leads to difficulties in obtaining health insurance and paying out of pocket for health and rehabilitation services. So even though education, transportation, and employment are not part of health systems, they have an effect on the actual health and wellbeing of persons with disabilities.

Society also fails people with disabilities in many other ways that end up jeopardizing people's health. Information is often not available as to what services exist and where. Transportation to far flung and distant health clinics may be particularly difficult for those living alone and in rural areas. Public transportation often isn't accessible, either for people with mobility impairments or other disabilities. Taxis are often unwilling to stop for people with visible

disabilities or are not adapted for accessibility. Communication systems, such as emergency telephone numbers, are often inaccessible for people with hearing disabilities as they strictly require that someone speak on a phone versus allowing for text messaging or video interpreting. Many websites providing information about available health services lack the basic design features to be digitally accessible for people with sensorial disabilities that use screen readers and other software to navigate the web.

Barriers within Health Systems

Besides these and other barriers around health systems, once people with disabilities finally reach a hospital or clinic, they face additional obstacles: the facility may not provide accessible materials and appropriate signage. In Chile, for example, 30-37% of people with disabilities report low rates of accessibility to health care services, which is 50% higher than for people without disabilities.[8] Few doctors and nurses are trained specifically in the needs of people living with disabilities. Health staff may have biased attitudes, or they may lack basic skills. For instance, doctors and nurses may fail to take the complaints of people with cognitive disabilities seriously, or they may not know how to engage and interact physically during exams.

The result is that while in many countries people with disabilities often seek out health services more than the average citizen, they have less access to these services. This puts people with disabilities at much greater risk of developing complications. People with disabilities tend to have lower rates of medical testing compared to the general population, like screening for breast and cervical cancer in women and prostate cancer for men, and can suffer from common conditions, like influenza or pneumonia and not receive treatment. Health problems, typical of people with mobility issues, like urinary tract infections, chronic pain, and obesity, can also be left unaddressed, and sexual and reproductive health, including contraceptive needs and the prevention and treatment of HIV/AIDs, may be ignored under the widely shared and mistaken assumption that people with disabilities don't have a sexual life.

Rehabilitation, including training exercises and counseling, lies at the core of empowering people with disabilities to live autonomous lives, and make independent decisions about health, education, work, family, and leisure activities. Assistive technologies, like prostheses, computer screen readers, hearing aids, and magnetic loops are part of that. But in the region, only 3% of people with disabilities have access to rehabilitation services; in Peru and Haiti, less than 10% of people with hearing impairments have access to assistive technologies. Stigma—and the failure to prioritize mental illness—also mean that psychosocial disabilities like schizophrenia and mood disorders are left untreated. The population with psychosocial disabilities that has received rehabilitation, to cite just two examples, is less than 25% in both Colombia and Mexico.

These deficiencies tell a story of unmet needs and violated rights throughout the region in contravention of the CRPD. The convention recognizes that countries should provide the same quality and standard of free or affordable health care to people with disabilities as to other persons, provide services for early identification to prevent further disabilities, and prohibit discrimination of health care on the basis of disability.

Can we do better?

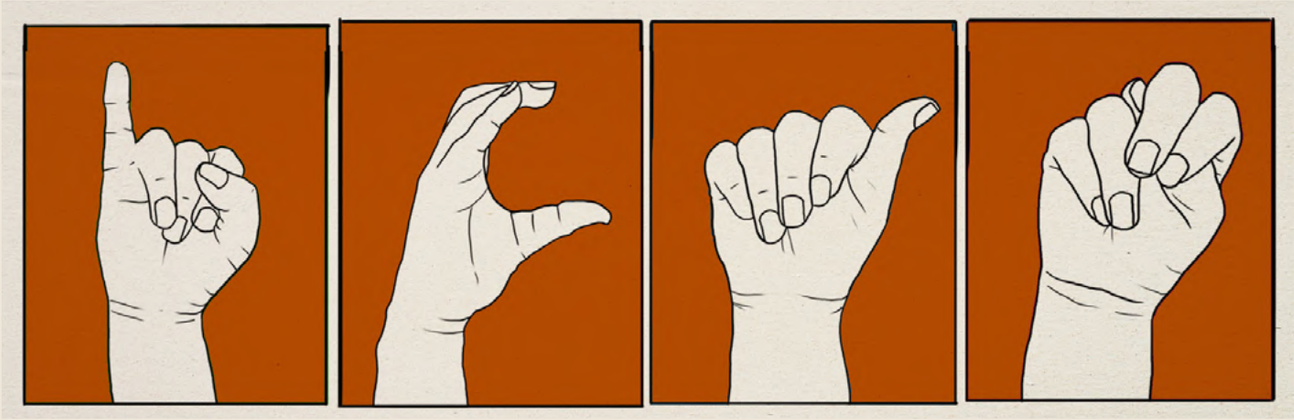
The good news is that promising ideas and initiatives have emerged—some of them in Latin America and the Caribbean.

Cash Transfers for Inclusion and Quality of Life

Consider the issue of healthcare costs. A person with disabilities in a low- or middle-income country dedicates 15% of household spending to healthcare costs compared to 11% for a person without disabilities, according to the World Health Survey. Catastrophic health expenditures that push families into poverty are also more common among households with a member with a disability. Fortunately, the region's well-developed system of conditional cash transfers offers the possibility of targeting funds directly to an underserved population.

In Ecuador and Paraguay, the conditional cash transfer programs known as the Human Development Grant and Programa Tekoporâ provide an additional subsidy for people with disabilities who meet the poverty criteria. Government programs in Ecuador, the Dominican Republic and other countries also provide wheelchairs, hearing and visual aids, and prosthetic devices, as well as psychological services and rehabilitation.

Meanwhile in Chile, the National Service for Disability (SENADIS) provides assistive technologies and rehabilitation services, either for free or with a subsidy for children under 10 who are below the income threshold.



I - C A N

Finger-spelled in ASL

This helps empower children at a critical moment of their development, giving them a greater chance at full inclusion into society.

Community Programs: A Path to Move Forward

Some of the most longstanding endeavors applied in rural and under-resourced areas involve community initiatives that often work in collaboration with nongovernmental organizations (NGOs), local districts, and people with disabilities to mobilize local resources and promote autonomy.

It starts at the beginning—with early identification and rehabilitation. In Quilpué, Chile, a pilot program in a local hospital trains nurses to identify signs of autism in children before age two. In addition, parents volunteer and receive accreditation as community agents in teaching parenting skills for children with autism. Studies have repeatedly shown that intervention at an early stage in a child's life in the autism spectrum has a greater positive impact than when introduced later.

In Nicaragua, a community program collaborates with self-help groups focused on disabilities, like high blood pressure or diabetes. People in the groups raise money for treatment. They share experiences on how to monitor their conditions and help each other adjust to healthier lifestyles.

Another community program in El Salvador, involving the Italian association **Amici di Raoul Follereau and its partners**, provides health professionals to train self-help groups for spinal cord injuries so that people can manage issues related to immobility, including bladder and kidney problems.

Adaptive Sports

A different way to approach health and wellbeing for persons with disabilities is by promoting healthy lifestyles. Sports, for example, help keep people in shape and maintain cardiovascular health while offering the thrill of competition and improving socioemotional skills such as self-esteem and communication. A regional IDB project

is extending adaptive sports to more than 650 athletes in 25 communities in 8 countries. Moreover, the project has provided a path for elite athletes with disabilities to showcase their talents, with some joining the Paralympic movement en route to tournaments at the international level. Hundreds of similar local organizations exist in Latin America and the Caribbean—examples of how an energized civil society can do much to promote 21Th century skills while transforming common perceptions about disability in the community.

A Healthier Way to Go

But governments must do much more. First and foremost, they need better systems to assess and certify people with disabilities. These systems are critical for connecting people with disabilities to ample, integral services, and providing individualized information on pathways to inclusion in schools, the labor market, and recreational activities.

Governments must also train health workers better. This could involve special courses in medical school, continuing education, and courses taught by people with disabilities themselves. Ignorance of disability among health workers must end. Health workers need to learn to identify disabilities early, to know how to touch people with disabilities, deal with related health issues, communicate, and most importantly to shed prejudices, especially when it comes to cognitive and psychosocial disabilities.

"I threw myself in – I didn't think that I could win it!" **Alejandra Aybar**, athlete from the Dominican Republic

Finally, governments need to find ways to fund health care for people with disabilities, taking into account the higher levels of poverty and unemployment that often make it difficult for them to afford private health insurance or participate in contributory health insurance schemes. Means-tested programs should consider the higher costs of living with a disability.[9] Nobody should be forced into economic catastrophe because of a health care need and struggle to survive. Governments can build a safety net, subsidizing health insurance for people with disabilities, providing targeted transfers, and moving towards systems of universal insurance. Health coverage in Colombia is a good example. The National Disability Insurance Scheme (NDIS) in Australia is another, with grants that allow people to make their own choices about which healthcare services to purchase.[10]

More robust and inclusive health systems, well-funded and free of prejudice, can prevent a kind of multiplier effect in which illnesses compound and disabilities pile up. They help provide the basic conditions for people with disabilities to receive education, participate in the workforce, and enjoy happy lives, so that their basic rights are respected, and nations can further prosper through their contributions. Working towards those goals is a sign of modernity. The stakes in getting it right are immense.

The Right to Say "No" and The Right to Say "Yes"

Girls and women living with disabilities in Latin America and the Caribbean face harrowing levels of violence. These crimes often go undetected and unpunished. While it shocks the conscience, societies as a whole are only now becoming aware of the problem and governments moving to address it.

In 2006, the CRPD drew special attention to the vulnerability of girls and women with disabilities to mistreatment, neglect, violence, and exploitation. It also called for measures to guarantee their rights and make disability a key part of development strategies. More than a decade later, there has been far too little progress, with limited data collection and halting advancements on prevention.

Getting a handle on the scope of the problem is crucial. But in Latin America and the Caribbean, only Colombia collects a data sample large enough to calculate precise estimates of violence against women and girls with disabilities. Globally, one in every three women experiences physical or sexual violence in the course of their lifetime. The rates for women with disabilities are much higher. In the United States, for example, women with disabilities are two to three times more likely to suffer physical and sexual abuse than women without disabilities. Women—as well as men—with intellectual disabilities face sexual abuse at seven times the rate of those without disabilities.

Part of the problem is the segregation and isolation of people with disabilities: the failure of societies to fully grant rights and ensure full participation in economic and social life. It often happens in the home, where people with disabilities have been confined because of poverty and longstanding exclusion. It could be a spouse, other family member, or paid personal assistant. Attention can turn abusive, ranging from verbal attacks and threats, to neglect of medical and nutritional needs, outright physical violence, and sexual abuse. If communication with the outside world is constrained as a result of never learning sign language or all communication being directed through family members, then isolation is exacerbated. Opportunities for abuse escalate when the decision-making capacity of the person with disabilities is deprived through an unjustified guardianship.

Personal intimacy with an assistant makes it hard to report the abuse. So does shame and stigma. In Colombia, for example, women with disabilities report being threatened or abandoned by their husband or partner at a rate 4.5 times greater than women without disabilities, and they are physically assaulted at a rate of more than 10 percentage points higher. But less than half of Colombian women with disabilities report seeking help for violence.[11]

The insularity of rural communities, often bound by their own rules and cultures, can make the problem worse, whether it occurs at home or in a public place. Women's shelters are an option in many parts of the world, and they exist in large parts of the region. But they are less likely to exist in rural areas. They also may lack personnel specifically trained to deal with issues related to disability and the infrastructure may not be accessible for women with physical or sensorial disabilities.

That leaves women with disabilities with few alternatives. In 1994, countries in the region signed the Inter-American Convention on the Prevention, Punishment, and Eradication of Violence against Women, which calls for measures to both prevent and provide justice for domestic violence and violence in the public sphere. As a result, countries in the region have implemented a host of strict laws punishing domestic violence and providing relief, including emergency phone lines, free legal advice, and police protocols to address the problem.

But women with disabilities may be deprived of those protections. Breaking free from an abusive situation and navigating to a police station to denounce the mistreatment may not be feasible. Emergency hotlines may not be accessible to people with hearing or speech difficulties. And with an intellectual impairment, one may lack the tools to articulate what happened and to be taken seriously by skeptical police.

With respect to the population of institutionalized people with disabilities, although representative data on this population are not available in the region, assessments of specific institutions for people with disabilities in Brazil and Mexico have revealed extremely disturbing conditions. A recent report in Brazil found poorly funded centers operating as detention facilities. Staff in eight institutions reported that given personnel shortages they resorted to using physical restraints to incapacitate individuals until personnel were available. Moreover, the report found there was no mechanism through which an individual could challenge their involuntary commitment.[12] A 2015 report by Disability Rights International (DRI) revealed that more than 40% of women who had been treated at four psychiatric institutions in Mexico City had been sexually abused and that 40% had been coerced into being sterilized, with some cases meeting the standard of forced sterilization.[13] Both are inconsistent with the CRPD.[14] The practice of forced sterilization of women with psychosocial and intellectual disabilities has also

been documented worldwide beyond institutionalized populations. Experts such as Ana Peláez, a member of the U.N. Committee on Elimination of Discrimination against Women, has called for legal reforms in Europe and other regions.[15]

There are few topics more personal than sexual agency and the decision to have children; but women with disabilities, particularly women with intellectual disabilities are too often deprived of their rights either through guardianship or institutionalization. Moreover, women with cognitive impairments may not know about sexual and reproductive rights because of a lack of education on how to exercise these rights and how to make informed choices. Direct access to police authorities may be constrained and women may be forced instead to rely on intermediaries who may not have their best interests at heart. DRI founder and executive director, Eric Rosenthal, alluded to this fact in a communiqué accompanying the release of its 2015 report. "After two decades of investigating abuses against people with disabilities," he said, "it is DRI's experience that the main reason for forced sterilization is to cover up sexual abuse against women and girls by preventing pregnancy."

Latin America and the Caribbean faces an epidemic. Over just the first 10 months of 2018, there were more than 1,500 reports of violence against people with disabilities in Peru, more than 70% of which corresponded to women, according to the National Program to Combat Domestic and Sexual Violence. That may very well be an underestimate. But it is only one of many examples of the abuses inflicted around the region.

The question is what can be done. First and foremost, there has to be better prevention. That means improving the reporting and investigation of violence against women with disabilities so that abuses can be stopped, police procedures made more effective, and data harvested using international standards that allow for comparisons across countries and the design of better policies.

It means improvements in the safety of public transport and the establishment of emergency hotlines that allow women with hearing and speech difficulties to communicate and receive information safely through text. While some 911 systems in specific geographic areas can already support text messages, there are country-wide efforts such as New Generation 911 that are being developed

in the United States and Canada, which will also support images as well as texts. As part of this project, mobile networks in Canada are required to enable real-time-text to 911 by December 2020. Hotlines in Latin America and the Caribbean can adapt the existing prototypes as the underlying technology not only expands but becomes more cost-effective.

The institutions of justice, including the courts, can be improved to meet the needs of people with disabilities by updating frameworks that strengthen legal capacity, providing legal aid, and reasonable accommodations such as sign language interpreters when necessary. Shelters and centers providing services for women also need to be made accessible and inclusive, with staff trained in sign language, and protocols for determining legal capacity as well as interacting with personal assistants.

Sexual and reproductive education for girls and women with disabilities is critical. In Malawi, after a rash of unintended pregnancies among women with hearing and visual impairments, many victims of rape, the Visual Hearing Impairment Membership Association (VIHEMA) launched an initiative to teach people about both personal care and their rights under the CRPD. Health care workers were trained in how to communicate with people with sensory impairments and shown the fallacies of using sterilization as a way to protect women. Campaigns on national radio, led by people with hearing and visual impairments, explained where and

how people could gain access to sexual and reproductive health. Thinking in communities changed, and a multiplier effect was created in which both those with disabilities and those without strived to increase their knowledge of women's needs, according to VIHEMA.

In the United States, a Safety Awareness Program (ASAP) conducts eight weekly, 2.5-hour sessions, led by women with disabilities, to teach peers how to better protect themselves and resist sexual and domestic violence. Another program, A Personal Safety Curriculum for Adults with Intellectual and Developmental Disabilities, focuses especially on improving decision-making to help women escape abuse. Both programs seem promising, and if they stand up to further independent evaluations, should be considered for piloting in Latin America and the Caribbean.

Although most Latin American and Caribbean countries have ratified the CRPD and the Convention on the Elimination of All Forms of Discrimination against Women, and most laws that directly or indirectly protect the rights of persons with disabilities, only a few have specific laws that address violence against women with disabilities comprehensively. Uruguay's 2018 Law on Violence against Women Based on Gender stands out in this regard, including among other measures, the rights of survivors of violence to interpreters and

other reasonable accommodations for preventing, attending to, and rehabilitating survivors. Peru and Colombia's recent laws on legal capacity are also important instruments that can be deployed to promote the autonomy and independence of women with disabilities, including sexual and reproductive rights. Finally, improved data collection is necessary such that experts can rigorously demonstrate progress made in eradicating violence against women and girls with disabilities in Latin America and the Caribbean.

Legal Capacity

Under current laws on legal capacity, many people with intellectual and psychosocial disabilities are prevented from exercising their full citizenship. Guardianship laws allow for a third person to take all decisions relevant to a person's life, including health, family, and residence, sexual and reproductive choices, political and financial decisions. A person placed under guardianship cannot vote, cannot render valid testimony before courts, cannot marry or adopt, and cannot make decisions about their life in society.

A handful of countries have advanced regulatory frameworks for legal capacity consistent with the CRPD. Under these frameworks, the government cannot presume that a person requires supported decision-making; an assessment must occur to determine the level of support to make decisions. Supports for the exercise of legal capacity include, among others, technological and communicational accommodations as well as facilitators to provide accompaniment in decision-making processes.

Graduating Special Education

In 1994, representatives of nearly 120 countries and international organizations gathered in the ancient Spanish city of Salamanca to declare a new era in education. Schools, the representatives stressed, should be inclusive of all children, regardless of disabilities. The time of separate but equal in education—with special education schools and mainstream schools in separate worlds—was over, never having been equal to begin with.

Today, 25 years after the statement issued in Salamanca and the specific recommendations laid out in its framework of action, that goal remains elusive, including in Latin America and the Caribbean. Many countries have aspired towards fuller inclusion in education, seeking to eliminate discrimination in schools and ensure all children have an opportunity for a good education. But they are yet to invest sufficiently in the data collection, infrastructure, resources, and teacher training to turn that aspiration into a concrete achievement. If there has been some progress, the attainment of genuinely egalitarian educational systems is still far off.

This is distressing not only because of the obvious issues of morality and human rights. It is also because special education schools struggle to provide high-quality education that opens doors to labor market inclusion.

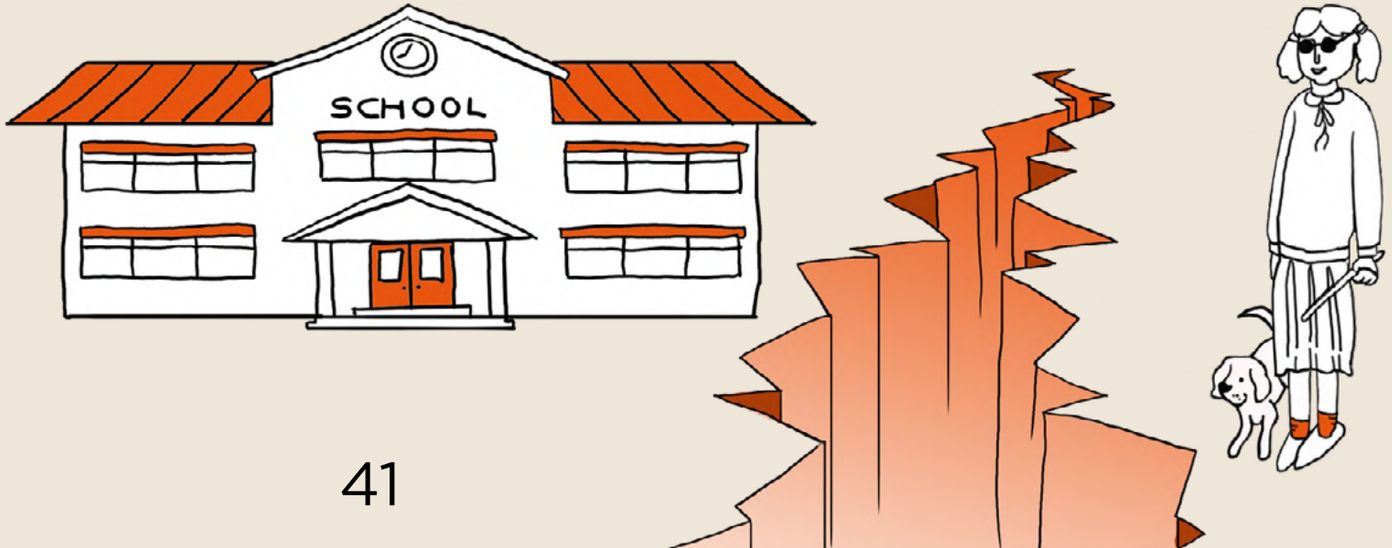
"Editor's note: recent studies have shown attendance rates of children with disabilities to be above 60% in Latin America and the Caribbean. 16"

Even though special education schools often have well-trained and dedicated teachers, striving to serve children with disabilities they tend to have lower academic standards than mainstream schools and are not aligned with education standards in the CRPD. In the worst of cases they perpetuate a caste system that feeds stigma and discrimination. What is required is to harness the existing good practices in special education schools, such that this can be redirected to inclusive schools.

Gaps in School Attendance and Completion

This outdated approach contributes to large-scale losses in education. Globally, children with disabilities are less likely to attend school and complete secondary school, a crucial step in emerging from poverty. So too in our region. A review of eight countries from Latin America and the Caribbean shows that school attendance for primary school age girls and boys with disabilities lags behind those without disabilities by at least 7 percentage points, with an average gap of 10 percentage points at the secondary school level. The average gap in secondary school completion for children with disabilities at 13 percentage points is similarly alarming.[16]

This all means that the move towards full inclusion is urgent, that change has to happen on all fronts.



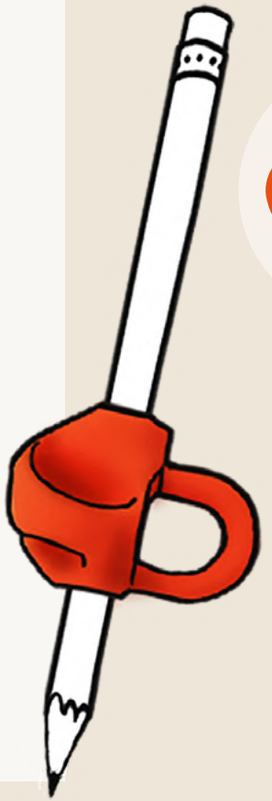
Catalyzing the Transition to Full Inclusion

The path to inclusive education requires transformation at the philosophical level. A dramatic paradigm shift in education must occur from a teacher-centered one—a "one-size-fits-all" approach to which every student must conform—to a student-centered one, in which the distinct student strengths and styles are taken into account and a common curriculum is adapted through differentiated instruction such that every child can flourish. In such a system, kids with disabilities wouldn't be separated into a different space with a distinct curriculum. Children might learn at a different rate or tackle subjects in a different order. But all would have access to the same material.

In such a system, **students would not be rigidly categorized.** Teachers and school administrators wouldn't refer to students as "special ed" or ¨slow¨ as they have in the past, shunting them in the process into categories that exclude and distance some from others. They would instead describe student's difficulties neutrally and avoid labels that result in alienation and loss of self-esteem.

Teachers would also be better trained. Few teachers at mainstream schools know sign language—and there is no need to expect that all would. But teachers should receive training in how to manage diverse classrooms and resource specialists with specific skills can provide additional support for inclusion.

Infrastructure and equipment are critical. New schools may have to be built and old ones modified, with wider doorways for people in wheelchairs, accessible toilets, or other changes to make them genuinely user friendly. Signage should include easily recognized symbols or simple wording for people with intellectual disabilities and braille for blind people. Schools need to be well equipped. Reasonable accommodations encompass assistive technologies of all levels of sophistication. The examples of this include digital screen readers with text-to-speech technologies and braille materials for children who are blind or have low vision; and simple creative solutions such as easy-grip pencils for children

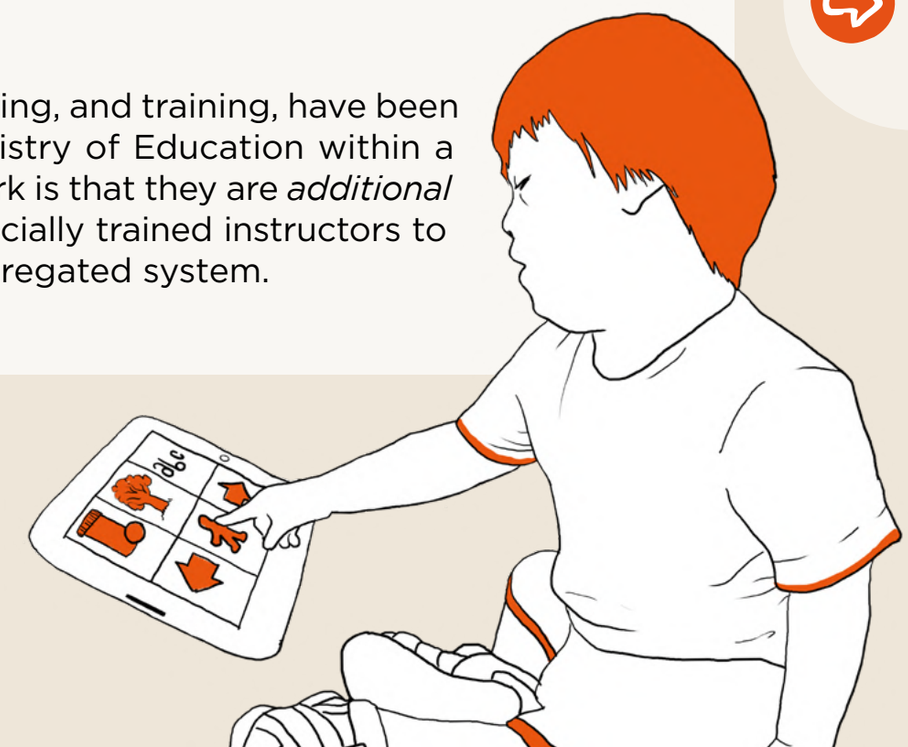


with fine motor skill impairments. Buses have to be adapted with lifts and ramps for children with mobility issues, as called for in the U.S. Disabilities Education Act of 2006 and also exemplified in the accessible transportation systems of the Brazilian cities of Curitiba and Uberlandia.

The little information available shows that the region lags behind in school infrastructure. Censuses in Mexico, Argentina, and Peru find grave deficiencies in even the most basic items. To cite just a couple examples, the percentage of primary mainstream schools with ramps for access ranges from 2.4% in Peru to 29% in Mexico, and the percentage of primary mainstream schools with accessible toilets ranges from 1% in Peru to 14% in Mexico, with Argentina between these two countries in both categories.

Transformation away from special education to inclusive schools does not occur overnight, and must take into account the environment in which special education institutions function. Some countries such as Portugal transformed their special education schools to serve as centers of support and teacher training for mainstream schools, recognizing the pool of professional talent in the institutions. Or, as in Barbados, they can serve as bridges, where students with disabilities study a couple of days a week, with access to reasonable accommodations that are not yet universal, enabling inclusion the rest of the week in the mainstream schools.

In El Salvador, extra assistance, including assessments, additional tutoring, and training, have been established in so-called “support rooms” that are funded by the Ministry of Education within a few mainstream schools. Essential to making such “support rooms” work is that they are *additional* to inclusive classrooms, ways of providing the needed expertise of specially trained instructors to students and teachers, rather than an attempt to create a parallel, segregated system.



To move towards full inclusion in education, of course, will take political will and resources as attendance for children with disabilities already falls off rapidly in much of the region at the secondary school level.

Consider Chile, where virtually every child with a disability attends both primary and secondary school; the 1990s witnessed the birth of the School Integration Program (Programa de Integración Escolar or PIE), which seeks to make inclusion the reigning approach of the country. Today, more than half of mainstream schools participate in the voluntary program, which offers grants to schools that enroll children with disabilities. These grants can only be used for specific purposes including diagnostic material, assistive devices, and inclusive teaching materials. They also cover training for teachers that need extra skills and help to ensure that resource specialists are on hand in classrooms to help both teachers and students.

PIE is far from perfect. It has been criticized for its voluntary nature. In addition, its discretionary character allows schools to specialize in areas where staff have existing capacity, rather than tailoring programmatic support to student needs. Still, in a region where the segregated model often prevails, Chile's movement toward greater inclusion is a step in the right direction.

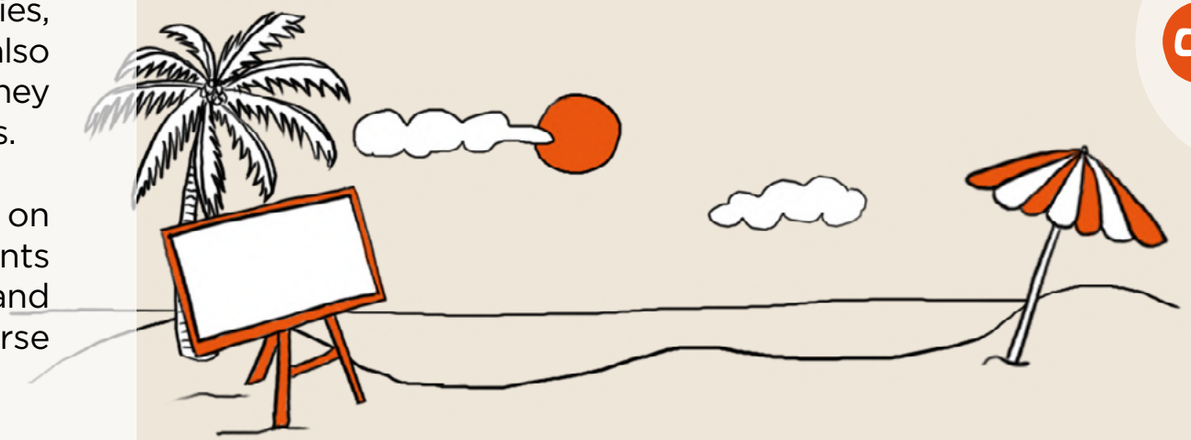
The Fiji Model

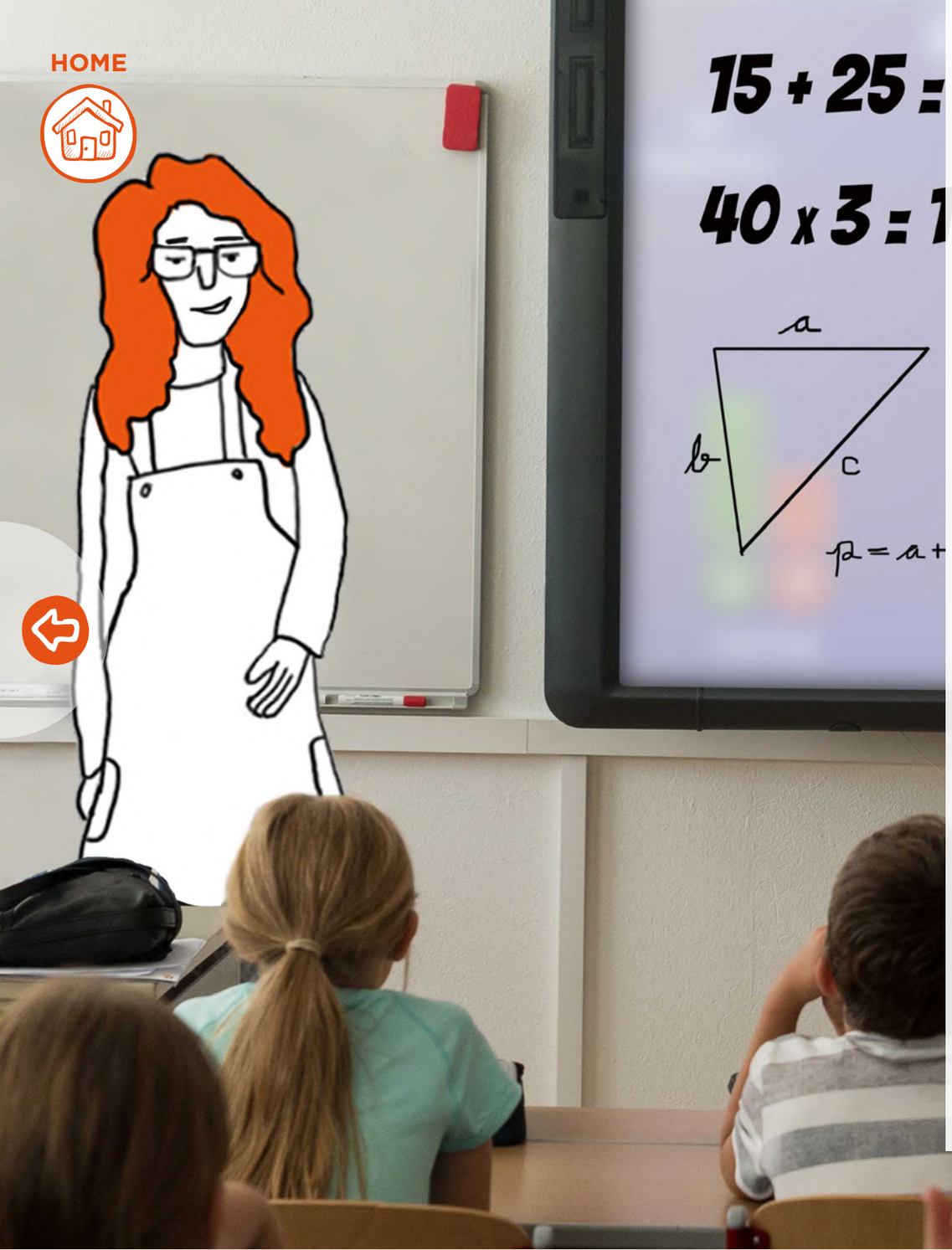
In the developing world—indeed in the entire world—Fiji stands perhaps as the most remarkable example of how a country can most fully pursue educational inclusion. The small nation of islands strung across the South Pacific has not only adopted policies to embrace inclusion but also dedicated resources to the cause. It has harnessed one of the most powerful tools to ensuring that education is truly child centered and customized to each individual student's needs: data.

Most school systems in the world administer what is known as an education management information system (EMIS), an annual census with information on all the children, facilities, materials, and teacher certifications in each school. Some also collect information on children with disabilities, even if they tend to undercount by registering only high support needs.

Yet school systems generally do not have information on whether facilities are adapted and accessible to students with disabilities, whether they have adequate materials, and whether teachers have been trained to handle more diverse classrooms.

The Fiji Management Information System (FEMIS) fills in those gaps. It has very detailed information on all a school has to offer in terms of facilities, equipment, and teacher training. And it has a remarkably granular student assessment form.





That form doesn't simply ask whether a child is "blind." It asks whether the child has "no difficulty," "a little difficulty," or "a lot of difficulty" seeing, or "cannot see at all." By asking the questions relevant to physical and sensorial disabilities, as well as learning and cognitive disabilities, behavior, socialization, and mood, it captures a level of detail that assessments in other countries do not.

But that is not all. Each student assessment form evaluates whether the services a child needs are offered at the school, and if not, where outside the school system they might be met. Thus, if services cannot be met within the school and the school budget, the assessment enters a wider system to assign scarce resources in order of priority.

This information is digitalized, available on-line, and linked to the national teacher data system and the national literacy and numeracy assessment data base. As a result, the country as a whole also knows how its students and teachers are doing and what can be done better.

Challenges Ahead

The example of Fiji's progress is way beyond what Latin America and the Caribbean has achieved. Many school systems in the region have much less dynamic and comprehensive data collection, making complex decisions and tracking of student performance, teacher training, inclusive infrastructure, and budgets exceedingly difficult. All this has to change.

"We should be implementing student-centered educational programs"

Many Latin American and Caribbean countries have embraced the idea of inclusion, and many teachers in the region are committed to the cause. Still, too many schools remain segregated and inaccessible to students with disabilities, while lacking the assistive technologies and teacher training to move forward rapidly. Also, families are often unaware of children's rights to attend mainstream schools or sometimes hesitant as to the benefits of inclusive education.

The transformation must start at schools themselves with teachers fully mobilized, but support from the top is necessary. Without a clear endorsement from school principals, it is very difficult for teachers generally to practice a more open, tolerant, and ultimately productive form of education. Without support from governments and education ministries, the additional investments needed to make the transition throughout school systems will be impossible. The region has adopted many of the right ideas. It must now put them into practice.

References

1 Huete (2019). Autonomía e Inclusión de las Personas con Discapacidad en el Ámbito de Protección Social. *IDB Policy Brief* No. 302.*

2 Loeb, Cappa, Crialesi and de Palma (2017). Measuring child functioning: the Unicef/Washington Group Module.

3 Berlinski, Duryea, and Pérez (2019). Prevalence and Correlates of Disability in Latin America and the Caribbean: Evidence from National Censuses.

4 Contreras, Riveros and Vargas (2019). Measuring the Macroeconomic Benefits of Labor Market Inclusion of People with Disabilities in LAC.

5 Duryea, Madrigal and Urquidi (2019). Promoting Disability Inclusion in Latin America and Caribbean Labor Markets.

6 Bosch, Gonzalez, Silva-Porto (2019). Intervención conductual y cumplimiento de la obligación de seguridad social y de cuota de empleo de personas con discapacidad.

7 Kuper and Heydt (2019). The Missing Billion: Access to Health Services for 1 Billion People with Disabilities.

8 SENADIS (2016). II Estudio Nacional de la Discapacidad en Chile.

9 Mitra, Palmer, Kim, Mont and Groce (2017). Extra Costs of Living with a Disability: A Review and Agenda for ResearchDisability.

10 Pardo, and Llorente (2019). Insumos para Incorporar Políticas Orientadas a la Inclusión Social y a la Autonomía de las Personas con Discapacidad en la Agenda de Salud del BID.

11 Ozemela, Ortiz and Urban (2019). Violence against Women and Girls with Disabilities: Latin America and the Caribbean. *IDB Policy Brief No. 302.*

[12] Human Rights Watch (2018). "They Stay until They Die" A Lifetime of Isolation and Neglect in Institutions for People with Disabilities in Brazil.

[13] Rodriguez (2015). Twice Violated: Abuse and Denial of Sexual and Reproductive Rights of Women with Psychosocial Disabilities in Mexico.

[14] Frohmader and Ortoleva (2014). The Sexual and Reproductive Rights of Women and Girls with Disabilities.

[15] European Disability Forum and Fundacion CERMI Mujeres (2017). Ending Forced Sterilisation of Women and Girls with Disabilities.

[16] Hincapie, Duryea and Hincapie (2019). Education for All: Advancing Disability Inclusion in Latin America and the Caribbean. *IDB Policy Brief No. 299.*

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