

FOREWORD

David Towell writes:

The Down's Syndrome Association in Peru (SPSD) is the most visible civil society association working nationally, and through several allies locally, to improve the lives of people with intellectual disabilities. It is led by parents but it is also able to attract very well-qualified and committed professional staff to its work.

Aime Apaza, an educational psychologist by qualification, is their lead on inclusive education. She describes here how SPSPD has sought to explore and influence Peruvian education through all the routes identified by arrows in the diagram included within the introduction. Perhaps most fundamentally, she explains how her association has come to see that improving opportunities for students with Down's syndrome requires a commitment to advancing inclusive education for all children and young people. Faced with the huge diversity and massive inequalities in Peruvian society and of course, the extra challenges posed by the pandemic, this is very much work in progress.





Sociedad Peruana de Síndrome Down: Challenges and strategies for advancing inclusive education in Peru

by Aime Apaza, SPSPD Coordinator for inclusive education

Peru is a country of great diversity: in its population with different ethnic traditions and customs; in its fauna, flora and beautiful natural landscapes. It has around 32 million people and is recognized for having great gastronomy and one of the pre-Colombian wonders of the world. As rich as it is in its territory, it has enormous challenges in recognizing and valuing the diversity of its people.

In recent years, education has taken on greater importance in debates and investments, with the aim of improving the quality of educational institutions. However, the liberal political system has promoted competition in schooling, benefitting those with most resources instead of making education a fundamental right that is guaranteed for all people and tailored to each student, whether provided publicly or privately. This limits efforts to improve the quality of learning; and therefore makes inclusive education difficult. In turn there are major differences in the coverage and quality of education negatively affecting poor or extremely poor students, indigenous people, those living in rural areas, and students with disabilities. This last group is at greatest risk of exclusion.

It is essential that society change its way of comprehending education. Although we have a national and international regulatory framework that supports inclusive education in all modalities

and levels, there are still prejudices, myths, negative attitudes, and legal and information gaps that lead to frequent violation of this right.

SPSD, origins and mission

The SPSPD is formed by families of people with Down Syndrome with the mission to achieve the inclusion and rights of people with DS. Currently we have as members more than 4000 families throughout Peru and its main headquarters are located in Lima, the capital. This organization is supported by the international organizations such as the Open Society Foundation (OSF), finance provided by projects such as those undertaken with Down Syndrome International, Inclusion International, and the educational arm of the Development Analysis Group, among others, and the organization's own fund raising such as the annual "Run with me 5K" race.

Currently, Pablo Gomez is the president of the SPSPD and together with a board of directors made up of relatives of people with DS, they guide the work of the SPSPD team. This team is led by Julie Escudero, executive director, who oversees four main the areas of action, each with their own leader: Carmen Albines is coordinator of the Early Intervention area, Aime Apaza is coordinator of the inclusive education area, Patricia Andrade is coordinator of the area of Citizenship and Rights and Evelyn Salas is

coordinator of the communications area. All are committed to inclusion and human rights.

Regarding inclusive education, we advocate that difference and diversity should be recognized as an opportunity and not as a problem. It has taken dialogue and reflection within the SPSD team and its leaders to see that this philosophy requires us to address the quality of education generally, beyond an initial focus only on students with DS. We have found it necessary to build a common language that understands that the right to inclusive education implies that we must work to advance education for all, not only for a specific group, since people with DS and their families are part of the diversity that exists in society. Our actions should seek to benefit not only one group, but the whole of society.

National policy and its weaknesses

In 2012, the Peruvian State established a General Law of Persons with Disabilities (29973) in which inclusive education is recognized as a right, as specified in the United Nations Convention on the Rights of Persons with Disabilities. Later, in 2017, a modification (28044) was made to this general education law to provide a fuller definition of inclusive education, specify the role of psychologists in the educational community and address violations to the exercise of this right. However, there are still limitations for disabled people in relation to access and educational quality; for example, there is a quota of 2 students per classroom with mild or moderate disabilities in regular schools and people with more severe disabilities can only access segregated spaces such as special schools.

In general, there is a lack of oversight in the implementation of this right and lack of awareness in the educational community



Figure 1. The SPSD Community

We are convinced that achieving inclusive education requires that all educational institutions transform their policies, practices and cultures; requiring that the educational community reflects together to identify possible barriers (attitudinal, communicational, architectural, pedagogical, etc.) and acts together to implement improvements.

about its significance for all learners. Currently (2021), work is being done on a National Policy on Disability and a new regulation of the Peruvian Education Law that emphasizes this right: both are the subject of initial consultation.

The SPSD has been an active advocate in the construction of these legal regulations. Specifically, it has campaigned at the regional (Latin America), national and local levels so that inclusive education is recognized as a right and effectively implemented.

Networking internationally

An important element in this work is the alliance with other allied organizations at the regional (i.e. Continental) level. We are part of the Regional Network for inclusive education in Latin America that allows us to share experiences and advocacy strategies with similar organizations from Argentina, Brazil, Colombia, Paraguay and Uruguay. In 2018 we participated in a meeting of inclusive education organizations in Buenos Aires (Argentina) and more recently we have helped form a regional advisory team of international experts in inclusive education.

We have had technical support from Inclusion International's Catalyst for Inclusive Education in training leaders at the Ministry of Education (MINEDU) and other levels in policy implementation. Another important link is with the United Nations Children's Fund (UNICEF) which has a strong presence in Peru. Working with their +Inclusion Project has strengthened our connections with MINEDU and reinforced nationally the work we are doing locally with families and schools to raise awareness about inclusive education and challenge violations of fundamental rights.

An important example at the national level was a meeting as part of the MINEDU diversity awareness week in 2015 in which two self-advocates supported by SPSD, Jaime Cruz and Bryan Russell (both with DS) joined the then Minister of Education (until 2016), Jaime Saavedra, in promoting the need to guarantee inclusive education for all young people. It was under this Minister that MINEDU initiated the 2017 policy changes noted above and so far there have been efforts to move towards it, although there are still barriers to tear down.

Strengthening coalitions across Peru

In 2016, we saw the need to promote the creation of a broad Coalition for the right to inclusive education in Peru that links organizations, institutions and networks committed to the right to education of all girls, boys and adolescents, including those with disabilities, language and ethnographic differences and specific needs for educational support, among others. With this alliance we have magnified the impact of our proposals, the spread of our documents and the strength of our contributions to MINEDU about national policies on educational inclusion.

More recently, we convened more than 30 local associations from different parts of Peru under the heading of "Forming Trainers", with the intention to share experiences and advance local understanding of the 'social model' of disability.

In turn, meetings with these associations made it possible to begin to establish the network, "Allies for Inclusion", currently made up of associations in Arequipa, Ica, Lambayeque, Huánuco, Cajamarca, Lima, Ayacucho, Tacna, Loreto and Piura. Each association has a particular history and context such as *Pintando Vidas* (Huánuco) which is led by Elizabeth, a mother of a child with DS, who created this organization to empower more families and has managed to establish alliances with the government of her territory so as to get involved in capacity building for teachers in inclusive education.

It's also been important for us to be part of the Coalition for Education - Peru Chapter, which together with MINEDU has focused effort on the educational challenges generated by Covid-19 - articulating the need for an inclusive approach to transforming the educational system in the face of the health emergency.



Figure 2. Creating the Coalition for the right to inclusive education



Figure 3 'Citizen dialogue for inclusive education' project

Research and its application

We have promoted research and other projects in the field of inclusive education to examine the situation and develop guidelines to support the transformation of state schools. In 2017, the project "Citizen Dialogues for Inclusive Education" was carried out with the support of FORGE (Strengthening Educational Management part of the Development Analysis Group). We were partners in the Peruvian part of another study, "Our opinion is valid: the perspective of children and adolescents on discrimination and barriers to inclusive education" in association with UNICEF, which studied violations of the rights of people with disabilities by teachers, managers, colleagues and families across Latin American.

The most recent project "Valuing diversity in the school" undertaken during 2019, focused on the realities of educational experience in a sample of public schools from the perspective of different stakeholders, drawing implications for improving inclusive education and providing advice to policy decision-makers.

These projects have not only strengthened our broad understanding of inclusive education but also raised our profile with a range of relevant institutions including MINEDU, regional governments, municipalities, universities, and other educational institutions in Peru.

Developing the capacity to advance change

With this history and experience, we are able to provide training and participate in national and international workshops on inclusive education. We share what we have learnt about the experiences of schools, students and families as well as theoretical and practical tools relevant to transforming the educational system, not least through strengthening competences in the attention to diversity in classrooms. So far, we have offered training to more than 2,000 professionals from schools, universities, institutes, civil associations and MINEDU.



Figure 4. Inter-school exchange, 'Valuing diversity in the school' project



Figure 5. Teacher training

In addition, we have invested in developing public awareness campaigns. One of these campaigns organized together with the McCann Erickson advertising agency and with the support of the production company, Saturno, has been recognized by the Effie Awards Peru for the powerful message it transmitted about the difficulties faced by families of children with DS in obtaining quality education.

However, most fundamental to all our work as a family association is the creation and support of family networks in which parents and other family members meet others to share their experiences and concerns about their children's development and inclusive education. In this network we seek to inform and empower each family to be a spokesperson for the changes that are required in our education, take concrete actions towards inclusion and so together help build better education for all.

Looking forward

From SPSP's inclusive education team, we recognize the important challenges facing Peru's educational system and especially the growing problems for students with disabilities.

However we are convinced progress is possible towards inclusive education providing all of us - families, institutions, teachers and the entire educational community - are positively involved.

In our work we have had to learn, unlearn and co-construct multiple actions. Central to these actions are the voices and efforts of families and young people with disabilities; their expertise is essential to building more inclusive schools and a more equitable education system.

Throughout these 25 years, we have worked to ensure that each child, teenager and young person, without exception, enjoys the right to a quality education that allows them to achieve their life plan and dreams: an education increasingly transformative, creative, flexible, and of course, inclusive.



Figure 6. On-line meeting of the family network for inclusive education