

INVESTIGACIÓN

El siguiente informe regional fue preparado por Cayetano De Lella (Universidad de General Sarmiento) y el experto Hugo Mercer en colaboración con el Centro Internacional de Estudios Políticos de la Universidad de San Martín, como aporte a una investigación compilada por el Campus Global de Derechos Humanos¹ en 2013.

El informe da cuenta de los desafíos identificados por las organizaciones de personas con discapacidad en conexión con la implementación de la Convención sobre los Derechos de las Personas con Discapacidad. Tras ofrecer un panorama de sobre discapacidad en la región, el informe resume una serie de entrevistas con informantes clave a nivel regional, pertenecientes a estas organizaciones.

IMPLEMENTING THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES THE PARTICIPATION OF DISABLED PEOPLE'S ORGANISATIONS (DPO'S)

Latin America and the Caribbean

The present report examines the role of Disabled Persons Organisations (DPOs) in the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in the Latin America region. Interviews were conducted with representatives of leading DPOs in some countries in order to assess both the progress of States in the region towards meeting the rights of persons with disabilities and the role of DPOs in that progress.

During the last decade there has been an improvement in the legal protection of persons with disabilities via the national constitutions of the countries of the region. Some countries have also

¹ El Campus Global de Derechos Humanos comprende seis programas regionales que juntos conforman una extensa red académica que engloba más de 80 universidades y centros de estudios a nivel mundial. Todos los programas están asociados al *European Inter-University Centre for Human Rights and Democratization* (EIUC). Los programas regionales incluyen a: América Latina (Buenos Aires), Europa (Venecia), Europa del Este (Sarajevo), Cáucaso (Ereván), África (Pretoria), Asia-Pacífico (Sídney). El Campus Global persigue la educación de profesionales en derechos humanos conforme a valores y estándares universales y regionales en la materia, mediante actividades vinculadas a la enseñanza, entrenamiento e investigación.



adopted legislation specifically protecting the rights of persons with disabilities. However, there are still pending challenges regarding enforcement.

DPOs from the countries of the region are concerned, it is clear that they have grown in recent decades. The strengthening the role of civil society through special platforms for systematic – rather than sporadic— participation continues to be crucial. DPOs must also deepen their understanding of public policy and governmental performance.

Overall there is a positive outlook for Latin America and the Caribbean in terms of the progressive implementation of the UN Convention and the participation of DPOs. Among the challenges is the residual effect of obsolete definitions of disability which still have a negative impact in the manner in which the issue is addressed in some States of the region.

Improvement in the area of awareness, assistance, representation and participation require inter sectorial policies and a better response from the public sectors as well as extra support at the level of the national budgets.

I. Latin America and the Caribbean

The region of Latin America and the Caribbean spans through 46 States and territories² with a combined population of approximately 609 million inhabitants.³ Spanish, Portuguese, English, French and Dutch as well as a large number of indigenous languages are spoken in this region, which has remained free from nuclear weapons and major ethnic or religious conflicts.

² The information provided by the United Nations Population Division on the region covers 46 countries and territories of Latin America and the Caribbean, which make up the sub regions of Central America, South America and the Caribbean. Central America. ECLAC Statistical Yearbook for Latin America and the Caribbean 2012, page 132, available at http://www.eclac.cl/publicaciones/xml/4/48864/AnuarioEstadistico2012_ing.pdf.

³ See ECLAC's population projection for 2013 at ECLAC *Statistical Yearbook for Latin America and the Caribbean 2012*, page 23, available at http://www.eclac.cl/publicaciones/xml/4/48864/AnuarioEstadistico2012_ing.pdf. See also data gathered in 2012 by the World Bank, available at <http://data.worldbank.org/region/LAC>, with a figure of 581.4 million inhabitants (79% urban population), for 2012.



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The consolidated GDP of the region amounts to \$5.348 trillion dollars. Although there is a continuing and cumulative decline of income concentration since the early 2000s –more than 73 million people were lifted out of poverty and 50 million joined the ranks of the middle class over the past decade— inequality indicators have come down only slightly, and the region is still among the most unequal in the world.⁴

From the late 19th century, the States of the region have pioneered the creation of regional and universal multilateral organisations and the development of international law. Within the framework of the Organization of the American States (OAS), these States promoted the adoption of the Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities (CIADDIS) in 1999.⁵ So far, this Inter-American Convention has been ratified by 19 of the 34 member states of the OAS. A Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities (CEDDIS) –composed of one representative and two alternates appointed by each State Party— draws conclusions, general observations and suggestions for the gradual fulfilment of this OAS Convention and promotes cooperation among States Parties and civil society organisations, as well as with international organisations and agencies. The OAS Convention has been criticised for its approach based upon clinical parameters, such as physical impairment, which has been superseded by the more inclusive and rights oriented approach of the UN Convention, which has gained wider acceptance in the region –24 out of the 34 member States of the OAS have ratified it.

In 2007 OAS member states also adopted the so-called 'Program of Action for the Decade of the Americas for the Rights and Dignity of Persons with Disabilities' (PAD) as a political commitment to make progress in nine specific areas: social awareness, health, education, employment, accessibility, political participation, participation in sports and cultural, artistic and recreational activities, welfare and social assistance, and international cooperation.⁶

⁴ Data gathered in 2012 by the World Bank, available at <http://data.worldbank.org/region/LAC>.

⁵ Inter-American Convention for the Elimination of All Forms of Discrimination against Persons with Disabilities (CIADDIS) adopted on June 7th, 1999, by OAS AG/RES. 1608 (XXIX-O/99). The Convention entered into force on September 14th, 2001.

⁶ 'Program of Action for the Decade of the Americas for the Rights and Dignity of Persons with Disabilities' (PAD) (AG/RES. 2339 (XXXVII O/07), adopted during the 37th Regular Session of the OAS General Assembly, in June 2007. Text available at http://www.oas.org/en/mre/iddsa/pages/index-4_pda.asp

Despite the adoption and entry into force of these international instruments, the situation of persons with disabilities has not been fully incorporated into the human rights agenda of the region's national human rights institutions and in some cases, there is a marginal or somewhat unfocussed reference to the issue.

In some cases, national legislation defines disability in a manner that fails to encapsulate the current model of human rights and social development, and rather follows the definitions from the 1980 World Health Organization (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH1) according to which a disability involves 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.'⁷ This definition, based upon arbitrary parameters of normality and functionality, follows a charity and care model⁸ still utilised by some institutions and professionals, in contrast with the new social model embraced by disabled persons organisations and academic circles, based on human rights and social inclusion.

In spite of all this, during the last decade there has been an improvement in the legal protection of persons with disabilities via the national constitutions which –in almost half of the countries of the region- expressly recognise the rights of persons with disabilities. Some countries have also adopted legislation specifically protecting the rights of persons with disabilities and others have prohibited discrimination against them.⁹ It has been argued, though, that these pieces of legislation frequently lack clear enforcement rules and sanctions in case of non-compliance and in those cases where these are provided for, they are not always applied. Thus the adoption of legal protections has not been fully accompanied by the political will or the ability to ensure their enforcement.

⁷ WHO, International Classification of Impairments, Disabilities, and Handicaps. A manual of classification relating to the consequences of disease, Geneva, 1980, page 143.

⁸ This model promotes state response to individual needs rather than a collective assessment based on recognition of rights and social inclusion.

⁹ See, for instance, Brazil, Constitution chapter II, article 7 (1988) (against discrimination in hiring individuals with disabilities) available at <http://www.dredf.org/international/brazil.html>; Dominican Republic, *Ley General sobre Discapacidad* (2000) at http://www.primeradama.gob.do/trans/normativas%20%20derechos%20de%20los%20ciudadanos/ley_general_sobre_discapacidad.pdf, and the provision of a so-called solidarity pension, see <http://www.cnss.gob.dom>; Mexico, *Ley para personas con discapacidad del Distrito Federal* (1995) at <http://www.dredf.org/international/mexico.html>; Paraguay, Political Constitution of 1992 at <http://www.dredf.org/international/parag1.html>. See World Bank *Disability and Poverty in Developing Countries* (2011), page 73.

As far as the DPOs from the countries of the region are concerned, it is clear that they have grown in recent decades. At the time of their inception they were focused on individual litigation and on securing their participation in the setting of standards relating to the situation of persons with disabilities. In recent years there has been a tense dialogue between these organisations and state entities. In some cases, DPOs have failed to acknowledge in their recent strategies the new approaches towards social inclusion adopted international standards and incorporated by some States.

II. Methodology

The eight independent States from South America included in this study are active participants of the International Community and they are members of the United Nations and the Organization of the American States: 1. Antigua and Barbuda; 2. Argentina; 3. The Bahamas; 4. Barbados; 5. Belize; 6. Bolivia; 7. Brazil; and 8. Chile.

Data for this chapter was gathered both through secondary sources and interviews with DPO representatives. The secondary sources consulted ranged from reports issued by inter-governmental organisations (WHO, PAHO, World Bank, UN ECLAC, OAS), to official national reports and shadow reports and papers prepared by national and regional non-governmental organisations. Interviews with key DPO representatives as well as national institutions working with them in Argentina, Brazil, and El Salvador were conducted in person, on the phone and by electronic means.

III. Snapshot Data on Latin America and the Caribbean

Between 2000 and 2011 an estimated 66 million persons were living with some form of disability in Latin America and the Caribbean: 12.3% of the total regional population, 12.4% of the

population of Latin America and 5.4% of the population of the Caribbean.¹⁰ Given that these figures are based on 2000-2006 data in over half the countries for which information is available, the number of persons with disabilities could easily exceed the 85 million estimated by the World Bank.

The population groups with a higher prevalence of disability include women over 60 years of age, senior citizens, inhabitants of rural areas, indigenous peoples and afro-descendants, as well as persons with lower income. These groups suffer a higher incidence of disability due to a lack of opportune attention and a lack of means or access to appropriate services.

Figures on disability vary widely across the region and may even differ between one census and another conducted by the same country. The three main sources of data include: (a) the waves of censuses from 2000 and 2010, (b) the specialised surveys on disability, and (c) the permanent household surveys. National sources employ heterogeneous criteria when measuring impairment and limitations. These methodological differences have a direct impact on the figures, and therefore it is not really possible to draw comparisons. For instance, in those countries that have already completed the most recent census round, the prevalence of disability ranges from 5.1% in Mexico to 23.9% in Brazil. In the Caribbean, the disparity is not so marked: the population living with some form of disability ranges from 2.9% in the Bahamas to 6.9% in Aruba.¹¹ These figures confirm the need to strengthen the harmonisation of measurements to compare regional information.¹²

¹⁰ ECLAC Social Panorama on Latin America 2012, available at http://www.eclac.cl/cgi-bin/getProd.asp?xml=/publicaciones/xml/4/48454/P48454.xml&xsl=/publicaciones/ficha-i.xsl&base=/publicaciones/top_publicaciones-i.xsl. See also Panamerican Health Organization, *Application of the International Classification of Functioning, Disability and Health in Studies of Disability Prevalence*, Washington, D.C, 2012; World Bank, *World Report on Disability 2011*, available at <http://web.worldbank.org/WBSITE/EXTERNAL/TOPICS/EXTSOCIALPROTECTION/EXTDISABILITY/0,,contentMDK:23063040~menuPK:282704~pagePK:148956~piPK:216618~theSitePK:282699,00.html>; and WHO, *Global Status Report on Non-communicable Diseases*, Geneva, 2011.

¹¹ ECLAC Social Panorama on Latin America 2012, available at http://www.eclac.cl/cgi-bin/getProd.asp?xml=/publicaciones/xml/4/48454/P48454.xml&xsl=/publicaciones/ficha-i.xsl&base=/publicaciones/top_publicaciones-i.xsl.

¹² Pan-American Health Organization, *Application of the International Classification of Functioning, Disability and Health in Studies of Disability Prevalence*, Washington, D.C, 2012. See also WHO, *Global Status Report on Non-communicable Diseases*, Geneva, 2011.

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The Washington Group on Disability Statistics –established by the UN in 2002— and the Latin American and the Caribbean Demographic Centre (CELADE), a Population Division of ECLAC, have been working with many States of the regions with a view to improving the measurement of disability at the international level. As a result, some countries have abandoned the impairments-based approach and they have already conducted their census for this decade used the new approach, based on difficulties or limitations in activities, and incorporated at minimum the four domains recommended by CELADE. The new census decade has the potential of finally addressing the lack of consistent information on persons with disability.

In terms of response to disability, usually the services offered to disabled persons are mainly focused on medical attention, with less emphasis on comprehensive care and disability supports. Due to a higher incidence of chronic disease and the visibility of disability, care becomes a social demand to be taken into account by States, communities and families. Persons with disabilities require social support in order to enjoy a good quality of life and participate in the economic and social life of the country with equal opportunities *vis-à-vis* the rest of the population.

In Latin America, the vast majority of persons with disabilities receive care from close family members according to a variety of living arrangements. This state of affairs usually involves a high emotional and financial costs for families and there are few options in terms of direct care services by the State, the market and civil society organisations working in the area of disability. Some States provide subsidies to care givers both from the NGO and for profit sectors. In any case, the forecasts predict include a growing need for care at home, strengthening of available networks, and a more efficient use of the limited resources and services provided by the States.

Thanks to the entry into force of CRPD, there is a growing expansion of government programmes offering support to family care givers, the granting of care services at home, independent life support as well as other measures linked to the enjoyment of economic, social and cultural rights through access to inclusive education, employment and social security for persons with disabilities.

The care programmes offered by the Governments of the region include home care for persons with disabilities and their families; the provision of technical assistance, orthoses, prostheses with direct delivery or through full or partial purchase; the adaptation and refurbishment of homes for persons with disabilities; residential homes and economic support at different rates for the financing of care and rehabilitation services. Some States also offer programmes of integrated and inclusive education for disabled children.

There is also progress in the modalities of employment and training for disabled persons. These programmes have an impact both on their income and their long term financial autonomy and they are implemented through the social welfare system. A minority of states in Latin America and the Caribbean provide benefits which are delivered independently of any employment activity. Most States grant a family stipend, focal benefits, and/or a minimum pension to persons whose disability has been certified or to their disabled children subject to their status within the national welfare services.

A. Country Snapshots

1. Antigua and Barbuda

Antigua and Barbuda has a population of approximately 91 thousand inhabitants. According to ECLAC, the prevalence of disability for males is 4.4% and for women 5.7%. In its 2011 census it incorporated parameters promoted by CELADE and the Washington Group. It is the country in the Caribbean with the highest employment rate for persons with disability (63.6 % for males and 64.5% for females).

Antigua and Barbuda signed the CRPD on March 30, 2007 but has not ratified it yet. It is not a party to the OAS Convention either. Constitutional provisions prohibit discrimination against persons with physical disabilities in employment and education, although no specific laws mandated accessibility for persons with disabilities. Within the Ministry of Health, Social Transformation and Consumer Affairs the Department of National Vocational and Rehabilitation Centre for Disabilities provides financial assistance for the acquisition of assistive devices and medical treatment.

The *Antigua & Barbuda Association of Persons with Disabilities* is a non-for-profit organisation managed by volunteer persons with disabilities that relies on private donations. It is a National Assembly Member of *Disabled People's International* and it has reported on disability in the context of the Universal Periodic Review 12th Session of August 2011, on Antigua and Barbuda.

2. Argentina

Argentina has a population of approximately 41 million inhabitants. According to ECLAC, the prevalence of disability for males is 6.8% and for women 7.3%. In its 2010 census it opted for yes/no responses and it also conducted specialised surveys.

It ratified both CRPD and the Optional Protocol on September 2, 2008. It has been a party to the OAS convention since January 10th, 2001. The UN Committee on CRPD recommended that Argentina systematise its collection, analysis and dissemination of statistics and data, taking into consideration the situation of specific groups of persons with disabilities who may be subject to multiple forms of exclusion and the changeover from a medical to a human rights model of disability.¹³ Access to employment in the public sector by persons with disabilities is regulated in National Act No. 22431 providing for an employment quota of at least 4%. However, only 0.66% of the national public administration work-force are certified as persons with disabilities, 82.5% of which are concentrated in the City of Buenos Aires and the Province of Buenos Aires. According to its own Constitution, the City of Buenos Aires has an employment quota of 5%. However the enforcement of this quota –which remains unfulfilled— was deferred in 2009 by Act No. 3230 despite the public campaign launched by the local disability organisations.

Despite the inclusive policies of the Federal Council for Education, the agency for the prevention of discrimination (*Instituto Nacional contra la Discriminacion, la Xenofobia y el Racismo - INADI*) has found that there is an important number of disabled students excluded from the regular

¹³ Committee on the Rights of Persons with Disabilities Concluding observations on the initial report of Argentina as approved by the Committee at its eighth session on 17-28 September 2012. CRPD/C/ARG/CO/1, para. 50.

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education system because of lack of resources, lack of accessibility, lack of trained professionals, and the persistence of communication barriers.¹⁴

The National Advisory Commission on the Integration of Persons with Disabilities (CONADIS) has the role of facilitating and coordinating matters relating to the implementation of the Convention at all levels and in all sectors of government. Although there are numerous pieces of legislation relating to the implementation of the rights of persons with disabilities¹⁵, there are pending challenges for the full harmonisation of domestic legislation with CRPD. These challenges have been identified by the local DPOs in the shadow report to the UN Committee CRPD.¹⁶

As far as DPOs are concerned, in Argentina there are a number of federations of disabled persons, and a number of organisations for disabled persons. The federations of persons with disabilities or their family members are FAICA –visual impairment¹⁷; CAS –hearing impairment¹⁸; FENDIM –mental impairment¹⁹; and autism –FAPADEA. Apart from these federations, there are numerous first grade organisations involving the participation of persons with other disabilities.²⁰

¹⁴ INADI *Derecho a la Educación sin Discriminación*, 2012.

¹⁵ See, for instance, Act No. 26571 (2009) on the democratization of political representation, transparency and electoral equity; and Act No. 26522 (2009) on audiovisual communication services. Also the creation of the Disabilities and Occupational Integration Unit, attached to the Supreme Court in December 2010; and a national programme for the assistance of persons with disabilities in their dealings with the bodies responsible for the administration of justice (Decree No. 1375/2011).

¹⁶ See alternative report filed by Argentine DPOs before the UN Committee on the Rights of Persons with Disabilities, available at <http://redi.org.ar/docs/Informe%20alternativo-%201ra%20evaluaci%C3%B3n%20Argentina-%20CRPD%20-%20FINAL%20%284%29.pdf>

¹⁷ Federación Argentina de Instituciones de Ciegos y Amblíopes. See website at <http://www.faica.org.ar/>.

¹⁸ Confederación Argentina de Sordos, which was founded in 1957. See website at <http://www.cas.org.ar/>.

¹⁹ Federación Argentina de Entidades Pro Atención a las Personas con Discapacidad Intelectual (Argentine Federation of Entities for the Assistance of Persons with Mental Disabilities) (FENDIM) was founded in 1966, as a forum for associations of parents and family members. Through a solid network of more than 140 institutions throughout the country, it has participated in the development and implementation of public policies, legislation –in particular Act No. 22.431 For the Comprehensive Protection of Persons with Disabilities— and public awareness activities. It also runs Day Centers, and Protected Production Workshops, Therapy Workshops and Recreation Centers. It also follows up and participates at the national level in all issues relevant to the application of the Single System for Basic Services for Persons with Disabilities (Act No. 24.901), in conjunction with state organs and other NGOs. See website at <http://www.fendim.com.ar/home.htm>.

²⁰ See, for instance, *Asociación Síndrome de Down de la República Argentina* (ASDRA) which gathers persons with Down syndrome and their families, since 1988. Available at <http://www.asdra.org.ar/>.

The organisations for persons with disabilities provide assistance and care through federations such as CAIDIS²¹ or AIEPESA (*Asociación de Institutos Educativos Especiales de Argentina*). These organisations promote awareness of and follow up on compliance with the UN Convention as part of an Advisory Committee to CONADIS (created by Decree No.678/2003) or through the Disability Observatory (created by Decree No.806/2011). They also participate in Civil Society Consultative Council which gathers at the request of the Ministry of Foreign Affairs within the framework of MERCOSUR in order to promote standards, programmes and policies at the regional level.

3. The Bahamas

The Bahamas has a population of approximately 355 thousand inhabitants. According to ECLAC, the prevalence of disability for males is 3.1% and for women 2.7%.

It has not ratified or even signed CRPD. It is not a party to the OAS Convention either. The Constitution does not prohibit discrimination on the grounds of disability. In 2005 the Committee on the Rights of Children expressed its concern at the lack of disaggregated and analytical data on persons under the age of 18 years in the most vulnerable groups, including children with disabilities. It recommended the State to provide for the systematic collection of disaggregated quantitative and qualitative data on disability as well as the legal mechanisms to prevent discrimination against children with disabilities.²² According to ECLAC, the Bahamas incorporated questions on disability in its 2010 census.

International Disability Alliance has been filing information on the Bahamas before UN treaty bodies.²³

²¹ Consejo Argentino para las Personas con Discapacidad. See website at <http://www.caidis.org.ar/>.

²² Committee on the Rights of Children CRC/C/15/Add.253, March 2005.

²³ International Disability Alliance (IDA) Member Organizations: Disabled Peoples' International, Down Syndrome International, Inclusion International, International Federation of Hard of Hearing People, World Blind Union, World Federation of the Deaf, World Federation of the Deaf Blind, World Network of Users and Survivors of Psychiatry, Arab Organization of Disabled People, European Disability Forum, Red Latinoamericana de Organizaciones no Gubernamentales de Personas con Discapacidad y sus familias (RIADIS), Pacific Disability Forum. See for instance <http://www2.ohchr.org/english/bodies/cedaw/docs/ngos/IDABahamas52.pdf>

4. Barbados

Barbados has a population of approximately 275 000 inhabitants. According to ECLAC, the prevalence of disability for males is 3.8% and for women 4.2%.

It ratified CRPD on the 27th of February 2013. It has not ratified the Optional Protocol. The National Disabilities Unit was established on December 3, 1997. The Barbados Country Assessment of Living Conditions 2010 reported that 'among persons with disabilities, there was a clear connection between poverty and social exclusion, especially among those whose disability had rendered them physically immobile' and that such exclusion was linked to lack of suitable employment opportunities, lack of support and protection within families and communities, and inadequate transportation and services.²⁴

The main civil society organisation working with disabled persons – the Barbados Council for the Disabled – was created in 1976 and it receives an annual subvention from the State. The Barbados National Organisation for the Disabled (BARNOD) is a cross-disability organisation run by disabled persons that also provides services. They are affiliated with Disabled Peoples' International (DPI), Disabled Peoples Organisation of the Caribbean (DPOC) and the Barbados Council For the Disabled (BCD).

5. Belize

Belize has a population of approximately 331 000 inhabitants. According to ECLAC, the prevalence of disability for males is 6.0% and for women 5.9%. In its 2010 census it incorporated parameters promoted by CELADE and the Washington Group.

Belize ratified CRPD on the 2nd of June, 2011. It has not ratified the Optional Protocol. It has not ratified the OAS Convention. Although articles 3 and 16 of the national Constitution prohibits discrimination and provides for equal treatment, on the grounds of race, place of origin

²⁴ Barbados Country Assessment of Living Conditions 2010 Available at <http://www.caribank.org/uploads/2012/12/Barbados-CALC-Volume-1-MainReport-FINAL-Dec-2012.pdf>

and colour, there is no comprehensive anti-discrimination legislation guaranteeing equal treatment to all persons.²⁵

The Belize (an) Assembly (or Alliance) of and for Persons of Diverse Abilities was created in 2009. No DPOs filed stakeholder's information for Belize's 2009 Exam at the Universal Periodic Review of the UN Human Rights Council.

6. Bolivia

Bolivia has a population of approximately 10.4 million inhabitants. According to the World Bank, the prevalence of disability was 10.8% in 2004.²⁶ There are no available updated figures on Bolivia from ECLAC.

Bolivia ratified the UN Convention and its Optional Protocol on the 16th of November 2009. It ratified the OAS Convention on May 30, 2003.

The Constitution of Bolivia contains provisions that protect the human rights and freedoms of all citizens, and prohibit discrimination on the ground of disability. The prohibition of disability related discrimination in employment, education, health and social services, both public and private, was introduced by Law No.1678 of 15 December 1995. The National Council of People with Disabilities is the decentralised body of the Ministry of Human Development charged with the implementation of disability policy in Bolivia.

In February, 2012 the Chamber of Deputies of the Bolivian Congress passed a law for the preferential treatment of people with disabilities (*Ley general y trato preferente para personas con discapacidad*). However, as a response, a group of persons with disabilities participated in a protest – after a 100-day journey across the country – to demand an increase in state

²⁵ See UN Committee on the Elimination of Racial Discrimination, Concluding observations on Belize, adopted by the Committee under the review procedure at its eighty-first session (6–13 August 2012) CERD/C/BLZ/CO/1.

²⁶ World Bank, *World Report on Disability 2011*, page 271. Available at http://www.who.int/disabilities/world_report/2011/report.pdf



subsidies for people with disabilities. The protest ended in a violent clash with police in La Paz.²⁷

The Bolivian Confederation of Persons with Disability (COBOPDI) was founded in 1989 and brings together nine local organisations representing constituencies in the disability community.

7. Brazil

Brazil has a population of approximately 200 million inhabitants. According to ECLAC, the prevalence of disability for males is 21.2% and for women 26.5%. In its 2010 census it incorporated the four degrees of severity recommended by the Washington Group on Disability Statistics and CELADE.²⁸ The data from the 2010 census round concerning disability rates by ethnicity showed that in Brazil disability is more prevalent among people of African descent.

Brazil ratified CRPD and its Optional Protocol on the 1st of August 2008. It is also a party to the OAS Convention since August, 2001. CRPD has constitutional status. The National Secretariat for the Promotion of the Rights of People with Disabilities (SNPD) is responsible for the implementation of public policies concerning people with disabilities. The Brazilian government has declared its intention to transform the traditional model, focused on assistance measures, into one that also enables persons with disabilities to exercise a central role in society.

The priorities highlighted are: access to orthotics and prosthetics and rehabilitation in the Unified Health System (SUS); specialised educational services from the perspective of inclusive education; the extension of social protection to those in need; the promotion of accessibility to all public and common use areas; the promotion of employability of persons with disabilities, through the integration of public actions, negotiations and awareness of employers; and to disseminate a culture of inclusion and respect for diversity.

²⁷ See Amnesty International News Release, February 25, 2012. Available at <http://www.amnesty.org/en/news/bolivia-must-investigate-violence-disability-protest-2012-02-24> See also <http://www.theguardian.com/global-development/poverty-matters/2012/jan/11/disabled-people-march-for-equality-bolivia>

²⁸ According to the 2000 Census –which used biomedical criteria—only 14.5% of Brazilians were living with disabilities. In 2007 the ICF model was adopted in the implementation of the Continuous Cash Transfer Program (CCT) as a welfare income transfer to the disabled and poor elderly.

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There is a wealth of civil society organisations working in Brazil. Among the ones particularly active in the implementation of CRPD are: the Brazilian Association for Action on Rights of Persons with Autism (ABRAÇA), the National Federation of Education and Integration of Deaf People (FENEIS), *Conselho Nacional dos Centros de Vida Independente (CVI-BRASIL)*, *Fraternidade Cristã de Pessoas com Deficiência – FCD/BR*, *Instituto Baresi*. They have accused the Government of failing in its obligation to actively consult with and involve persons with disabilities and their representative organisations in the development of legislation, policies and other decision making processes concerning them (Article 4(3) of CRPD). Specifically, regarding the 'Living Without Limits – National Plan on the Rights of Persons with Disabilities' 2011- 2014, during the preparation of the Plan, the government did not sufficiently consult with nor seek the participation of DPOs, and as a result the Plan did not effectively incorporate the gender perspective as a guideline for projected actions.²⁹

8. Chile

Chile has a population of approximately 17.6 million inhabitants. According to ECLAC, the prevalence of disability for males is 10.9% and for women 14.9%.

Chile ratified both CRPD and the Optional Protocol on the 29th of July, 2008. The National Disability Service (*Servicio Nacional de la Discapacidad (SENADIS)*), created by Law No. 20.422, has the role of ensuring equality of opportunities and social inclusion for persons with disabilities. This State entity works with a number of Regional Civil Society Councils and a National Disability Council. DPOs can apply to participate in these Councils and provide their views on SENADIS's role, and on the design of public policies at the regional level and national level. The DPOs represented at the level of the National Disability Council are: *Unión Nacional de Ciegos de Chile*; *Corporación Ayuda al Paciente Mental (CORPAM)*; *Fundación Chilena para el Síndrome de Down*; *Red de la Discapacidad de la provincia de Arauco (REDISPA)*; and *Fundación Teletón*.

²⁹

See http://www2.ohchr.org/english/bodies/cedaw/docs/ngos/Joint_IDA_NGOs_for_the_session_BRAZILCEDAW51_en.pdf

It is relevant to note that since 1978, a TV show known as 'Teletón' has had a major role in popular perceptions regarding social response to disability. The show is a 27-hour fundraising show broadcast live on every major Chilean TV station, and sponsored by a number of major business partners. The donations by corporations and individual members of the public help finance eleven *Teletón* foundations scattered around the country which offer rehabilitation services to children and young people under the age of 25 with specific disabilities. Disability activists in Chile argue that the show is disturbingly symbolic of the state of disability rights in the country and that it deflects attention away from the government's lack of investment in services for Chile's disabled, while allowing businesses to profit from the publicity generated by the campaign. In fact it has been argued that SENADIS' annual budget is roughly half of the proceeds raised by *Teletón* in one year.³⁰

The National Foundation for the Disabled (FND) has a critical view on the achievements in terms of compliance with the goals of social inclusion. Specifically, it highlights that 94% of disabled persons over the age of 24 have never had access to rehabilitation; 42% have not completed a basic education level; 75% is unemployed; and 56% are indigent.³¹

IV. Disabled People's Organisations (DPOs) in Latin America and the Caribbean

There are a number of networks operating in Latin America, most notably the Latin American Network of Non Governmental Organizations of Disabled Persons and the Families (RIADIS); the Iberio-American Network of Experts on the Convention on the Rights of Persons with Disabilities. The regional chapters of the International Alliance on Disabilities (IDA)³² and the

³⁰ For the opinion of Alejandro Hernández, president of National Foundation for the Disabled (FND), See <http://www.santiagotimes.cl/opinion/special-reports/25432-the-teleton-image-and-reality-of-disability-rights-in-chile>

³¹ See <http://www.fnd.cl/discapacidadenchile.html>

³² International Disability Alliance (IDA) Member Organizations: Disabled Peoples' International, Down Syndrome International, Inclusion International, International Federation of Hard of Hearing People, World Blind Union, World Federation of the Deaf, World Federation of the DeafBlind, World Network of Users and Survivors of Psychiatry, Arab Organization of Disabled People, European Disability Forum, Red Latinoamericana de Organizaciones no Gubernamentales de Personas con Discapacidad y sus familias (RIADIS), Pacific Disability Forum. See for instance <http://www2.ohchr.org/english/bodies/cedaw/docs/ngos/IDABahamas52.pdf>

Global Partnership for Disability and Development (GPDD) are also important players in the Caribbean.

The Latin American Network of Non-Governmental Organizations of Persons with Disabilities and their Families (*Red Latinoamericana de Organizaciones no Gubernamentales de Personas con Discapacidad y sus familias* -RIADIS) is a regional international organisation, composed of 60 national organisations from 18 countries in Latin America. Its main purpose is to act in defense of human rights of persons with disabilities. RIADIS was founded in 2002 in Caracas, Venezuela with the purpose of rationalising the information on the situation of persons with disabilities, following up on the Inter-American Convention on the Elimination of all Forms of Discrimination against Persons with Disabilities and later following up on compliance with CRPD.³³

There is also an active Inter-University Network on Disability and Human Rights for Latin America and the Caribbean that meets periodically, studies proposals for joint action and exchanges information on individual and joint activities.

A. Case Studies

The following case studies have been prepared on the basis of interviews held with key DPOs representatives in Argentina, El Salvador, Ecuador, Peru, and the Dominican Republic: REDI, FAICA, AGROCOPI and ALGES.

REDI *Red por los Derechos de las Personas con Discapacidad* (Network for the Rights of Persons with Disabilities)

This organisation was founded in 1998 in Buenos Aires, thanks to the alliance of a number of organisations of persons with disabilities and their families, working for full inclusion and legal recognition, right to labour and accessibility. Specifically, when sliding lift doors in the buildings in the City of Buenos Aires –ostensibly to ‘protect’ children’s safety– began to be replaced by

³³ Web page available at www.riadis.net

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single doors, the entrance gap to the lifts narrowed, causing the majority of buildings to become inaccessible to wheelchair users. This gave rise to the amendment of the city's Building Code, and the addition of inclusive provisions. It was the starting point for the subsequent modification of the Code as a whole (Law 962 of the City of Buenos Aires). From the beginnings, REDI organised meetings with civil servants, legislators and their advisors, and put pressure on the legislative and executive branches through the media, public campaigning and court actions. Since then, REDI has used individual cases affecting disabled persons to trigger reform in issues relating to accessibility in transportation, inclusiveness in schools, labor quotas, and visual, tactile or oral indicators for persons with hearing or visual impairment, with the support of the National and City Ombudsman, and NGOs such as the Association for Civil Rights (ADC), and *Poder Ciudadano*.

Although initially REDI mainly incorporated persons with motor disabilities, it later focused on the protection of equality and inclusiveness for all types of disabilities. The organisation is conducted by persons with disabilities themselves. In recent years, the REDI has made a qualitative leap through strategic alliances with local and international organisations. Its involvement in the process leading to the adoption of the UN Convention, cemented it as key player before governmental institutions, human rights and disabled persons organisation, international inter-governmental bodies.

The interview was conducted with Ana Dones. Regarding her organisation's strategies to promote the full implementation of the UN Convention, she highlighted the interaction with official institutions specialised in the area of disability; the follow up on compliance with the provisions of the UN Convention by competent organs; litigation of cases relating to compliance with the UN Convention; filing of reports before the Human Rights Committee and the Committee on the Rights of Persons with Disabilities.

As far as obstacles in the implementation of the UN Convention are concerned, she highlighted the lack of full understanding on the contents of the UN Convention and the absence of political decision to ensure its full enforcement.

1. FAICA *Federación Argentina de Instituciones de Ciegos y Amblíopes* (Argentine Federation of Institutions for the Blind and Partially Sighted)

FAICA is aimed at forming a caring and active unit of the movement for the blind in Argentina. It strives for the sustained promotion of the capabilities of blind and partially sighted persons, for their overall well-being and for the rightful recognition of their situation as useful and active citizens. To this end, they work in conjunction with other non-governmental organisations concerned with disabilities, various public government departments, companies and all those who contribute to enabling those with visual impairment to be included and participate in society.

In order to respond to the actual necessities of this area, FAICA has also developed various programs with the support of state bodies, international cooperation organisations and entities from the business sector. These activities encompass, in the main, qualifications in new technologies, access to employment, and promoting women and young people with visual disabilities. They have actively followed up on compliance with CRPD.

The interview was conducted with Mariano Godachevich, a lawyer with visual impairment, who held the position of Vice-President of FAICA for a number of years and has represented it in its international advocacy work.

Regarding his organisation's strategies to promote the full implementation of CRPD, he highlighted awareness and training activities.

As far as obstacles in the implementation of CRPD are concerned, he pointed to the persistence of an assistance and care model that is incompatible with the spirit of the CRPD but that is still a source of funding for many OPDs. For their part, States maintain institutional practices that are also incompatible with the Convention. He emphasised that this model must be reviewed and updated in light of the standards of the Convention. The standards should reach, legislators and officials working within the administration of justice, in particular.

Regarding the identification of good practices in the implementation of



CRPD in Argentina, he indicated that there is no particular mechanism devoted to that purpose. At the official level, that is a role fulfilled by the Observatory on Disability created by the Presidency.

Regarding recommendations for the empowerment of OPDs, he reiterated the importance of reviewing and updating past models based on an assistance role.

Regarding the existence of research centres focused on the rights of persons with disabilities, he remarked that although there was a line of research, it was mainly connected with technological innovation in the medical field.

2. ABRAÇA Associação Brasileira para Ação por Direitos das Pessoas com Autismo (Brazilian Association for Action for Rights of Persons with Autism)

ABRAÇA was established in Brazil in 2008 with the purpose of defending the interests and rights of people with autism spectrum disorders, also called Pervasive Developmental Disorders (PDD).³⁴ The organisation is based upon the following principles: the protection of rights to full citizenship of people with autism; the promotion of alternatives to institutionalization and the strengthening of family ties; the respect for the plurality of methodologies of support for persons with disabilities, as long as they are compatible with human rights; the rejection and denunciation of abuses and authoritarian practices affecting persons with disabilities. ABRAÇA is affiliated with the Latin American Network of Non-Governmental Organizations of Persons with Disabilities and their Families - RIADIS.

The interview was conducted in writing with Alexandre Mapurunga, Legal Director of ABRAÇA with extensive experience at the level of the national and regional networks (RIADIS and International Disability Alliance - IDA) and at the level of the UN treaty bodies and the Human Rights Council.

³⁴ Web page available at <http://abraca.autismo.org.br>

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He indicated that the first organizations devoted to the rights of persons with disabilities in Brazil appeared at the beginning of the '80s. At present a majority of these organizations are gathered in federations of local organisations which provide services to persons with disabilities.

Regarding the UN Convention, after its ratification on July 9, 2008, it became the first human rights treaty with constitutional status in Brazil. Civil society organisations have strengthened their articulation since the entry into force of the UN Convention by Brazil and the treaty has become a main reference in their platforms. Discussions, written commentaries and academic works regarding changes of paradigm and social models of human rights vis-a-vis the UN Convention have contributed to the general and the academic debate on the issue. Some organisations have worked specifically on the harmonisation of domestic legislation with the Convention.

Regarding the action taken in order to become full participants in the implementation of the UN Convention, Brazilian DPOs have intervened directly in conjunction with the Executive branch and the Parliament with the objective of raising awareness with the population, call the attention of political leaders, participate in institutional consultations on specific public policies, provide legal advice, and organize conferences.

Regarding the obstacles in the implementation of the UN Convention, the interview indicates that that the more conservative elements many times provide extravagant and even absurd interpretations to justify the continuity of segregation and discrimination. However the constitutional status of the Convention has contributed to its enforcement. In this context, these organisations face the challenge of consolidating the notion of discrimination and the elimination of practices discriminating against persons with disabilities.

Regarding the identification of good practices in the implementation of the UN Convention, ABRAÇA has systematically worked to promote and monitor the implementation of the treaty. Although other DPOs have worked in the same direction, there is still a high degree of segmentation and there is still much to be done in terms of joint implementation.

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Regarding any results on the implementation of the UN Convention, the State has consistently highlighted the impact of DPOs' participation in events and mechanisms of popular consultation, on public policies. In turn, these policies have as a priority the plan "Life without Limits" (*Plano Viver sem Limite -Plano Nacional dos Direitos da Pessoa com Deficiência*) which seeks to incorporate the UN Convention. However, many times this participation translates into the assimilation of the contradictions of these organisations and society, in general. This plan was launched in November, 2011 and has the objective of investing seven billion *Reais* during four years in public policies relating to accessibility, health, social inclusion and education.

In terms of improving the empowerment of DPOs in Brazil, Abraça recommends multiplying training for key players in the movement of persons with disabilities; strengthening awareness of the population regarding the rights of persons with disabilities; providing more specific funding for the protection and follow up on the implementation of the UN Convention.

In Brazil the research centres have had an important role in the change of discourse on disability and the gradual transformation of the manner in which society considers the issue.

3. ACOGIPRI *Asociación Cooperativa del Grupo Independiente Pro Rehabilitación Integral de Responsabilidad Limitada* (Cooperative Association of the Independent Group for Rehabilitation, Ltd.)

This association was created in 1979, as an initiative of a group of blind and physically persons with disabilities, in order to tackle unemployment and economic dependency of disabled young persons with limited resources. ACOGIPRI has technical offices in Ecuador, Peru, El Salvador and the Dominican Republic allowing. The main objectives of the organisation are the fulfilment of the rights of persons with disabilities, through political impact; employment of persons with disability through production and training programs; and working with disabled women by focusing on their particular vulnerability.

The interview was conducted with Fatima Chavez de Solis, a representative from AGROCOPI in El Salvador.

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Regarding his organisation's strategies to promote the full implementation of CRPD, she emphasised the role of cooperation among approximately 30 organisations, in the area of access to education and health. AGROCOPI run an arts and crafts workshop with the participation of persons with a variety of disabilities; they provide rehabilitation in areas of the country where persons with disability have no access to services normally available in urban area; they also provide training for disabled persons who must learn how to care for their health and explain how to obtain a prosthesis.

She highlighted the joint initiative to work with RIADIS and other 25 DPOs from Latin America in a position paper on the implementation of the UN Convention to be presented in Geneva in September, 2013. They have also received support from the Office of the General Attorney (*Procuraduria General de la República*)

As far as obstacles in the implementation of CRPD are concerned, she indicated that they had faced challenges when trying to reach indigenous peoples and members of *maras*³⁵ with disabilities. In the case of the indigenous peoples, a special committee charged with visiting these communities periodically to provide advice and training has been established.

Regarding the identification of good practices in the implementation of the UN Convention, she highlighted the collaboration with other DPOs within the framework of RIADIS and with the Office of the General Attorney for Human Rights in areas relating to family violence affecting persons with disabilities.

Regarding recommendations for the empowerment of OPDs, she emphasised the importance of working with the Ministry of Health in the interior of the country; working with engineers in the building of accessible homes; working with the Police when a person with disabilities is detained; and working with the Mayors in the interior.

³⁵ *Maras* are gangs of youths operating in urban areas of El Salvador.

Regarding the existence of research centres focused on the rights of persons with disabilities, she indicated that there are no research centers with that mandate in El Salvador and that DPOs organisations produce studies when required.

4. ALGES Asociación de Lisiados de Guerra (Association of War Wounded)

ALGES was established on July 12, 1997, in El Salvador by wounded veterans from the FMLN, from the Army and civilian with the aim of promoting the interests and fulfilment of the rights of persons incapacitated as a result of armed conflict situations. ALGES not only works for the adoption and enforcement of legislation in favour of persons with disabilities, but it has been specifically resolute demanding compliance with the Law of Benefits for the Protection of the Wounded and Disabled in the Armed Conflict. The main objectives of this organisation are achieving the involvement of the highest possible number of persons wounded and disabled due to the war, in order to make ALGES the authentic organisational expression in this area; defending its member's interests before the Protection Fund; promoting the complete rehabilitation of its members; implementing social and economic projects and programs which contribute to improving the lives of its members; exerting a positive influence on the formulation of public policies affecting the lives of persons wounded and disabled due to the war.

The interview was conducted with Elba Chacon, a representative from ALGES in El Salvador with responsibility in the area of management and impact.

Regarding his organisation's strategies to promote the full implementation of the UN Convention, they contribute to a common agenda on disability for El Salvador, with the participation of numerous organisations representing persons with different types of disabilities, the General Attorney for Human Rights and National Council for the Comprehensive Assistance of Persons with Disability (CONAIPD). In the case of ALGES, they concentrate on persons wounded during the internal armed conflict. These organisations gather to prepare the shadow report to be submitted to UN treaty bodies.

As far as obstacles in the implementation of CRPD are



concerned, she indicated that CONAIPD has encountered important financial limitations; and that not enough has been done to raise awareness regarding the standards of the Convention and to train those who are in contact with persons with disabilities.

Regarding the identification of good practices in the implementation of CRPD, she explains that ALGES produces evaluation reports on compliance with the convention on the basis of the situation of its own members and the perceptions of sister organisations. She considers that there are important pending challenges connected with public awareness and strengthening of state institutions.

Regarding any recommendations for the empowerment of DPOs, in her view CONAIPD should support DPOs more fully. At present it is somewhat distant vis-à-vis the claims filed by persons with disabilities.

Regarding the existence of research centres focused on the rights of persons with disabilities, she indicated that there are no research centres with that mandate in El Salvador and that DPOs organisations produce studies when required.

V. Conclusion

There is a positive outlook for Latin America and the Caribbean in terms of the progressive implementation of CRPD and the participation of DPOs. At the same time, its effective incorporation and enforcement continues to involve challenges for governments and civil society organisations.

Among the challenges is the residual effect of obsolete definitions of disability which still have a negative impact in the manner in which the issue is addressed in some States of the region. The heterogeneous choice for the definition of disability at the institutional level in the States of the region has a negative impact on the measurement of prevalence and thus on the visibility of the issue.

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Improvement in the area of awareness, assistance, representation and participation require inter sectorial policies and a better response from the public sectors as well as extra support at the level of the national budgets.

The strengthening the role of civil society through special platforms for systematic –rather than sporadic— participation continues to be crucial. DPOs must also deepen their understanding of public policy and governmental performance.

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Appendix: Methodology (Latin America and the Caribbean)

Data for this chapter was gathered both through secondary sources and interviews with DPO representatives. The secondary sources consulted ranged from reports issued by inter-governmental organisations (WHO, PAHO, World Bank, UN, ECLAC, OAS), to official national reports and shadow reports and papers prepared by national and regional non-governmental organisations. Interviews with key DPO representatives as well as national institutions working with them in Argentina, Brazil, and El Salvador were conducted in person, on the phone and by electronic means.

Interview methods and tools

The interview subjects were selected with the participation of a professional with extensive organisational knowledge and the professional relationships in the area of disability rights and inter-governmental organizations, particularly the Pan American Health Organization and the United Nations. He also provided essential input into the questions to be asked in the interviews.

Information about the scope of research project was provided to potential participants by the researchers involved. A copy of the questions was submitted in advance.

Telephone interviews were conducted with participants from El Salvador and Argentina (REDI). In these cases audio recordings were made in order to enable detailed transcripts to be made and ensure no valuable interview data was lost. One of the interviews from Argentina (FAICA) was conducted in person and later received in writing. In all these cases the interviews were conducted in Spanish. The interview from Brazil was conducted in writing and the answer received in Portuguese.

The following questions were asked in the interview:

Which are the main organizations involved in the protection of the rights of persons with disabilities and what is their mandate?

Which is the role of DPOs in the implementation of the UN CRPD?

What types of actions have DPOs themselves taken to ensure that they are fully involved in the process of implementation?

Which are the barriers that DPOs have faced when engaging with the implementation of the UN Convention?

Are there specific instances that provide 'best-practice models' for ensuring proper involvement of DPOs?

Are there any specific outcomes regarding successful implementation and/or improved recognition of the rights of persons with disabilities that resulted from the engagement of DPOs in the implementation process?

Are there recommendations as to how DPOs might be more comprehensively empowered in your country?

Are there specific research institutes in your region that work on the rights of persons with disabilities?