

DIRECTORATE-GENERAL FOR EXTERNAL POLICIES POLICY DEPARTMENT



The situation of indigenous children with disabilities

DROI



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STUDY

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ABSTRACT

Indigenous children with disabilities (ICwD) have received little attention in academic research and development policies. However, they face discrimination at many levels, based on ethnicity, age, ability and gender and this often leads to serious human rights violations. The lack of data, both on the prevalence of disabilities among indigenous children and young people and on specific violations of their human rights, is a serious constraint to any policy intended to respect, protect and promote their human rights. This study seeks to identify these gaps, point to certain patterns and recommend ways of improving data collection and the situation of ICwD in future.

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Table of contents

List	of abl	oreviations	5
Exec	utive	summary	7
1.	Intro 1.1 1.2	Methodology Basic definitions	9 9 9
2	Inter 2.1 2.2	 Inational legal framework and relevant initiatives Legal framework 2.1.1 The United Nations Convention on the Rights of the Child 2.1.2 The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2.1.3 The 1989 ILO Convention No. 169 on Indigenous and Tribal Peoples 2.1.4 The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) The 2030 Agenda and the Sustainable Development Goals 	11 11 12 12 13 13
	2.32.4	The Indigenous Navigator project Recent initiatives to promote the rights of indigenous children with disabilities	14 15
3	Exist 3.1	ing data and research Human rights of indigenous children with disabilities 3.1.1 The rights to life, physical integrity and dignity 3.1.2 Right to participation 3.1.3 Right to education 3.1.4 Access to land and intercultural basic services	18 19 20 23 23 25
	3.2	Specific factors contributing to disability among indigenous communities 3.2.1 Poverty and exclusion 3.2.2 Cultural barriers 3.2.3 Remoteness 3.2.4 Natural hazards and conflict exposure	25 26 26 27 27

4	Case	e studies establication of the studies established the studies established the studies established the studies	28	
	4.1	Latin America	29	
		4.1.1 Brazil	29	
	4.2	Asia	31	
		4.2.1 Nepal	31	
	4.3	Africa	32	
		4.3.1 Kenya	33	
5	EU policies and actions			
	5.1	Regulation (EU) No. 233/2014 of the European Parliament		
		and of the Council of 11 March 2014 establishing a financing	ıg	
		instrument for development cooperation for the period		
		2014–2020	35	
	5.2	The Multiannual Indicative Programme 2014–2017 for the		
		Thematic Programme on 'Global Public Goods and		
	5 2	Challenges' for the Period 2014–2020.	37	
	5.3	The 2014–2017 EIDHR multiannual indicative programme	38	
	5.4	Relevant Council conclusions for IP	39	
	5.5	Other relevant documents for EU external action on	20	
	F 6	children and disability Other FII human rights instruments	39 40	
	5.6 5.7	Other EU human rights instruments European Parliament Resolutions	41	
_		•	41	
6.		ommendations to the EU and the European		
Parli	iame	nt	43	
	6.1	Improving data collection	43	
	6.2	Improving legal frameworks	44	
	6.3	Targeted actions	45	
Bibliography				
Appendix1: Interviewees				
Арр	endi	x 2: English version of the questionnaire for		
IP or	gani	sations	56	

List of abbreviations

ACHIPR African Commission for Human and Indigenous People's Rights

CEPAL United Nations Economic Commission for Latin America and the Caribbean

CHIRAPAQ Center for Indigenous Cultures of Peru

CRC Committee on the Rights of the Child

CRPD Committee on the Rights of Persons with Disabilities

CSOs Civil Society Organisations

CSOLA Civil Society Organisations and Local Authorities

CwD Children with Disabilities

DG DEVCO Directorate General for International Cooperation and Development

DIHR Danish Institute for Human Rights

DOCIP Indigenous People's Centre for Documentation, Research and Information

DRAF Disability Rights Advocacy Fund

DRF Disability Rights Fund

DRR Disaster Risk Reduction

EIDHR European Instrument for Democracy and Human Rights

EMRIP Expert Mechanism on the Rights of Indigenous People

EU European Union

FPIC Free, Prior and Informed Consent

FRA European Union Fundamental Rights Agency

GPGC Global Public Goods and Challenges

HIV/AIDS Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

HLPF High Level Political Forum

HRW Human Rights Watch

ICwD Indigenous Children with Disabilities

IDA International Disability Alliance

IGwD Indigenous Girls with Disabilities

IIDCWG International Indigenous Disability Convention Working Group

IWwD Indigenous Women with Disabilities

ILO International Labour Organization

INEI National Institute of Statistics and Informatics

IP Indigenous People

IPA Instrument for Pre-accession Assistance

IPACC Indigenous Peoples of Africa Coordinating Committee

IPwD Indigenous Persons with Disabilities

IPwDGN Indigenous Persons with Disabilities Global Network

IWGIA International Working Group on Indigenous Affairs

JOAS Indigenous Peoples Network of Malaysia

LGBTI Lesbian, Gay, Bisexual, Transgender and Intersex

NGOs Non-governmental Organisations

NIDA Nepal Indigenous Disabled Association

NIDWAN National Indigenous Disabled Women Association Nepal

OHCHR Office of the High Commissioner for Human Rights

PwD Persons with Disabilities

SDGs Sustainable Development Goals

UN United Nations

UNDP United Nations Development Programme

UNESCO United Nations Educational, Scientific and Cultural Organization

UNFPA United Nations Population Fund

UNICEF United Nations Children's Fund

UNPFII United Nations Permanent Forum on Indigenous Issues

UNCRC United Nations Convention on the Rights of the Child

UNDRIP United Nations Declaration on the Rights of Indigenous Peoples

UNCRPD United Nations Conventions on the Rights of Persons with Disabilities

VET Vocational and educational training

WG Washington Group on Disability Statistics

WHO World Health Organization

Executive summary

Indigenous Children with Disabilities (ICwD) have frequently been ignored in academic research and development policies. However, they face multiple layers of discrimination based on their ethnicity, age, abilities and gender that often lead to serious human rights violations. Lack of data, both on the prevalence of disabilities among indigenous children and young people and on specific human rights violations they are suffering, is a serious constraint for any policy aiming to respect, protect and fulfil their human rights. This study attempts to identify these gaps, suggests certain patterns that have been observed and recommends future ways of improving both data collection and the situation of ICwD.

While reliable data are scarce, the most widely accepted estimation from the United Nations Permanent Forum on Indigenous Issues (UNPFII) suggests that the number of Indigenous Persons with Disabilities (IPwD) is approximately 54 million. Moreover, previous studies have shown that disabilities are more frequent among indigenous peoples (IP) than among the rest of the population, although the prevalence of disabilities among different indigenous communities remains uneven. Different prevalence rates may be due to differences in how data are collected. In fact, most of the countries surveyed in this study do not include the questions recommended by the Washington Group (WG)¹ in their national censuses.

This study moves away from a charitable and medical perspective, which centres the analysis on the causes of impairments in children, and focuses instead on a rights-based approach, giving attention to human rights enjoyed by ICwD. The main human rights that are at risk for ICwD are the right to life, the right to physical integrity (freedom from violence, torture and cruelty) and freedom of movement. Another crucial right for these children, while often forgotten, is the right to participation and non-discrimination in society in accordance to their age. That means the right to play, the right to education, the right to be heard and the right to a life free from child labour and domestic exploitation. Moreover, all other relevant rights, such as the right to intercultural justice, the right to culture, the right to live in their own community, the right to social protection and the right to intercultural health care, are closely linked to the access to basic services, which are often lacking in rural and remote areas. Finally, the main causes that jeopardise the full enjoyment of ICwD rights are poverty and exclusion, cultural barriers, prejudice and stigma, remoteness and lack of other relevant rights related to land and territory.

This study has identified common patterns across countries and peoples by means of questionnaires and detailed interviews. In fact, all interviewees reported at least one example of ICwD in their communities. However, most of these children did not have access to special assistance devices (such as wheelchairs, hearing aids, etc.). Most of the interviewees reported that these children are less likely to attend school and that, for most of them, their main activity was staying at home. Moreover, 13 out of 14 respondents reported that ICwD in their communities have difficulties making friends. Furthermore, 10 out of 13 reported at least one case of sexual violence against ICwD, committed either by family members or people outside the community, or of harmful traditional practices against ICwD. Some respondents reported more than one case. Anyway, in 3 out of 4 cases, the victims were girls and, given their increased vulnerability, indigenous girls with communicational and intellectual difficulties are the most likely to suffer this type of violence.

This study provides key recommendations on how to improve data collection on ICwD, how to improve legal frameworks and in which targeted actions the European Union (EU) could become involved. All

¹The Washington Group on Disability Statistics (WG) is a UN group established under the United Nations Statistical Commission. The WG was constituted to address the urgent need for cross-nationally comparable population-based measures of disability. Its mandate is the promotion and co-ordination of international co-operation in the area of health statistics focusing on disability data collection tools suitable for censuses and national surveys. The questions recommended for censuses seek to provide internationally comparable data based on functional abilities. See: http://www.washingtongroup-disability.com/washingtongroup-question-sets/ (last accessed:13.11.2017).

recommendations collected in this study have been put forward by representatives of the IPwD Global Network (IPwDGN) and/or key stakeholders and partners such as the International Labour Organization (ILO), the International Disability Alliance (IDA), the Indigenous People's Centre for Documentation, Research and Information (DOCIP). They have been checked for their feasibility and suitability and were finally selected based on the literature and data analysis.

Regarding data collection, in order to improve data on the prevalence of disabilities among indigenous children, the EU should work on promoting the SDGs, while making efforts to support specific consultations among particular targeted groups, focusing on the rights-based approach methodology. In terms of the rights and vulnerabilities of ICwD, more research is needed on fundamental human rights, full and effective participation of ICwD in the social life of their communities and access to intercultural services, such as bilingual education. In addition, more action is required on physical and sexual violence and harmful traditional practices against ICwD. Gender should be mainstreamed in any research conducted on the rights of ICwD.

Regarding legal frameworks, the EU should use human rights dialogues, its work in the context of the Human Rights Council and the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) to ensure all international legal documents, policies and frameworks include intersectionality, which goes far beyond listing all 'vulnerable groups', and to encourage third countries to report on the situation of ICwD. The EU should also include ICwD in future reviews of EU Guidelines on the rights of the child and other relevant guidelines. The EU should also do more to ensure that in free, prior and informed consent processes, information and documentation on the consequences for the human rights of affected populations is accessible to PwD and that they enjoy full participation in these processes. Whenever possible, young people and children, with and without disabilities, should be included in consultations in a way that is appropriate for their age and capabilities.

Finally, regarding targeted actions, the EU can lend its support by promoting or supporting organisations of IPwD, paying particular attention to women, young people and organisations formed by parents of ICwD, while also ensuring the ICwD agenda is raised in all relevant international debates, especially in those related to the rights of IP, children, persons with disabilities and women. Any EU cooperation project related to IP should ensure all children, including those with disabilities, can fully participate in or benefit from them (for example including universal design in schools, playgrounds, etc.). The EU should strongly promote the right to education of every indigenous child with a disability by improving accessibility to intercultural schools and promoting specific training for teachers in indigenous communities and intercultural schools. The EU should also support intercultural awareness by promoting campaigns on the rights, abilities and opportunities of children with disabilities and more specifically ICwD.

1. Introduction

1.1 Methodology

This study aims to identify: 1) gaps in data regarding ICwD, both in terms of disability prevalence among indigenous girls and boys and of human rights enjoyed by these children; and 2) national and international instruments and initiatives designed to improve the situation of ICwD. The information in this paper comes from an extensive review of academic literature and relevant legal texts on the subject, as well as questionnaires and semi-structured interviews with IPwD activists and experts on ICwD. More specifically, interviews were conducted with co-chairs and regional focal persons of the IPwDGN, all of them IPwD, other IPwD who do not belong to the the IPwDGN and experts from the International Labour Organization (ILO), International Disability Alliance (IDA), the Danish Institute for Human Rights (DIHR), the DOCIP, the European Commission's Directorate-General for International Cooperation and Development (DEVCO – Directorate B, People and Peace) and members of the African Commission for Human and Indigenous People's Rights (ACHIPR) and the Indigenous Peoples of Africa Coordinating Committee (IPACC). ² Although due to time and budget constraints it was not possible to conduct consultations with ICwD, most IPwD interviewed for this study were themselves ICwD in the past. More specifically, 33 % of them were born with impairments, 50 % acquired impairments during childhood and adolescence and 17 % acquired impairments in their later adult lives.

In addition, 40 questionnaires were also distributed to IP organisations and disability organisations in the Philippines, Nepal, Bangladesh, Brazil, Peru, Colombia, Kenya, Tanzania and Cameroon.³ The response rate was around 32.5 %. Questionnaires included some of the WG's questions and explicit inquiries on the enjoyment of basic human rights of ICwD in specific communities.⁴ Although results from questionnaires may not be statistically representative of every indigenous community and the situation of every indigenous child living with a disability, they do show certain patterns that seem to be common for ICwD living in different countries and regions.

Even if this study drew on the information provided by the interviewees and questionnaire respondents, the spread of some serious human rights violations reported here may need to be verified through further studies. Finally, this paper compares several case studies on the situation of ICwD in different countries from Latin America, Asia and Africa—specifically Brazil, Nepal and Kenya. Cases were selected based on experiences of good practice in data collection and legislation initiatives aiming to improve the rights of ICwD.

1.2 Basic definitions

The main concepts used in this study are frequently contested by governments, non-governmental organisations (NGOs) and civil society organisations (CSOs), or are used differently depending on specific agendas. With this in mind, a few basic definitions will be provided at this point.

Indigenous peoples: Today, the definition of IP is based on self-identification, although the concept is still contested by some governments, especially in Africa and Asia (Tauli-Corpuz, 2008). For decades, the definition of IP was somehow related to an immemorial past, prior to colonisation or the invasion of European settlers, and therefore the identification of IP was linked to an ancestral connection with a

² See Appendix 1.

³ The EU is already contributing to improving data collection on IP in these countries through the Indigenous Navigator project. Therefore, some of the data collected in the present study can be later be contrasted with those collected by the Indigenous Navigator.

⁴ See Appendix 2.

specific territory and a shared ancestral culture. In this regard, the most widely accepted definitions of IP are those used in ILO Convention No. 169⁵ and the definition put forward by Martínez Cobo.⁶ However, these two definitions are based on Latin American and English-speaking countries' experiences and thus the concept of IP is very often linked to a pre-colonial age, excluding the situation of many communities in Africa and Asia (Inguanzo, 2016). In fact, Martínez Cobo adds that 'on an individual basis, an indigenous person is one who belongs to these indigenous peoples through self-identification as indigenous (group consciousness) and is recognised and accepted by the group as one of its members (acceptance by the group). This preserves for these communities the sovereign right and power to decide who belongs to them, without external interference' (Martínez Cobo, 1986). On a collective basis, IP are therefore those self-identified as such, but there are no longer cultural or historical requirements to fit the definition.

Children: The United Nations Convention on the Rights of the Child (UNCRC) defines a child as 'every human below the age of eighteen years unless under the law applicable to the child, majority is attained earlier' (United Nations, 1989, Art. 1). Nonetheless, 'there is still no concrete, consistent definition of "child" under EU law' (FRA, 2009). The Council of Europe usually adopts the UNCRC definition but some issues, such as education, defer to national law of member states. In some other issues, such as those related to occupation and employment, EU law distinguishes between young people (any person below 18 years of age), adolescents (from 16 to 18 years of age) and children (below 16 years of age) (FRA, 2015). However, it is noteworthy that in many indigenous communities adulthood is reached before the age of 18.

Disability: According to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 'persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others' (United Nations, 2006, Art. 1). Therefore, disability covers 'impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations' (WHO, 2007). Consequently, living with a disability is not just a health problem but a social condition. For example, a person with a physical impairment living in a highly mobile society, such as a nomadic indigenous community, may face greater obstacles in terms of integration and active participation in his or her own community. In the case of children, this could result in lifelong discrimination as well as other human rights violations.

However, disability might have different meanings depending on the culture. For a long time, and due to previous colonisation, being indigenous has been in fact considered a disability by the non-indigenous state authorities (Hollinsworth, 2012). In fact, some scholars have noted that 'in developing a conceptual framework for research and policy development regarding indigenous people with disabilities, each indigenous community must be understood in the context of their experience of colonisation, disadvantage and cultural heritage' (Gilroy et al., 2013).

Intersectionality: The concept of intersectionality relates both to an experienced situation and to an analytical and/or policy approach. Firstly, intersectionality refers to the multiple layers of discrimination and oppression experienced as a consequence of belonging to different subordinated categories in a

⁵ The ILO Convention No. 169 states that people are considered indigenous either because they are descendants of those who lived in the area before colonisation or because they have maintained their own social, economic, cultural and political institutions since colonisation and the establishment of new states(ILO, 1989).

⁶ 'Indigenous communities, peoples and nations are those which, having a historical continuity with pre-invasion and pre-colonial societies that developed on their territories, consider themselves distinct from other sectors of the societies now prevailing in those territories, or parts of them. They form at present non-dominant sectors of society and are determined to preserve, develop, and transmit to future generations their ancestral territories, and their ethnic identity, as the basis of their continued existence as peoples, in accordance with their own cultural patterns, social institutions, and legal systems' (Martínez Cobo, 1986).

particular society. The first time the concept of intersectionality was used, it referred to the specific situation of black women, where it was highlighted that the separate analysis of categories such as gender and race was unable to account for the experience of oppression and discrimination suffered by black women (Crenshaw, 1989). Later on, it was highlighted that intersectionality can be structural, political and representational, leading not just to discrimination and oppression but also to increased violence against the people belonging to specific subsets of subordinated groups (Crenshaw, 1991).

However, intersectionality also refers to an analytic or policy approach. More specifically, this approach 'focus[es] on seeing multiple institutions as overlapping in their co-determination of inequalities' (Choo and Ferree, 2010). An intersectionality perspective requires us to pay 'special attention to the experiences of individuals that exist at the "intersection" of more than one identity marker' (Davis, 2013), such as gender, disability status, age, ethnic background or sexual orientation, among others. Those living in the overlap of these identity markers suffer from lapses in legal recognition that need to be identified and analysed through an intersectional lens. So far, at the international level, the intersectionality approach helped to re-conceptualise discrimination as a process. Chow argues that 'intersectionality has contributed to substantially transforming the UN human rights treaty body practice [especially] on gender discrimination' (Chow, 2016). However, the way intersectionality is currently applied reduces it to 'a form of "additive exercise" owing to a misperception that multiple identities necessarily contribute to an accumulative form of oppression' (Chow, 2016).

Intersectionality has been more frequently addressed in gender studies and ethnic studies, although it is also a useful analytic tool when focusing on disability. For example, in this study, the subset of people who suffer the widest range of discrimination is indigenous girls with disabilities. In this case, the layers of discrimination affecting them include ethnicity, gender, the type and degree of disability and their age. Furthermore, it has been highlighted that not every form of disability faces the same degree of stigma. There is a difference between disabilities that are visible and stable and disabilities that are invisible and variable (Goldberg, 2015).

2 International legal framework and relevant initiatives

2.1 Legal framework

2.1.1 The United Nations Convention on the Rights of the Child

As stated above, under the UNCRC, a child is determined as any person below 18 years of age (Article 1). The guiding principles of the UNCRC that are especially relevant to the situation of indigenous children living with disabilities include the followings:

- Non-discrimination (Article 2): the UNCRC applies to all children, whatever their race, religion or abilities, whatever they think or say and whatever their background;
- **Best interests of the child** (Article 3): the best interests of children must be the primary concern in making decisions that may affect them. 'All adults should do what is best for children. When adults make decisions, they should think about how their decisions will affect children. This particularly applies to budget, policy and law makers' (UNICEF, 2014). This article is particularly crucial for ICwD since multiple forms of discrimination can come from very different sources, both outside and within a community. In addition, state authorities and policy makers should take special care of the balance between the individual and collective rights of these children, since on some occasions these two sets of rights can be difficult to reconcile;

⁷ See Schiek and Lawson, 2011; Hollinsworth, 2012; Davaki et al., 2013.

- **Right to life, survival and development** (Article 6): Children have the right to live. Governments should ensure that children survive and develop into healthy adults;
- Respect for the views of the child (Article 12): When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account.

In 2009, the Committee on the Rights of the Child issued a General Comment on the situation of indigenous children with disabilities, where the intersectionality lens was applied, encouraging State Parties to adapt legislation, measures and basic services to ICwD (Committee on the Rights of the Child, 2009).

2.1.2 The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

According to the UNCRPD, 'discrimination on the basis of disability means any distinction, exclusion, or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment, or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field. It includes all forms of discrimination, including denial of reasonable accommodation' (United Nations, 2006).

Article 7 in particular refers to children with disabilities, requiring governments to 1) take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children; 2) take the best interests of the child as a primary consideration; 3) ensure children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability-and age-appropriate assistance to realise that right.

The UNCRPD has no specific articles on indigenous peoples, although the preamble recognises 'the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age, or other status' (United Nations, 2006).

Since many indigenous communities live in remote and conflict areas, Article 11 of the UNCRPD is also relevant in that it expands the role of state authorities to ensuring the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters. Another important article for IPwD is Article 19, which recognises the right of people with disabilities to live in their own communities.

Other relevant articles of the UNCRPD relate to equal access to justice (Articles 12 and 13), equal dignity and physical integrity (Articles 15 to 17), the right to education and health (Articles 24 and 25 respectively) and the right to participate in public and cultural life (Articles 29 and 30). Finally, Articles 31 to 33 encourage governments to improve data collection on people with disabilities, set minimum guidelines for international cooperation and establish requirements for the implementation and monitoring of the UNCRPD.

2.1.3 The 1989 ILO Convention No. 169 on Indigenous and Tribal Peoples

This legal instrument was the first International Convention on the rights of indigenous peoples that was legally binding. However, only 22 states have ratified it, most of them in Latin America.⁸

⁸ The exceptions are Spain and Denmark in Europe, Nepal in Asia and Fiji in The Pacific.

This convention considers the particular situation of indigenous children in Articles 28 and 29 but these articles are mostly related to the right to education, understood both as an individual and a collective right. However, there is no reference to IPwD or ICwD.

This convention set up the criteria for the establishment of processes of consultations with indigenous peoples. These criteria do not explicitly mention indigenous children or IPwD but are still relevant for the inclusion of IPwD and ICwD in decision making processes. In fact, 'Article 6 (2) requires that consultations are carried out "in good faith and in a form appropriate to the circumstances, with the objective of achieving agreement or consent' to the proposed measure". Although the obligation to consult under the provisions of the Convention is interpreted as not requiring that an agreement is reached with indigenous peoples, article 6 (2) nonetheless requires that there shall be an 'objective of achieving agreement or consent' to the proposed measure' (Henriksen, 2008).

Convention No. 169 also contains other relevant rights and obligations linked to the concept of participation:

- Right to 'participation' (articles 2, 5, 6, 7, 15, 22 and 23);
- Right to be 'consulted' (articles 6, 15, 17, 22, 27, 28), for example in relation to school curricula (article 28);
- Obligation to 'cooperate' with indigenous peoples (articles 7, 20, 22, 25, 27 and 33);
- Right for IP to 'decide their own priorities' (article 7);
- Obligation not to take measures contrary to the freely-expressed wishes of IP (article 4);
- Obligation to seek 'free and informed consent' from IPs (article 16).

2.1.4 The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)

The singularity of this document is that IP were deeply involved in its drafting. Although the UNDRIP is not legally binding, 'the standards affirmed in the declaration share an essentially remedial character, seeking to redress the systemic obstacles and discrimination that indigenous peoples have faced in their enjoyment of basic human rights. From this perspective, the standards of the declaration connect to existing state obligations under other human rights instruments' (Anaya, 2009).

In any case, the UNDRIP affirms in Article 21(2) that 'particular attention shall be paid to the rights and special needs of indigenous elders, women, youth, children and persons with disabilities' (United Nations, 2007). It also further developed the right to Free Prior and Informed Consent (FPIC) of IP.

2.2 The 2030 Agenda and the Sustainable Development Goals

In 2015, the 2030 Agenda was adopted by the UN General Assembly, establishing 17 Sustainable Development Goals (SDGs) and 169 associated targets. One third of the SDGs take up provisions contained in the UNDRIP, making it a useful tool for measuring IP rights. In fact, IP are specifically mentioned in two SDGs relating to food security (Goal 2) and education (Goal 4) and their two corresponding indicators, while persons with disabilities are specifically mentioned in relation to social protection (Goal 1), education (Goal 4), employment and decent work (Goal 8), economic and political inclusion (Goal 10), affordable and accessible transport and safe public places (Goal 11), participatory and representative decision-making processes (Goal 16) and improved and disaggregated data collection (Goal 17). Other indicators that are relevant for ICwD are those dealing with child mortality and adolescent birth rates (related to Goal 3 on good health and well-being), child labour (related to Goal 8), child violence and abuse (related to Goal 5 on gender equality), among others. Therefore, the SDGs are a tremendous opportunity for improving the situation of ICwD, since they provide a binding framework for enhancing policies for disabled and indigenous peoples, but also for data collection.

The High Level Political Forum (HLPF), the UN body responsible for the follow-up review of the SDGs, has met twice since the 2030 Agenda was adopted. Civil society, together with national governments, can participate in these meetings through the UN Major Groups. For ICwD the relevant ones are the Major Group for Indigenous Peoples, the Major Group for Children and Youth, the Major Group for Persons with Disabilities and the Major Group for Women. In 2016, 22 countries submitted voluntary national reviews to the HLPF, while in 2017, 7 SDGs were specifically reviewed and 43 countries submitted voluntary national reviews. The SDGs that were reviewed in 2017 were Goals 1, 2, 3, 5, 9, 14 and 17.

2.3 The Indigenous Navigator project

One of the most significant attempts to address the measurement of gaps in how the UNDRIP is implemented is the Indigenous Navigator project, funded by the European Commission through two grants held by the ILO, to define the indicators and conduct the pilot projects, in coordination with other partners. The project aims to construct indicators that truly capture the real enjoyment (if any) of the rights of IP. The indicators were selected via a process which involved active participation and brought together IP organisations and experts on the rights of IP and SDGs. The pilot phase of the project, in which several countries were targeted, has now been completed. This tool makes it possible to measure the enjoyment of 12 fundamental rights of IP, using national and community questionnaires: 1) cultural integrity; 2) lands, territories and natural resources; 3) fundamental rights and freedoms; 4) participation in public affairs; 5) legal protection, access to justice and remedy; 6) cross-border contact; 7) freedom of expression and media; 8) general economic and social development; 9) education; 10) health care; 11) employment and occupation; 12) self-determination.

While the potential of this tool is tremendous, disability is not an issue which is comprehensively tackled in the project. The only question related to disabilities is question 108 in the community questionnaire, which asks: 'Does/do the school/schools in your community/communities provide access to the following facilities: [...] (IV) adapted infrastructure and material for students with disabilities' (Indigenous Navigator, 2017). This is an important question, since it directly relates to a fundamental right of ICwD. Two further questions are somewhat related to disability, although they are not properly disaggregated. Question 107 asks how accessible primary school facilities are for the children of the interviewed community, specifically referring to remoteness and distance between the community and the school. However, this question does not incorporate the principles of universal design, universal access and all-user-friendly environment requested by Doreen Deemas, former member of the IPwDGN and the Disability Caucus within the UNFPII (Deemas 2015). 11 Question 95 asks 'approximately how many men and women of your people/community are covered by social welfare programmes (health care, old age pensions, unemployment benefit, benefits during maternity leave)' (Indigenous Navigator, 2017). This particular question relates to Global SDG Indicator 1.3.1, which does include 'persons with disabilities', although this specific target group of social welfare programmes is not considered in the Indigenous Navigator questionnaire. Moreover, the question considers all the programmes together, so it is not possible to know how many people are benefitting from each specific programme.

Regarding the remainder of the questionnaire, it is noteworthy that when the questionnaire does address discrimination (questions 14 and 15 of the community questionnaire), these questions do not include

⁹ See https://www.humanrights.dk/sites/humanrights.dk/files/media/dokumenter/sdg/info brochure navigator 3 web.pdf (last accessed: 16.10.2017).

¹⁰ See Indigenous Navigator project, http://indigenousnavigator.org/index.php/en/data (last accessed: 16.10.2017).

¹¹ Not to be confused with the International Disability Caucus, which is a global network of more than 70 civil society organisations focused on promoting the rights of persons with disabilities in different countries and regions. The International Disability Caucus was very active in the negotiations for the UNCRPD.

disability as a reason for discrimination.¹² Furthermore, question 67, on sexual and gender-based violence against indigenous women and girls over 15 years of age, is problematic in many ways. Firstly, it is problematic because it leaves out violence against boys and girls below 15 years of age. Secondly, it does not specify whether such sexual and gender-based violence is committed against persons with disabilities. Thirdly, and most significantly, this particular question is problematic because it is not clear who is answering the question or how. For the purposes of the Indigenous Navigator project, the ideal situation is that questionnaires are answered in focus group discussions or communal assemblies.¹³ However, this is extremely inappropriate and even dangerous when addressing sexual and gender-based violence. The World Health Organization (WHO) has a special protocol on how to research sexual and gender-based violence at community level and, although conducting research on sexual and gender-based violence against indigenous women, girls and boys is paramount, it may well be that the Indigenous Navigator questionnaire is not the most effective tool. Partners of the Indigenous Navigator project are currently tackling this issue by hosting the technical training sessions and workshops and advising field researchers that gender-sensitive issues should be put to women on a separate basis.¹⁴

Furthermore, throughout the questionnaire, children are identified as a single homogenous group and barely disaggregated by sex. In order to find an appropriate balance between detail and feasibility, the rule of thumb was to disaggregate whenever the UN SDGs do. ¹⁵ This produced sex-disaggregated data for girls and boys when addressing enrolment at different educational levels, unemployment among young people, child labour and vocational education. However, further gender disaggregation is needed for other questions such as child mortality, violence, etc.

In conclusion, the Indigenous Navigator project is an impressive and extremely useful tool for measuring the enjoyment of fundamental rights of IP. However, it does not specifically target IPwD and of course does not include ICwD either. Representatives from the IPwDGN, as well as from the IDA and ILO, have strongly recommended including the WG questions¹⁶ whenever there is a survey conducted among indigenous communities and persons.¹⁷ The consultations which form part of the Indigenous Navigator project may be a good opportunity to do just that. Furthermore, a way of introducing data on indigenous children through the Indigenous Navigator project is to hold separate group discussions with relevant target groups, such as women, children and/or adults and children with disabilities, as mentioned above. Addressing the questionnaire specifically to indigenous children and young people is very much in line with Article 12 of the UNCRC, which states that children are entitled to be heard and their opinions to be taken into account in all decisions that affect them. In this regard, Plan International has recently developed some guidelines for consulting children and young people with disabilities (Plan International, 2016).

2.4 Recent initiatives to promote the rights of indigenous children with disabilities

Both the UN and civil society organisations have undertaken various initiatives aimed at promoting the rights of indigenous adults and children living with disabilities. Some of them are focused on improving data collection, while others attempt to raise awareness and improve international and national policy

 $^{^{12}}$ Grounds included are indigenous identity, gender, age (in general, not disaggregated) and income.

¹³ Interview with a representative from the DIHR.

¹⁴ Interview with a representative from the DIHR.

¹⁵ Interview with a representative from the DIHR.

¹⁶ The WG list of questions asks if a particular person has any difficulty performing certain activities such as hearing spoken words or music, walking a certain distance, recognising people or seeing things a short distance away, etc., instead of asking whether the interviewee suffers from a disability.

¹⁷ Interviews conducted with Martin Oelz and Stefan Tromel (ILO), Tchaurea Fleury (IDA), Olga Montúfar and Pratima Gurung (IPwDGN).

frameworks. The following sections will review the most significant of these initiatives. It is important to note that the issue of the rights of IPwD is a quite recent topic on international agendas: initially championed by just a few individuals and organisations, ¹⁸ it is now garnering more attention and support.

During the drafting negotiations of the UNCRPD and the UNDRIP, a small group of IPwD formed a network called the International Indigenous Disability Convention Working Group (IIDCWG) that tried to advocate including the rights of IPwD in the UNCRPD. Their success was limited, since IPwD are included in the preamble but not in a separate article. Founders of IIDCWG alleged this was due to lack of resources and economic support from the international community (Hickey, 2014).

In May 2012, six indigenous leaders with disabilities attended the UN Permanent Forum on Indigenous Issues (UNPFII) and participated in a pilot side event on IPwD, jointly organised by the Disability Rights Fund and UN Department of Economic and Social Affairs. This was funded by Australian Aid and the Disability Rights Advocacy Fund (DRAF). Three indigenous leaders with disabilities—Olga Montúfar, (Nahuatl leader from Mexico), Kamala Sen Chakma (Chakma male leader from Chittagong Hill Tracts in Bangladesh) and Ipul Powaseu (leader from Papua New Guinea) — participated as speakers in the side event. The event was chaired by Myrna Cunningham, former chairperson of the UN Permanent Forum on Indigenous Issues, who called for bridges to be built between the Global Indigenous Peoples Rights Movement and the Global Persons with Disabilities Rights Movement. This was an opportunity for the indigenous leaders with disabilities to establish a Disability Caucus within the UNFPII. The founders of this Disability Caucus were Felipe Flores (from Peru), Kamala Chakma (from Bangladesh), Olga Montúfar (from Mexico), Savina Nongebatu (from Solomon Islands), Setareki Macanawai (from Fiji) and Ipul Powaseu (from Papua New Guinea).

An Expert Meeting on IPwD was held for the first time in November 2012 in Madrid. It brought together IPwD and experts on the UNCRPD and the rights of IP. The rights of IPwD were again brought up during the 12th session of the UNPFII in 2013, together with a paper entitled Study on the situation of indigenous persons with disabilities, with a particular focus on challenges faced with respect to the full enjoyment of human rights and inclusion in development (United Nations, 2013b). This study constitutes the most comprehensive exploration of the situation of IPwD to date. It makes several references to the situation of ICwD, although it was not the main focus of attention. This study will be further analysed in the next section of this paper.

During the 12th session of the UNFPII, the Indigenous Persons with Disabilities Global Network (IPwDGN) was established to promote the rights of IPwD, reach out to new communities and engage with international and regional human rights and development processes. The IPwDGN brings together indigenous leaders from different regions and is guided by the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and advocates the application of the twin-track approach. In IPwD from this session were collected in a special issue of Cultural Survival Quarterly Magazine (Cultural Survival, 2015).

A year later, the Outcome Document of the World Conference on Indigenous Peoples (2014) was presented. It included several mentions of IPwD and indigenous children, although it did not make any specific mention of ICwD. However, the inclusion of references to IPwD is considered a great achievement. In paragraph 9, states commit to providing and protecting 'the rights of indigenous persons with disabilities and to continuing to improve their social and economic conditions, including by developing

¹⁸ Álvaro Pop and Myrna Cunningham from UNPFII, Olga Montúfar and Setareki Macanawi (current co-chairs of IPwDGN), Juan Nones (IDA), with the support of US-based Disability Rights Fund (DRF) and the Disability Rights Advocacy Fund (DRAF).

¹⁹ The twin-track approach includes mainstreaming disability in every development programme and policy targeting IP, but at the same time taking measures specifically targeting IPwD.

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targeted measures for the [...] action plans, strategies, or measures, in collaboration with indigenous persons with disabilities. [They] commit to ensuring that national legislative, policy, and institutional structures relating to indigenous peoples are inclusive of indigenous persons with disabilities and contribute to the advancement of their rights' (United Nations, 2014). In paragraph 10, states also commit to working with IP to disaggregate data and developing holistic indicators on persons with disabilities. Relevant references to indigenous children and young people are made in paragraphs 14 and 15, with a special mention to the right of indigenous young people to full and effective participation in all issues affecting them. That same year, on the occasion of the 2014 Expert Mechanism on the Rights of Indigenous People (EMRIP) held in Geneva, a study on access to justice for IP with a specific focus on women, children and young people and persons with disabilities was presented (Expert Mechanism on the Rights of Indigenous Peoples, 2014).

Victoria Tauli-Corpuz, the UN Special Rapporteur on the Rights of Indigenous Peoples, and Catalina Devandas, the UN Special Rapporteur on the Rights of Persons with Disabilities, have played a critical role in raising the profile of this issue in the international arena and building up the advocacy network. In 2015, on the occasion of a key UN meeting on Disaster and Risk Reduction (DRR) in Sendai, Japan, they both called on national governments and other participants to consider IPwD in the new global strategy initiatives that take into account disability and allow full participation of IPwD. The rights of IPwD were again brought up in October 2016 on the occasion of the Officer of the High Commissioner for Human Rights' (OHCHR) Expert Meeting on Climate Change and Human Rights, through the participation of Nelly Caleb from the Pacific Disability Forum and the participation of both UN Special Rapporteurs.

In April 2015, the 14th session of the UNPFII took place, and one of its side events was 'Intersectionality of the UN Declaration on the Rights of Indigenous Peoples and UN Convention on the Rights of Persons with Disabilities in Asia-Pacific'. This was possible thanks to indigenous leaders from Asia (Bangladesh and Nepal) and the Pacific (Fiji, Papua New Guinea and Solomon Islands), who have been very active in advocating the issue since the very first meetings in 2012. The UNPFII also issued several recommendations to UN agencies and member states regarding IPwD,²⁰ most of which are also included in this study. Later that year, in June 2015, the IPwDGN hosted a two-day workshop together with the IDA and Asian Indigenous Peoples Pact, aiming to promote the rights and inclusion of IPwD in mainstream, indigenous and disability-related human rights and development mechanisms and to increase the institutional capacity of the IPwDGN (International Disability Alliance, 2016). Furthermore, in 2015, the regional chapters of IPwDGN in Latin America was also strengthened through a regional workshop held in Brazil.

The Expert Meeting on IPwD was held again in July 2016 in Geneva. For that occasion, ILO hosted a two-day meeting prior to the EMRIP, co-organised by the Special Rapporteur on the Rights of Indigenous Peoples, Victoria Tauli-Corpuz and the Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas, with the participation of other experts of the EMRIP, IDA, OHCHR and representatives of the IPwDGN. This time, the meeting identified the main areas where action and measures needed to be taken: access to education, health care, justice, employment and the protection of languages, identity and culture. Measures on guaranteeing the full inclusion and participation of IPwD in consultations for completely realising free, prior and informed consent were further highlighted. This meeting was held in order to prepare a three-hour session on IPwD the next week at the EMRIP.²¹ During the 2015 EMPRIP, a study on health of indigenous children and young people was presented. The study incorporated an intersectional perspective and made several references to ICwD, in particular to the discrimination, abuse and bullying from their peers, caregivers and members of their communities (Expert Mechanism on the Rights of Indigenous Peoples, 2016).

The complete list of recommendations can be found https://esa.un.org/unpfiidata/UNPFII Recommendations Database list.asp?action=backtolist (last accessed: 16.10.2017).

Regarding other international initiatives on indigenous young people and IPwD, in 2013, a paper entitled Study on the right to participation of indigenous youth in the Nordic countries in decision-making processes (United Nations, 2013a) was presented at the 12thsession of the UNPFII. This study reviewed the participation of young people at the youth councils and committees of the Sami Parliaments in Norway, Sweden, Finland and the youth parliament of the Inatsisartut in Greenland, and compiled the demands of the indigenous young people of these four countries. One of the most interesting findings is that political participation was higher among indigenous young women than among indigenous young men. Among the main demands of Sami young people from Norway, Sweden and Finland were raising awareness of their own concerns regarding the future of the Sami culture, especially Sami languages, the increasing racism against Sami people, because of stereotypical representations and widespread ignorance of Sami culture and history among non-IP. In all three countries, Sami young people were also very concerned about the high suicide rates among indigenous young people. In Greenland, however, demands were different: indigenous young people wanted further and more meaningful participation in political life and specific facilities for those in remote areas. However, this study did not analyse the political participation of Sami young people with disabilities. It is however noteworthy that European IP are often ignored in EU policies and programmes, since most of the EU actions on improving the rights of IP are usually implemented in third countries.

A year later, the UN adopted a study on access to justice for IP, with a special focus on women, children and young persons with disabilities (Expert Mechanism on the Rights of Indigenous Peoples, 2014). The study has an intersectional perspective and was supported by Ipul Powaseu, co-founder of the Disability Caucus and the IPwDGN.

Regarding local civil society organisations, there have been various initiatives to promote the rights of ICwD at local level. For example, in Sabah (Malaysia), where IP constitute 47.2 % of the national population, parents of ICwD engaged with the United Nations Children's Fund (UNICEF) and the Borneo International Marathon to organise a race in order to raise awareness of ICwD rights. In Mexico, the Step by Step Foundation (Fundación Paso a Paso) campaigns to raise awareness of the issues facing IP by means of various disability policies and programmes, while also championing the cause of disability issues among IP with a further range of policies and programmes. It has also conducted certain studies on disabilities among Nahuatl indigenous communities and promoting education of ICwD. In Nepal, the National Indigenous Disabled Women Association Nepal (NIWDAN) also carries out research on issues which affect indigenous women and girls with disabilities, in particular on the consequences of the 2015 earthquake on Nepalese IPwD. In Kenya, the Endorois Welfare Council and the Pastoralist Development Network of Kenya conduct training sessions and raise awareness regarding the rights of IPwD among the Endorois people.

3 Existing data and research

While reliable data are scarce, the most widely accepted estimation from the United Nations Permanent Forum on Indigenous Issues (UNPFII) suggests that the number of IPwD is approximately 54 million (United Nations, 2013b). However, previous studies have shown that the prevalence of disability among indigenous children is uneven. In countries such as Brazil and Colombia, the number of children with disabilities is lower among IP in comparison with non-IP, while in Canada and New Zealand, the disability rate is higher for IP (United Nations, 2013b). However, there is an enormous lack of systematic data. According to the country reports submitted to the Committee on the Rights of Persons with Disabilities (CRPD), just a few countries have undertaken surveys to analyse the prevalence of disability among different social or ethnic groups. Furthermore, these surveys are frequently undertaken by the respective

²² More information can be found at http://borneomarathon.com/ (last accessed: 16.10.2017).

national bureaus of statistics or ministries of health, thus linking disability with physical impairments instead of with human rights. Moreover, data on disability among IP are often not disaggregated.

As stated previously, some Asian and African governments contest the definition of IP, which makes data collection and disaggregation more difficult.²³ For instance, in countries such as China or Thailand, states do not recognise the existence of IP within their borders (Kingsbury, 1998), which makes the prevalence of disability among indigenous children almost impossible to assess. As a consequence of this non-recognition, IP in some countries (such as Thailand) are not even considered citizens (Inguanzo 2016). Therefore, there is no birth registration of many indigenous children, which in turn blocks the access of ICwD to any state service (justice, healthcare, social protection, education, etc). Moreover, the comparability of data may be jeopardised, since different states may use different definitions or categorisations which, in turn, could mask actual prevalence rates among indigenous children.

In terms of the particular situation of ICwD, throughout the decades, in development and poverty-reduction programmes, disability has been addressed through three different approaches: the charitable approach, the medical approach and the rights-based, social model (Yeo and Moore, 2003). Both charitable and medical approaches are based on an individual perspective of disability, focused on individual physical functions that need to be prevented, cured or treated, while the social model of disability focuses on social barriers. The third, more heterogeneous and critical approach, has claimed 'that disabled people are an oppressed social group. It distinguishes between the impairments that people have, and the oppression which they experience. And most importantly, it defines "disability" as the social oppression, not the form of impairment' (Shakespeare and Watson, 2002). Therefore, the rights--based approach brings the context and the environment into play and considers how two persons with the same impairment, but living in different communities, might be considered as having a disability in one particular setting but not in the other. In conclusion, when considering this approach, any research or policy would need to incorporate social and contextual indicators as well as understand disabilities in terms of rights enjoyed by people with disabilities, environmental and social barriers, opportunities, etc. This study supports the rights-based approach, thus focusing on social, economic and political inclusion and on the need for social change.

3.1 Human rights of indigenous children with disabilities

The study submitted to the UNPFII in 2013 on the situation of persons with disabilities among IP highlights 11 issues to be considered by the international community and the relevant stakeholders: a) the right to self-determination; b) the participation in the decision-making process; c) discrimination on multiple grounds; d) access to justice; e) the importance of education in language and culture; f) the access to health care; g) the lack of adequate living standards; h) the importance of living within the community; l) the particular situation of indigenous women with disabilities; j) the particular situation of ICwD; and k) emergency situations and DRR(United Nations, 2013b).

Although these rights relate to IPwD in general, some specific rights are particularly at risk in the case of ICwD. The same study identifies specific challenges to human rights of ICwD. According to this study, in some cases, these children are victims of infanticide, violence, forced sterilisation for girls and female adolescents, sexual abuse and sexual violence, denial of their right to education, discrimination and forced segregation from their communities (United Nations, 2013b). When IPwDGN representatives were asked

²³ The Americas, Australia and Europe have a clear understanding of the term IP. The policy implication is that it will be easier to address the data disaggregation issue in countries where the terms are accepted and understood and more complex in regions where this is not the case.

which basic human rights of ICwD are usually at risk,²⁴ the following list was identified: right to life and dignity, right to full participation, right to education and access to basic services.

3.1.1 The rights to life, physical integrity and dignity

All representatives of the IPwDGN interviewed for this study highlighted that **infanticide** was an issue in their communities.²⁵ This fact was also confirmed by representatives of IP organisations from Africa and representatives of the IDA. This may be due to many different reasons: for some cultures, disability is seen as a 'spiritual punishment' for something that the family has done and therefore there is a great deal of stigma surrounding a newborn with a disability.²⁶ As Manase Ntutu, African focal person of the IPwDGN states, 'in my community[...] there is a big problem in the Maasai community because when a family discover they have a child with a disability, sometimes they end up killing that child, because they fear the stigma of the community, [...] because the community believes the disability is a curse'. Sometimes a newborn with a disability even causes the rejection or ostracism of the whole family of that child.²⁷ This is why many ICwD, assuming they survived early childhood, are kept at home and only close family members know about their existence, since they do not frequently interact with other people from the community or they are sent to institutions outside the community.²⁸ 'And [for] those who get kept by the family, there is a lot of stigma, because they locked them inside the houses, and they don't come out', Mr Ntutu explains.

Of course, there are no data on the prevalence of infanticide among ICwD, since this is a very sensitive issue and would not be acknowledged. Manase Ntutu also says that among the Maasai community to which he belongs, sometimes the killing is perpetrated in secret within two to three days of the birth. Moreover, in rural and remote areas, most indigenous children do not have birth certificates and their pregnant mothers would not have received prenatal care, so it is very difficult to know how many of these children died a few days after they were born. One way to improve data collection on child mortality among indigenous children—and among ICwD—is to improve access to prenatal care and birth registration processes for these communities.

For African indigenous communities, the question of albinism among children was strongly highlighted during the interviews. As shown by several reports from Amnesty International, in Malawi, children with albinism suffer terrible discrimination and are even subject to intentional killings because of cultural beliefs (Amnesty International, 2016). Albino children were identified as the group of children most discriminated against, based on responses from representatives from the IPACC and the ACHIPR.²⁹ The issue was also highlighted by the UN Independent Expert on the enjoyment of human rights by persons with albinism, who reported that in several African societies, births considered 'abnormal', such as those of twins, 'badly born' children and persons with albinism are surrounded of complex systems of representations and rituals. She also reported cases of killing albino newborns and 'where these children are not killed at birth, they are often taken to a spiritual leader or traditional healer to be "healed" through various forms of violent exorcism' (Ero, 2017)

This lack of the basic human right to life is at the top of the list of priorities identified by the regional focal points of the IPwDGN of Africa, the Americas and Asia.

²⁴ Interviews and focus groups with members of the IPwDGN.

²⁵ Focus group discussion with Manase Ntutu (African focal point of the IPwDGN), Pratima Gurung (Asian focal point of the IPwDGN) and Setareki Mekanawi (Pacific focal person of the IPwDGN). This pattern was also confirmed in interviews with Olga Montúfar (Latin American focal person of the IPwDGN) and elsewhere (Henriksen, 2008).

²⁶ Interviews with Pratima Gurung and Manase Ntutu.

²⁷ Interview with Vital Bambanze (IPACC), Manase Ntutu and Pratima Gurung (IPwDGN).

²⁸ Interviews with Vital Bambanze (Burundi), Pratima Gurung (Nepal), Olga Montúfar (Mexico) and Tchaurea Fleury (International Disability Alliance).

²⁹ Interviews with Vital Bambanze (IPACC) and Soyata Maiga (ACHIPR).

Poverty and a lack of resources in general may jeopardise other fundamental rights of ICwD: 'Where there are limited resources it may be seen as economically irresponsible to give an equal share to a child with a disability who is perceived as unlikely to be able to provide for the family in the future' (Yeo and Moore, 2003). In many poor households in the developing world, for example in Latin America and Asia, most children with disabilities suffer from **malnutrition** and are denied access to education in comparison to their siblings or other children from the community who do not have a disability, since their disability is perceived as a burden for the family or community. This also affects ICwD, since indigenous communities are often the poorest in many regions, as reported by Olga Montúfar, co-chair of the IPwDGN and Pratima Gurung, Asian focal point of the IPwDGN. According to them, and to the representatives of the IDA, this is often due to the lack of social welfare and support, which transforms a disability into an insurmountable burden in terms of time and money. However, this pattern could be partially redressed if special social welfare mechanisms were in place in order to eliminate socio-economic inequalities associated with disabilities. Again, there are no statistical data on this specific issue for indigenous children.³⁰

Human rights of ICwD are also at risk in relation to the right to **dignity and physical and mental integrity.** It has often been reported that IPwD are more exposed to sexual and physical violence (Expert Mechanism on the Rights of Indigenous Peoples, 2014). ICwD are also more exposed to violence and abuse than their peers (European Union Agency for Human Rights, 2009). Furthermore, both indigenous ethnicity and disability constitute risk factors for violence against girls (UNICEF, 2013a). In this study, most indigenous representatives interviewed, both with and without disabilities, knew at least one case in their communities where an ICwD suffered sexual violence or harmful traditional practices that resulted in death or severe harm. In total, 10 out of 13 respondents reported knowing at least one incident in their communities and in 3 out of 4 cases, the victim was a girl.

These findings are in line with previous studies on sexual violence against women and girls. In fact, 'some groups of women with disabilities, including indigenous women, migrant women and women belonging to ethnic, linguistic, religious and other minorities face even greater risks of violence due to complex intersectional forms of discrimination' (United Nations, 2012). Indigenous women and girls with disabilities are therefore especially vulnerable to sexual violence and abuse (United Nations, 2013b). In fact, in her 2017 report, Catalina Devandas, Special Rapporteur for the Rights of Persons with Disabilities, stated that 'indigenous girls and women with disabilities face a higher risk of experiencing early marriage, sexual violence and unwanted pregnancy' (Devandas, 2017).

According to the representatives of the IPwDGN and IDA, survivors of sexual violence against ICwD are usually young girls with intellectual or communicational impairments. This pattern was also confirmed in the questionnaires. These survivors face even greater barriers when attempting to tell others about what happened to them or denounce the perpetrators—and it is precisely this which makes them more vulnerable, since it has been proven in many studies that one of the main reasons why men sexually assault or attack other persons is because of the perception of impunity, together with power inequalities (Scully, 2013).

In the case of Indigenous Girls with Disabilities (IGwD), the multiple intersectional layers of inequalities leave them highly exposed to these human rights violations. Perpetrators of these crimes have been reported to be family or community members, as well as non-community members, including staff or other people linked to boarding schools where ICwD went to get access to education. Again, this is a very sensitive issue and although extremely important, it is very difficult to capture data. The Indigenous Navigator project asks about this specific issue, but only focuses on girls above 15 years of age and looks at community level, which, as mentioned before, is not the ideal way to conduct research on these issues.

³⁰ The Indigenous Navigator project asks how many indigenous children suffer from stunted growth and how many people have experienced food scarcity, but again, there is no disaggregation by sex or disability.

This severe violation of human rights against mainly (but not only) indigenous girls with intellectual or communicational impairments is also usually underreported because of the lack of access to safe and culturally appropriate justice and healthcare services, which again add to the climate of impunity.

Ipul Powaseu, co-chair of the Papua New Guinea Assembly of Disabled Persons, states that 'in Papua New Guinea, [...] when it comes to access to justice, a lot of women and girls with disabilities are raped [...]. This is the issue—that our voices are not heard. We don't have the services that help us to have our voices heard. There are no interpreters, and even the justice system does not have people that are trained to have women with disabilities' voices heard' (Petrolewska, 2015). The procedures of many justice systems remain the main barrier for many indigenous girls and young women with disabilities. In Nepal, families are not aware of the specific procedures or legal processes to deal with cases of violence, rape, assault and harassment, and many of them remain silent, according to Pratima Gurung, President of the National Indigenous Disabled Women Association Nepal (NIDWAN).

Another violation of physical integrity that has also been reported on by the co-chair of the IPwDGN, Olga Montúfar, and a representative of the IDA, is the **forced sterilisation** of IGwD, because of eugenic reasons, both from community members and health professionals. Cases of forced sterilisation of indigenous women and girls have been documented in Australia, Mexico (Chiapas) and Peru (Frohmader, 2013). Cases of forced sterilisation of IWwD have been documented in Kiribati, Solomon Islands and Tonga, where the majority of the population is indigenous (UNFPA, 2013).³¹ In the case of sterilisation of women and girls with disabilities, the main rights violated are 'the right to inviolability of the person, to protection against illegitimate interference in private life, home and correspondence, to marry and found a family [in the future], to protection of motherhood including family planning, to appropriate health care, combined with discrimination on the grounds of sex, ethnicity and disability' (Bouchard and Meyer-Bisch, 2016). Cases of forced sterilisation of IGwD have been reported in Mexico, Peru, Brazil and Nepal.³² However, forced sterilisation is sometimes also a way families use to face sexual violence against those girls. As an indigenous mother of a Tharu girl with an intellectual disability stated: 'And [the] third time she was again [...] rape[d], [...] nothing was done to none of them, nor any punishment, nor any compensation, nothing, nor any services to my daughter [...], years have passed my daughter is still with me, we are compelled to do forced sterilization to her' (cited in Nepal Civil Society Organization's reply to the OHCHR's call for submissions on the right of persons with disabilities to participate in decision-making processes).³³ This is an area that requires further research, since there are almost no reliable data, although those working on the ground with indigenous women and girls with disabilities are aware of it.³⁴

Another fundamental right that is often violated is **freedom of movement.** As mentioned before, in many indigenous communities in Africa, ICwD never leave home, in order to avoid being seen. Depending on the degree of their disability, some children may never leave their bedroom or even their bed—there have even been some cases reported of ICwD chained to their beds in Nepal.³⁵ Chaining up people with mental disabilities is also common practice in Indonesia and it even has its own word to describe it: *pasung* (Human Rights Watch, 2016). The other side of the violation of freedom of movement is the case of forced institutionalisation of IPwD, separating them from their families and communities, and forced

³¹ Forced sterilisation in Peru was discuss in the DROI Committee on 20 June 2017.

³² Interviews with Olga Montúfar of the IPwDGN (Mexico), Raquel García of the CHIRAPAQ (Peru), Tchaurea Fleury of the IDA (Brazil) and Pratima Gurung of the IPwDGN (Nepal).

³³ See http://www.lan.ohchr.org/EN/lssues/Disability/SRDisabilities/Pages/DecisionMaking.aspx (last accessed: 16.10.2017). Sterilisation of young girls with mental disabilities in mental health facilities has also been reported in Indonesia, but not just for indigenous girls (Human Rights Watch, 2016:pp. 60–62).

³⁴ Interview with member of the CHIRAPAQ (Peru).

³⁵ Interview with Pratima Gurung, Asian focal point of the IPwDGN, Chair of the NIWwDA and General Secretary of the Nepal Indigenous Disabled Association (NIDA).

institutionalisation in general. It has been extensively ³⁶ reported in Canada and Australia that forced institutionalisation of IP has caused intergenerational trauma and reinforced multiple discrimination (Hollinsworth, 2012). Although these cases refer mainly to the previous century, particularly to the period from the 1930s to the1950s, there are still examples nowadays and more research is needed in this particular area.³⁷

3.1.2 Right to participation

The second set of fundamental human rights for ICwD that needs to be guaranteed, according to the representatives of the IPwDGN, is the right to full and effective inclusion in their societies through full participation in social activities appropriate for their age. The lack of development and cooperation programmes and projects including ICwD is mostly due to the fact that IPwD are often not included in consultative processes regarding development projects.

Regarding children, leisure time and playing games is a key element in the development of every child, even before starting school. Playing games with other children is paramount for ICwD in order for them to feel fully integrated with children of their own age. The right to leisure time, fun and games has been highlighted by Olga Montúfar, co-chair of IPwDGN, many times. It is by playing games that children learn role playing, how to interact with each other, trust each other, work together with others, etc. Furthermore, the lack of these activities during early childhood can severely jeopardise the success of these ICwD when they later enter school.

Therefore, any development programme involving indigenous children must take into consideration the rights of ICwD to leisure time and playing. This will also help create a friendly environment, so that other children also become accustomed to playing with ICwD, which will in turn encourage more understanding attitudes in the future. Leisure time for children with disabilities is often forgotten in local, national and international cooperation programmes but must be included, since it is key to every child's development.³⁸ In fact, according to the questionnaires, 13 out of 14 of respondents said that ICwD in their communities have problems making friends, and the same number of respondents indicated that the main activity of ICwD was 'staying at home'.

This right links to another very important right for IP: the right to cultural integrity. ICwD must also participate in all cultural activities where other children are included. This will again foster the sense of belonging, which is very important for IP. As the American and Asian focal points of the IPwDGN argue: 'First we were conceived as indigenous, later we were formed as women/girls, and lastly we happened to live with a disability, so our rights need to be ensured as indigenous persons, girls/women, and persons with disabilities, in a human rights based approach'.³⁹ Research on ICwD should include indicators such as how these children spend their leisure time and the ways in which they interact.

3.1.3 Right to education

The right to education is another fundamental human right that ensures full inclusion and participation. However, it is worth singling out due to its relevance for children's development and the effects it has on the enjoyment of other rights. Not having access to formal education may jeopardise children's opportunity to have access to a decent job in the future and their ability to speak or communicate in the

³⁶ However, the report makes no references to IPwD in Indonesia.

³⁷ Interview with Tchaurea Fleury (IDA).

³⁸ Interview with Olga Montúfar.

³⁹ Interviews with Pratima Gurung and Olga Montúfar.

national official language (which in turn can lead to severe human right violations in terms of accessing the justice and healthcare systems).

According to estimates from UNICEF and the United Nations Educational, Scientific and Cultural Organization (UNESCO), approximately 90 % of children with disabilities in developing countries do not attend school.⁴⁰ Although data on access to education among ICwD are scarce, it has been consistently reported that these children receive limited access to education and that in many cases they have no access at all. Low school enrolment figures among indigenous girls and boys with disabilities depends on the type and degree of disability, remoteness of school facilities, patterns of discrimination and cultural stigma and the economic situation of the family.

The Indigenous Navigator project does consider accessibility to school and adapted materials for children with special learning needs. However, in many countries, universally accessible schools are in towns, and ICwD from remote and rural areas do not have the opportunity to enrol in these centres. This is why some ICwD go to boarding schools. According to the questionnaires, 11 out of 14 respondents reported that schools are not accessible or are moderately inaccessible to children and that these children have to overnight outside the community to attend school. This study has found contradictory results regarding boarding schools for ICwD. In some cases, it was a positive experience, since discrimination against these children was lower than within the indigenous community.⁴¹ However, in some cases, such as in Sabah (Malaysia), boarding schools have been the scenario for episodes of physical and sexual violence against indigenous girls with disabilities.⁴² In fact, it has been recognized that in Europe "institutionalisation increases the likelihood of children becoming victims of neglect and mental, physical or sexual violence" (FRA, 2015).

When indigenous or bilingual schools are close to indigenous communities, sometimes teachers lack specific formation on how to teach to children with disabilities (CwD) or do not master the specific indigenous language in the area. For example, the contact between the indigenous teacher who can listen and the deaf indigenous student is restricted to basic communication within the classroom. In the school environment, teachers feel that the resources for transmission of knowledge to the student are limited by linguistic barriers' (Garcia Bruno et al., 2016). In any case, education is fundamental to ensuring several other rights throughout childhood and youth, such as meaningful participation, self-determination, right to work, right to justice, health care, land rights, etc. However, 13 out of 14 respondents indicated that infrastructure and materials in the schools of their communities are not adapted to the particular requirements of children with disabilities, and all 14 respondents reported that the teaching of their indigenous language (if it is even taught in school) is not adapted to children with disabilities.

These problems of lack of accessibility and adapted materials and contents usually prevent families from sending their ICwD to school. Most of them will stay at home or enrol in some kind of child labour. The most common forms of child labour for ICwD, according to the interviews, are begging in inner cities, sexual exploitation and domestic exploitation. Although there are no reliable data available, the two main implications in terms of human rights violations of these children are that they are denied their right to education and that they are isolated from other children and community members, which in turn erodes the support networks of these children and opens the door to further human rights violations (such as sexual violence).⁴⁴

⁴⁰ See Out-of-School Children Initiative (http://www.unicef.org/education/bege 61659.html) and UNESCO, 2015.

⁴¹ Interview with Christine Kandie, an indigenous young woman living with a disability, from the Endorois Women's Council in Kenya

⁴² Interview with Jannie Lasimbang (Indigenous Peoples Network of Malaysia—JOAS).

⁴³ Interview with Olga Montúfar.

⁴⁴ Interview with Tchaurea Fleury (IDA).

3.1.4 Access to land and intercultural basic services

Other rights that were also regarded as important for ICwD and IPwD in general are related to accessibility: access to land, access to intercultural justice, access to cultural sites and access to intercultural healthcare. Aside from physical barriers, there are also cultural barriers in terms of accessibility. In many areas, living with a disability means being considered a dependent person or even a child for your whole life. This is why in some regions, such as the Maasai communities in Kenya, IPwD are not permitted to inherit land or choose who they want to marry. Furthermore, in regard to access to justice, the lack of access to culturally appropriate education severely jeopardises the right to justice of indigenous children and young people with disabilities.

On the one hand, IPwD face many obstacles when attempting to access the legal system, especially those with communicational or intellectual disabilities (Expert Mechanism on the Rights of Indigenous Peoples, 2014). Children with disabilities among indigenous communities may face even greater challenges. This in turn affects the enjoyment of other human rights, since most of the offences committed against IPwD, and specifically ICwD, go unnoticed. Most of them are not even reported to the authorities (either state or community authorities) and there is an environment of wide impunity. These children and young people face many obstacles when reporting human rights violations, such as physical or sexual aggression, because of language barriers and stigma towards people with disability among police and judiciary staff. This in turn enhances the perception of generalised impunity when committing crimes against these children and then opens the door to further or continuous violations.

On the other hand, depending on the type of disability and their level of education, these young men and women may not be able to fully and effectively defend themselves in court. In fact, IP and persons with disabilities are over-represented in detention and correctional centres, in most cases because of lack of properly trained legal staff (United Nations, 2013b). It has also been highlighted that proceedings regarding the legal incapacitation of persons with disabilities in Mexico have been extremely problematic, since many IPwD are not being listened to, with other people acting or talking on their behalf—and not always in their best interests.⁴⁷

In general, ICwD lack access to basic services because of all the barriers described above. In fact, as stated by the study prepared by the EMRIP, in many cases, 'the first contact indigenous persons with disabilities, particularly intellectual disabilities, have with disability services is after they have come into contact with the criminal justice system' (Expert Mechanism on the Rights of Indigenous Peoples, 2014). Finally, many interviewees reported that health professionals are not aware of the specific needs of indigenous populations, mainly because of language-related matters.

3.2 Specific factors contributing to disability among indigenous communities

According to the Study on the situation of indigenous persons with disabilities, with a particular focus on challenges faced with regard to the full enjoyment of human rights and inclusion in development prepared for the 12th session of the UNPFII, there are several factors contributing to the higher prevalence of disability among indigenous communities. These factors are 'higher levels of poverty, increased exposure to environmental degradation, the impact of large projects such as dams or mining activities, and the higher risk of being victims/survivors of violence'(United Nations, 2013b). Regarding ICwD, children that are not born with impairments might acquire them 'later in their childhood, be it through disease, accidents or as a result of conflicts and natural disasters' (UNICEF, 2013b). These factors must be analysed

⁴⁵The latter has also been reported on in Mexico by Olga Montúfar.

⁴⁶ Interview with Pratima Gurung and Olga Montúfar.

⁴⁷ Interview with Olga Montúfar, co-chair of the IPwDGN.

with caution in order to avoid a medical perspective on disability. As mentioned previously, this study, in line with the UNCRPD, adopts a rights-based approach. In this sense, the focus is not on the factors that cause a specific impairment but on the factors that cause a disability among indigenous children.

Olga Montúfar stated that the situation of ICwD is different if the child was born with an impairment of if this impairment was acquired later. In fact, stigma is usually greater against those indigenous children that were born with an impairment. The representatives of the IPwDGN made it very clear that in terms of a rights-based approach, what really matters is why a specific impairment turns into a disability and which are the main obstacles indigenous children already living with a disability face in terms of the full enjoyment of their rights. According to them, these are the specific issues that policies on disability should be tackling.

3.2.1 Poverty and exclusion

There is a vicious circle concerning poverty and disability. Both conditions interact endogenously: disability leads to poverty but, even more importantly, poverty aggravates disability (Yeo and Moore, 2003). Disability may generate poverty both directly and indirectly—some of the most common ways are through attitudinal, environmental and institutional discrimination. Persons with disabilities usually attain lower levels of formal education, if any, and therefore their opportunities to get a job and a decent salary are reduced. Furthermore, in many developing countries, the cost of living for a person with a disability in order to enjoy most of their rights is relatively high. Trying to enjoy the same rights as any other person who does not have a disability could be an economic burden for the family.

However, poverty may also aggravate disability. When times are tough, ICwD are the first among their siblings to get a smaller amount of food and/or be taken out of school.⁴⁹ Parents may also not be able to pay for specific equipment such as wheelchairs, glasses or hearing aids, thus aggravating the feelings of exclusion. For example, according to the questionnaires, although 100 % of respondents indicated that in their communities there are indigenous children with hearing difficulties, only 4 out of 14 of the respondents reported these children having hearing assistance. Similarly, although 13 out of 14 of respondents indicated that in their communities there are children who have difficulties with walking, only 4 out of 13 reported that these children use special equipments for walking such as wheelchairs or crutches.⁵⁰

3.2.2 Cultural barriers

Cultural barriers, stigma and prejudices regarding disabilities are fundamental to understanding why ICwD are not fully enjoying all the rights to which they are entitled. In fact, as noted by both co-chairs of the IPwDGN, Setareki Mekanawi and Olga Montúfar, prejudices and stigma against ICwD are not the same if the children were born with a disability or if they acquired the disability later on. When a baby is born with a disability, cultural barriers are usually worse. As stated before, in many regions, people will believe the family has done something wrong or that they are under some form of curse. As noted, the most common consequences of these prejudices are either infanticide or keeping the child with a disability at home, far from people's sight. In that sense, awareness campaigns to end these prejudices and stigmas are urgently needed. A variation of this pattern is child neglect or malnutrition. More research is needed in terms of child mortality among ICwD. Infanticide (see above) is a very sensitive topic and usually families will not

⁴⁸ Interview with Olga Montúfar, co-chair of the IPwDGN.

⁴⁹ Interview with Olga Montúfar.

⁵⁰These questions are based on the extended set of questions of the WG. However, some interviewees, while highlighting the need to use the WG set of questions in national censuses, have also pointed out that some questions may not be appropriate for all cultures or rural areas.

⁵¹ Interview with Manase Ntutu (African focal person of the IPwDGN) and Pratima Gurung (Asian focal person of the IPwDGN).

talk about it, which is why ethnographic research is strongly recommended for this specific topic, as highlighted by Manase Ntutu, the African focal point of the IPwDGN.

If the child survives early childhood, cultural barriers will still keep him or her separated from other children, school and full participation in community activities. For many community members, including parents, it is unclear what abilities, opportunities and strengths a child with a disability might have. In the long run, the ultimate consequence of these cultural barriers within the community is the lack of proper participation and representation of IPwD in issues that affect them. Therefore, more support is needed in terms of raising awareness among parents, community members, teachers and other children.

Again, since these children come from an indigenous community, aside from physical barriers or adapted materials and trained staff, they face great discrimination on ethnic grounds. Language has been reported as the first cultural barrier they face. This happens in schools, justice and legal systems and healthcare centres. This cultural obstacle may keep these children away from basic services and social protection measures, even if they really need them.

3.2.3 Remoteness

In all censuses and reports reviewed in this study, the prevalence of disability is consistently higher in rural areas than in urban areas. In fact, remoteness may well aggravate the lack of access to proper intercultural education, healthcare, social services and justice, which in turn will worsen the opportunities of habilitation and rehabilitation within the indigenous community (Article 26 of the UNCRPD). In fact, as it has been pointed out in Nepal and Kenya, even if schools have adapted infrastructures and material, it maybe that the roads and pathways to these schools are not. Several studies conducted by UNESCO have reported on the higher exposure to violence of children who have to walk long distances to get to school. In addition, particularly for indigenous children, the probability of being sexually assaulted on their way to school is higher if logger companies and mines are in the area.

In general, most interviewees throughout the study highlighted the differences between rural and urban areas in terms of enjoyment of rights of ICwD.⁵² In fact, although in many countries there are some social protection measures for persons with disabilities, people from rural areas and specifically from indigenous communities usually do not benefit from them. This pattern has been confirmed in the questionnaires distributed for this study. As noted in various interviews, schools with adapted infrastructure and materials (if they exist) are usually located in big cities. In terms of access to basic services, it has been reported that 'indigenous persons living with a disability in remote areas are often required to periodically reconfirm their disability through central medical organizations to remain eligible for disability pensions, creating hardship' (Expert Mechanism on the Rights of Indigenous Peoples, 2016).

Problems of accessibility become more severe when remoteness is combined with cultural barriers. In fact, in Australia many aboriginal families of ICwD from the Torres Strait Islands do not approach social services because of fear and distrust of organisations, especially the fear that their children will be taken away from them (Di Giacomo et al., 2013).

3.2.4 Natural hazards and conflict exposure

There are some studies which, from a medical perspective, focus on the impact of certain extractive industries and development projects on the health of specific indigenous communities and how these can cause impairments among the local population, specifically among children (Lewis et al., 2015). Therefore, the projects and industries might cause secondary disabilities. However, the focus of this study is on how violent conflict and environmental degradation impact the lives of indigenous children who already live with disabilities. IP are specifically vulnerable to these incidents since they are more exposed to them. In

⁵² Focus group with representatives of the IPwDGN.

that sense, the most relevant issue is that in processes of forced displacement or relocation due to violent conflict, natural disasters or environmental degradation, the specific needs of IPwD and ICwD are almost never taken into account. In fact, in cases of sudden crisis, when indigenous communities are forced to flee their lands, ICwD are sometimes left behind. This pattern was reported both in the Democratic Republic of the Congo, as a result of the armed conflict,⁵³ and in Nepal, in the context of the 2015 earthquake.⁵⁴ It has also been reported that in Nepal 'language was a barrier that prevented some groups of Janajati indigenous people from accessing both information about relief and relief materials' in the context of the 2015 earthquake, and that this was even a greater problem for those Janajati with disabilities (Austin et al., 2016).

Moreover, the erosion of community links due to issues such as land loss, relocations and migrations causes the progressive disappearance of the extended family—in Brazil, this has been reported as an important support network for ICwD which is now at a higher risk (Pereira de Souza and Bruno, 2012). The importance of the support of extended family for taking care of ICwD was also mentioned as a critical factor in Sabah Indigenous communities by Jannie Lasimbang, representative of the Indigenous People Network of Malasia (JOAS). In addition, in the context of a natural disaster or migration situation, where community links are eroded, sexual and physical violence against women and girls perceived as vulnerable is more likely to occur (Thornton and Voigt, 2007). Finally, community erosion due to displacement, migration or relocation also results in community support networks for ICwD being broken, thus increasing the vulnerability of these children.

This is why it is paramount that DRR projects and other development programmes take into account the particular requirements of ICwD in terms of displacement and relocation. Setareki Macanawi, current cochair of the IPwDGN, stated that most DRR programmes are not inclusive of IPwD needs, because IPwD are not present when these programmes are discussed and 'elders in our communities often do not pay attention to small details that affect us when taking these decisions'. Participation is a key issue for IPwD so that their specific needs are taken into account in DRR programmes. However, most of the time, consultations are not adapted for IPwD, if they are held at all. According to the questionnaires, 100 % of respondents reported that information and documentation in FPIC processes on development projects in their territories are not adapted for persons with disabilities, while11 out of 13 stated that persons with disabilities do not take part in these processes when they are held.

4 Case studies

As stated above, data scarcity poses a particular challenge to any researcher conducting investigations into this topic. Therefore, case studies are based on reviews of existing literature, the little statistical data which is available, interviews with IPwD and questionnaires delivered to IP organisations. This allows potential patterns in human rights violations and gaps in data collection to be identified, so that concrete patterns can be further researched in future in-depth studies in the countries concerned. For the purposes of this study, cases were selected based on good practices in data collection, either carried out by state authorities or by civil society organisations, and on certain policy initiatives aiming to improve the rights of ICwD or IPwD.

⁵³ Interview with Mochire Diel from Democratic Republic of the Congo (IPACC).

⁵⁴ Interview with Pratima Gurung from Nepal (Secretary General of the NIDA).

4.1 Latin America

Among the eleven Latin American countries with an indigenous population within their borders that have submitted governmental reports to the CRPD, only nine refer to IP in their initial reports.⁵⁵ Furthermore, only Panama, Ecuador and to a greater extent Bolivia make any reference to indigenous children or young people. That said, most Latin American states have ratified the ILO Convention No. 169 on the rights of indigenous and tribal peoples (except for Panama and Suriname) and voted in favour of the UNDRIP in 2007, with the exception of Colombia.⁵⁶

The United Nations Economic Commission for Latin America and the Caribbean (CEPAL) and the United Nations Population Fund (UNFPA) issued a report on disability in Latin America in 2011, although this did not include references to disability among IP (Stang Alva, 2011). The CEPAL also issued a report in 2011 on the health of indigenous young people that included a short chapter on disability among this group (CEPAL, 2011). The chapter is based on REDATAM (the retrieval of data for small areas by microcomputer, hosted in CEPAL) and compares percentages of indigenous young people with disabilities in different Latin American countries. According to this report, higher prevalence rates of disability among indigenous young people (from 10 to 19 years of age) are found in Peru and Nicaragua, where prevalence reaches 10 %, followed by Brazil, Guatemala and Honduras, which have a prevalence of disability among indigenous young people over 6 % (CEPAL, 2011). However, the greater differences between indigenous and non-indigenous young people are found in Nicaragua and, to some extent, in Honduras. In both cases, prevalence of disability was higher among indigenous young people.

4.1.1 Brazil

Brazil ratified the UNCRC in 1990 and the UNCRPD in 2008. It also ratified the ILO Convention No. 169 in 2002 and voted in favour of the UNDRIP in 2007.

In Brazil, the National Secretariat of the Promotion of the Rights of Persons with Disabilities conducted a study on persons with disabilities using data retrieved from the 2010 population census. The Census' study asks both the WG list of questions and records the ethnicity of interviewees. According to the study, 20.1% of indigenous women and 18.4% of indigenous men live with at least one disability. The prevalence is then lower than for the rest of the Brazilian population, with a prevalence of 26.5% of the total female population and 21.2% of the total male population (Borges Oliveira, 2012). However, in 2000, disability prevalence among the indigenous population was higher than most of the other ethnic groups among the Brazilian population (Borges Oliveira, 2012). The reasons behind the variations of prevalence among different ethnic groups remain unclear, although this could be due to changes in how disability is measured.

At a national level, 7.53 % of Brazilian children below 15 years of age live with at least one disability, with a slightly higher prevalence among girls (7.8 % of girls compared to 7.2 % of boys) (Borges Oliveira, 2012). However, Borges Oliveira' study contains no disaggregated data on the situation of ICwD below 18 years of age. Indeed, a lack of data disaggregation for children remains one of the key problems (Committee on the Rights of the Child, 2015).

Brazil has developed policies and programmes addressing disability that in principle should also cover IP. IPwD should receive social assistance according to Articles 203 and 204 of the Brazilian Constitution and to Law 8742/93. A specific example is the country's Continuous Cash Benefit, 'a constitutional right for the provision of a monthly income for the elderly and people with disabilities living in extreme poverty' (Government of Brazil, 2017). However, as recognised by the Brazilian state in its reply to the list of issues

⁵⁵ These states are Mexico, Guatemala, Costa Rica, Panama, Ecuador, Peru, Bolivia, Paraguay, Argentina and Chile. Nicaragua has yet to submit its report at the time of writing, although it has ratified the CRPD.

⁵⁶ Although Colombia subsequently agreed to the UNDRIP in 2009.

produced by the CRPD, access to specific services and programmes is very uneven depending on the situation of particular indigenous communities. For example, peoples living in voluntary isolation could be, but in fact are not, covered by these programmes and services, as opposed to 'indigenous communities with a greater degree of interaction, especially through the National Foundation for Indigenous Peoples, [who] have access to the services provided to other persons with disabilities, including/social services and social security, where applicable' (Government of Brazil, 2015).

Regarding human rights, information on ICwD is very scarce.⁵⁷ However, according to a study carried out in Paranhos, a village in Mato Grosso do Sul, several indigenous children with intellectual disabilities were mistreated or neglected by their families (Pereira de Souza and Bruno, 2012). In 2007, congressman Henrique Afonso presented Bill 1057/07 to the Brazilian parliament, proposing measures to tackle infanticide among indigenous communities (Afonso, 2007). It was put forward after two cases came to light in the media. The bill has not yet been approved as it remains highly contested.⁵⁸ The president of the National Foundation for Indigenous Peoples and several NGOs and academic experts linked to IP have expressed their opposition to the bill, since according to them, it generalises a practice that is not at all widespread among Brazilian IP. The UN has also reported 'widespread sexual violence, abuse and exploitation carried out against children with disabilities, particularly girls, inter alia in institutional settings' and informed that 'Act No. 9263/1996, [...] permits the sterilization of children with disabilities without their free and informed consent' (Committee on the Rights of the Child, 2015).

In terms of right to education, some progress has been made, especially after the approval of the National Policy on Special Education from the Perspective of Inclusive Education in 2008. However, the Committee on the Rights of the Child (CRC) expressed its concerns about the segregation of children with disabilities in separate schools in the states of São Paulo, Minas Gerais and Paraná(Committee on the Rights of the Child, 2015), also highlighting the low enrolment rates among indigenous children. If these two layers of discrimination are combined, the right to education of ICwD is severely at risk. For example, according to the study carried out in Paranhos, only 3 out of 16 indigenous children with at least one disability were enrolled in school (Pereira de Souza and Bruno, 2012).

According to the same study, the school curriculum is taught orally and students are required to master both Guarani and Portuguese. 'Within this context, in which linguistic barriers are present on a daily basis, deaf students' process of teaching and learning and communication with their classmates and teachers in the classroom may be compromised' (Garcia Bruno and Lopes Coelho, 2016). However, 'even the teachers and education professionals report that students are able to learn and socialize; however, they realize that the system does not provide an environment suitable for deaf people to learn more elaborate and complex contents' (Garcia Bruno and Lopes Coelho, 2016).

According to the Brazilian 2017 Voluntary National Review of SDGs, in terms of access to healthcare, 'the More Doctors Program allocated 18,240 physicians in 4,058 Municipalities and 34 Special Indigenous Health Districts, providing health coverage to 63 million Brazilians by 2016' (Government of Brazil, 2017).

In terms of other severe human rights violations, such as child labour, the UN has also expressed its concerns about 'the high vulnerability of indigenous children to trafficking for the purposes of domestic labour, slave labour, and sexual exploitation', which is aggravated by the presence of local ranchers and illegal loggers (Committee on the Rights of the Child, 2015).

⁵⁷ For the purposes of this study, the author attempted to collect information on the specific situation of ICwD in Amazonas, since different factors, such as remoteness of non-contacted tribes and other indigenous communities, serious human rights violations in the context of land grabbing and specific cases brought to the attention of the media on infanticide of ICwD, may be seriously jeopardising the rights of ICwD. However, data scarcity on the subject for this particular region and the lack of Amazonian representatives among the representatives of the IPwDGN who met in Geneva during the context of the 2017 EMRIP made it impossible to pursue this avenue of research.

⁵⁸ Currently awaiting discussion in the senate.

4.2 Asia

No Asian country other than Nepal has ratified ILO Convention No. 169 on the rights of indigenous and tribal peoples. Among the 11 Asian countries with indigenous populations within their borders that have submitted government reports to the CRPD, only four of them consider IP or ethnic minorities. These countries are the Philippines, Bangladesh, Nepal and India. Both the Philippines and Bangladesh treat the issue in too broad and general a way, although India and Nepal specifically address the issue of indigenous children. Furthermore, the Government of India highlights the need to improve indicators on disabilities among girls from certain tribes and has recently passed a bill on the rights of persons with disabilities (PwD) in 2016.

4.2.1 Nepal

Nepal ratified ILO Convention No. 169 on the rights of indigenous and tribal peoples in 2007, the UNCRPD in 2010 and the UNCRC in 1990. However, although ILO Convention No.169 was ratified ten years ago, no national legislation on IP has yet been approved. Nepal has a dynamic civil society representing and defending the rights of IP, and a few organisations are starting to advocate the rights of IPwD. The chair of NIDWAN, Pratima Gurung, who is also the Asian focal person of the IPwDGN, highlights that there is still a challenge to ensure that other civil society organisations, IP organisations, duty-bearers, etc., realise that the issue of IPwD is a human rights issue. The NIDWAN conducts studies on the situation of indigenous women and girls with disabilities throughout the country in order to provide evidence on the complex and critical situation linked to the multiple identities of IPwD and ICwD.

According to the 2011 national census, just 1.94 % of the Nepalese population lives with some form of disability. This very low figure may well mask the stigma associated with and problems of how to measure disability, since questionnaires do not include the WG list of questions.⁵⁹ This census also inquires as to ethnicity and caste and, according to the census authorities, IP make up 35.81 % of the Nepalese population, although IP organisations claim that IP in fact account for 50 % of the national population. In any case, census results are not presented in a way that allows ethnicity and disability variables to be cross referenced.⁶⁰ However, there is some disaggregation by region, pointing to a slightly higher prevalence of disability in mountainous and hilly areas (around 3 %). In a separate study carried out by the Lawyers' Association for Human Rights of Nepalese Indigenous Peoples, with the support of the International Working Group on Indigenous Affairs (IWGIA), it was found that 'the prevalence of disability across castes and ethnic groups does not vary widely. However, higher rates of disability are found within the hill Brahmin (4.2 %), hill Dalit (4.1 %), Gurung (4.9 %), Tamang (4.8 %) and Terai indigenous groups other than Tharu (4.4 %)' (Subba et al., 2014).

According to a Human Rights Watch's (HRW) report on children with disabilities, '[t]here is a strong belief in Nepal that disability is due to sins in a past life. In fact, nearly 30 % of the parents of persons with disabilities surveyed for the 2001 Disability Sample Survey reported that the disability of their child was due to fate and God's will. These beliefs often prevent them from accessing appropriate education or health care for children with disabilities because families are ashamed of their children or do not see the benefit of sending them to school' (HRW, 2011). It is unclear how stigma affects ICwD and their families, since there are no reports on this. However, Pratima Gurung has confirmed that it was also the case for

⁵⁹ In fact, the way in which the questionnaires of the national census address disability is as follows: 'What is the physical and mental disability of (Name)?', with the following possible responses: 1) Not disabled; 2) Physically disabled; 3) Blind or partially sighted; 4) Deaf or hard of hearing; 5) Deaf and blind; 6) Speech problems; 7) Mental illness; 8) Intellectually disabled; and 9) Multiple disabilities.

⁶⁰ Tables for 2011 can be found here: http://cbs.gov.np/nada/index.php/catalog/54 (last accessed: 16.10.2017).

ICwD in Nepal and that, as a result of this stigma, ICwD are sometimes kept at home, neglected, chained up and largely excluded—and that in some cases they were also victims of infanticide.⁶¹

In terms of the right to education, graduation numbers for persons with disabilities are lower compared to the rest of the population, with figures particularly shocking for women (Austin et al., 2016). The Government of Nepal implemented a ten-year plan of action for children where the disability issue was addressed, specifically in relation to education. However, no specific references to indigenous children (only ethnic minorities) are made (Government of Nepal, 2012). There is a clear gender gap in terms of school enrolment, especially for girls with disabilities. The government has made serious efforts towards improving school facilities for children living with disabilities (UNESCO, 2015), yet even if school facilities are accessible for children with disabilities, it may well be that the roads or pathways to the education centres are not. In fact, only '51.4 percent of people have access to a paved road within 30 minutes' walk' (Government of Nepal 2017, iii), although the Ministry of Physical Infrastructure and the Department of Roads has developed a Rural Access Programme and a Community Access Programme that may also benefit ICwD. This is especially prevalent in remote and rural areas such as hilly and mountainous regions of Nepal (Human Rights Watch, 2011). However, according to the Nepalese Voluntary Review of SDGs, the enrolment of Dalit and Janajati students in primary and secondary education increased in 2015. This also benefited girls, given the gender parity indexes (GPI) of 1.05 and 1.02 respectively for primary education in 2015 and GPI of 1.05 and 1.09 respectively in 2015 for secondary education (Government of Nepal, 2017).

Moreover, Nepal's Government approved a Fourteenth Plan (2016–2019) that aims to ensure access to basic social services and providing adequate food, health care, energy and job security, and at the same time also calls for working towards the SDGs to pave the way to transform Nepal from a low- to a middle-income country by 2030 (Government of Nepal, 2017).

For the Voluntary National Review, civil society organisations in Nepal participated in an SDG forum where they identified 23 constituencies—including children, women, IP and persons with disabilities (PwD) among others. The Voluntary National Review makes repeated calls for improving data collection and disaggregation on many identity markers, including disability. According to the review, in 2007, quotas in the public service were introduced for women and marginalised groups, including Dalits, IP, Madhesi communities and persons with disabilities, (Government of Nepal, 2017).

Finally, according to a paper published by the United Nations Development Programme (UNDP), entitled Study of the challenges faced by persons with disabilities in post-earthquake Nepal, 'the earthquake affected the socially excluded groups, namely Dalits, Janajatis, and women, particularly those with disabilities, disproportionately [...] According to a small study conducted by [...] the Nepal Indigenous Disabled Association (NIDA) across 6 districts (Sindhupalchowk, Dolakha, Ramechhap, Dhading, Nuwakot and Kavreplanchowk), 65 % to 70 % of IPwD affected by the earthquake and 50 % to 55 % of IPwD did not receive relief. For example, NIDA informed [...] that among the 48 persons with disabilities who lost their lives during earthquake in Sindhupalchowk district, 29 of them were IPwD—indicating uneven vulnerabilities' (Austin et al., 2016). However, their vulnerabilities due to their multiple identities were not addressed in any relief or rehabilitation process. In this same study, it was reflected that 'during the emergency period, people were living in camps and their living conditions posed threats to women and children, especially persons with physical and intellectual disabilities. They were vulnerable to being physically abused' (Austin et al., 2016).

4.3 Africa

None of the eight African countries with indigenous populations within their borders that submitted government reports to the CRPD refer to the IP in their reports. Only Kenya and Ethiopia argue that ethnic

⁶¹ Interview with Pratima Gurung.

diversity should be taken into account and, according to the Ethiopian report submitted in 2013, a survey on disability by ethnic origin is being undertaken. Moreover, no African country apart from the Central African Republic has ratified ILO Convention No. 169 on the rights of indigenous and tribal peoples. However, the Republic of the Congo has recently approved a law on the rights of indigenous peoples.⁶²

4.3.1 Kenya

Kenya ratified the CRC in 1990 and the CRPD in 2008. However, the Kenyan government has not yet ratified the ILO Convention 169 and abstained from the vote of UNDRIP. Similarly, Kenya has not yet developed specific legislation on IP.

Article 5 of Kenya's Children Act (8/2001), states that 'no child shall be subjected to discrimination on the ground of origin, sex, religion, creed, custom, language, opinion, conscience, colour, birth, social, political, economic or other status, race, disability, tribe, residence or local connection' (Parliament of Kenya, 2001). Therefore, there is no specific mention of IP. The act contains multiple references to children with disabilities, yet Article 198 states that 'the Minister may, from time to time, by order, either retrospectively from the passing of this Act or prospectively, exclude from the operation of all or any of the provisions of this Act the members of any race, tribe, religious group, or sect in Kenya, or any part of such race, tribe, religious group, or sect, or to whom the Minister may consider it impracticable or inexpedient to apply such provisions, and may also from time to time revoke any such order, but not so that the revocation shall have any retrospective effect' (Parliament of Kenya, 2001). This constitutes a very wide scope for exemption. Moreover, the UNCRPD has not yet been translated into Swahili, as recommended by the CRPD, although there is a Swahili translation available in Tanzania (Kenya National Commission on Human Rights, 2016).

In 2016, the Kenya National Commission on Human Rights published a compendium on submissions to the CRPD (Kenya National Commission on Human Rights, 2016). This compendium replied to a list of issues regarding IP in Kenya that were not replied to by the member state (Government of Kenya, 2015). According to the compendium, IPwD in Kenya suffer from double discrimination and marginalisation, firstly as members of larger communities and secondly as members of their own communities. This is due to a widespread stigma against persons with disabilities expressed in 'derogatory terms referring to persons with disabilities, such as "unsound mind", "mental incapacity", and "mental infirmity" in Kenyan legislation, in particular the 2010 Constitution' (Committee on the Rights of Persons with Disabilities, 2015). However, the Kenyan government replied that Amendment Bill 2014 to the Persons with Disabilities Act 2003 'adopts a broader definition of disability. Disability means albinism, a physical, sensory, mental, or other impairment, including any visual, hearing, learning, or physical incapability, whether arising from natural or artificial causes, which is irreversible and long term and which impacts adversely on a person's capacity to participate in the social, economic, cultural, or political activities' (Government of Kenya, 2015).

The lack of data on IP throughout the country makes it very difficult to address specific policies on disability regarding minority groups. In fact, until very recently, several indigenous communities were included in the category 'others' in the national census, ⁶³ which constituted a challenge in terms of policy efficiency. In 2008, the National Coordinating Agency for Population and Development issued a report on persons living with disabilities in Kenya. Although this survey did not disaggregate data by ethnic origin, the key findings of the report in terms of prevalence were that 4.6 % of Kenyans live with at least one disability, although in Nyanza Province, this percentage is considerably higher (6.8 %). The same study showed that prevalence among children below 15 years of age is 2.4 % (National Coordinating Agency for Population and Development, 2008).

⁶² Interview with Soyata Maiga (ACHIPR) on the situation of IP in Africa.

⁶³ 'The Terrik of the western part of Kenya, the Boni, Wasini, Watta, Wariangulo, in the coastal region of Kenya, and the Sengwer, Illchamus, the Bongomet of Mount Elgon and Ogiek, of Kenya's Rift Valley' (Kenya National Commission on Human Rights, 2016).

According to Manase Ntutu, chair of the Narok South Disability Network in Kenya, infanticide of new-born ICwD is common among IP in Kenya. Particularly concerning is the situation of children with albinism, most of whom live with some kind or degree of visual impairment and skin cancer and who are regularly singled out and subjected to torture, cruel, inhuman and degrading treatment or killings because of cultural beliefs and witchcraft, particularly in border locations with neighbouring countries. This is despite the Witchcraft Act recognising witchcraft as an offence and the practice being included in some sections of the Kenyan penal code (Kenya National Commission on Human Rights, 2016). In fact, the UN advises not to criminalise witchcraft per se, but the criminal actions such as killings or other harmful practices, regardless of their link to witchcraft (Ero, 2017). Other severe violations of fundamental human rights of children with disabilities in Kenya are physical and sexual abuse, forced sterilisation and forced isolation.

In terms of participation and inclusion of ICwD, according to the Kenya National Commission on Human Rights, 'the Children's Act 2006 does not expressly make provisions for their facilitation to effectively make their views known and [have them] taken into account. There is a children's cabinet but there are no guidelines for participation by children with disabilities. There are therefore no formal measures in place for the realisation of this requirement of the convention with regard to children with disabilities, including the views of children living in rural areas and children who belong to minority communities. Children with disabilities in rural areas and those among minority communities are particularly inhibited by negative cultural practices. Some of these practices include female genital mutilation and disinheritance of persons with disabilities' (Kenya National Commission on Human Rights, 2016).

In terms of rights enjoyed, a survey conducted by the National Coordinating Agency for Population and Development found that although there are more persons with disabilities living in rural areas (2,531 persons compared to 664 in urban areas), persons with disabilities living in Nairobi are those who have more access to assistive devices (42.4 %) and to disability grants. In fact, 16.7 % of persons with disabilities living in urban areas received disability grants, as opposed to 2.9 % of persons with disabilities living in rural areas. In fact, those who receive disability support live either in Nairobi (32 %) or in Central Province (10 %), but according to the survey, nobody in the remaining six provinces receives disability grants (National Coordinating Agency for Population and Development, 2008). It is also noteworthy that according to the same survey, 47 % of persons with disabilities living in rural areas have had some kind of difficulty in attending school, as opposed to 31 % living in urban areas. Again, those living in Nairobi have fewer difficulties attending school: 23 % reported having some kind of difficulty, as opposed to 54 %, 58 % and 59 % of persons with disabilities living in Eastern Province, North Eastern Province and Western Province respectively (National Coordinating Agency for Population and Development, 2008).

According to the 2017 Kenyan SDG Voluntary National Review—which was conducted in consultation with civil society organisations and groups, including young people and persons with disabilities—submitted to the High Level Political Forum, there have been some improvements in terms of accessibility of basic services, ⁶⁴ such as through the delivery of mobile clinics to all county hospitals specifically for children and the establishment of Huhuma centres aiming to provide access to various public services.

In terms of child labour, it has been reported that in Kenya, children with disabilities are being trafficked by cartels and exploited as beggars in urban areas, where they are neither fed nor paid in order to worsen their disabilities (Kenya National Commission on Human Rights, 2016). In addition, many children with disabilities suffer from sexual abuse and exploitation, especially those who experience displacement, relocation or live in refugees camps (Kenya National Commission on Human Rights, 2016). Sexual violence and exploitation against women and children in refugee camps has been widely reported (Beswick, 2001;

⁶⁴ See https://sustainabledevelopment.un.org/index.php?page=view&type=30022&nr=372&menu=3170 (last accessed: 12.11.2017).

Stark and Ager, 2011). However, the particular requirements of ICwD are not taken into account in Kenyan emergency and humanitarian programmes.

5 EU policies and actions

The EU is party to the UNCRPD. The UNCRPD includes extraterritorial obligations to state parties through Article 32 on International Cooperation. ⁶⁵ In its report to the CRPD, the European Commission acknowledged the cumulative impact of discrimination that persons with disabilities may experience on other grounds, including ethnic origin, gender and age (European Union, 2014), although it made no reference to IP (neither outside nor within the EU). The Council of Europe's Disability Strategy has repeatedly highlighted the multiple discrimination faced by children and young people with disability and ethnic or social origin (Council of Europe 201), but no specific reference to IP is made. The EU has paid more attention to intersectionality in relation to gender and disability (Davaki et al., 2013) and in relation to healthcare access (FRA, 2013) but not in relation to IP. In fact, in most EU documents on disability, ⁶⁶ IP are not mentioned at all.

Thus far, there has been no specific policy or action targeting the rights of ICwD, basically because none of the documents related to IP reviewed here properly incorporate intersectionality. In fact, most of the documents refer at some point to disadvantaged or vulnerable groups, listing them all together. For example, under Objective 4 of the 2014 to 2020 Global Public Goods and Challenges (GPGC) programme, one of the expected results is 'enhanced capacities of partner countries to respond to the aspirations of socially and economically disadvantaged people (including vulnerable women, children, persons belonging to minorities, indigenous peoples, refugees, migrants, and persons with disabilities) and to strengthen their participation in policy processes' (European Commission, 2014b). Similar lists of vulnerable groups are found in the 2014 to 2017 European Instrument for Democracy and Human Rights (EIDHR) multiannual indicative programme (page 17), the EU Strategic Framework and Action Plan for Human Rights and Democracy (page 2) and the 2017 European Consensus on Development (page12, paragraph 30). These lists, although important as a first step, do not properly refer to the multiple layers of discrimination that ICwD might face nor do they include specific actions targeting PwD, CwD or ICwD, according to the twin-track approach.⁶⁷ Not addressing intersectionality may jeopardise the efficiency of policies and actions, since indicators would not properly measure how poverty, violence, education and healthcare is distributed among specific groups of children or specific groups within indigenous communities.

For this overview, several EU instruments on development and human rights are considered together with several of European Parliament Resolutions. There is room for improvement in every case, if only to incorporate intersectionality.

5.1 Regulation (EU) No. 233/2014 of the European Parliament and of the Council of 11 March 2014 establishing a financing instrument for development cooperation for the period 2014–2020

Regulation (EU) No. 233/2014 of the European Parliament and of the Council of 11 March 2014 establishing a financing instrument for development cooperation for the period 2014–2020 (European Parliament and

⁶⁵ Measures may include: (a) ensuring that international cooperation, including international development programmes, is inclusive of and accessible to persons with disabilities; (b) facilitating and supporting capacity-building; (c) facilitating cooperation in research and access to scientific and technical knowledge; and (d) providing technical and economic assistance, where appropriate.

⁶⁶ The European Disability Strategy 2010 to 2020(European Commission, 2010), several documents referring to the EU Framework for the UNCRPD (European Commission, 2012a; Council of the European Union, 2012b; European Union, 2015) and the EU implementation of the UNCRPD (European Parliament, 2016).

⁶⁷ Interviews with Olga Montúfar (IPwDGN), Tachurea Fleury (IDA) and Amalia Rodriguez (DOCIP).

Council of the European Union, 2015) makes several references to the rights of IP, the rights of children and the rights of persons with disabilities, although usually not from an intersectionality perspective. In this regulation, EU actions promoting the rights of IP are mainly related to the protection of human rights, particularly in Latin America, South Asia and North and South East Asia. IP rights are also linked to social inclusion and non-discrimination, cultural rights and the promotion of indigenous civil society organisations. In Regulation No. 233/2014, the rights of persons with disabilities constitute a cross-cutting issue that should be mainstreamed throughout all programmes (Article 3.3) and are mostly linked to nondiscrimination both from a human rights perspective and from a human development perspective. The rights of persons with disabilities are further highlighted in relation to social inclusion and equal access to and quality education. Finally, the rights of children and young people are mainstreamed in several areas, such as human rights, health, education, social inclusion, the fight against child violence, child marriage and child labour, while child participation is also enhanced when programming for countries and regions in crisis, post-crisis and situations of fragility (Article 12). Under this regulation, the promotion and protection of the rights of children is enhanced by: a) promoting the granting of legal documents; b) supporting an adequate and healthy standard of life and healthy growth to adulthood; and c) ensuring the provision of basic education to all. In terms of human development, in Regulation No. 233/2014, children and young people are considered victims of violent actors of development and specific groups with particular problems that need concrete interventions, especially in the areas of health, education and employment. However, most regional actions are based on the fight against child violence and abduction (especially in Latin America, South Asia and North and South East Asia) and on education and participation (the Middle East). The Indicative Financial Allocations for the Period 2014–2020 section in Annex IV of Regulation No. 233/2014 does not mention IP or persons with disabilities, although it makes specific reference to children (under the human development section of the Thematic Programme on Global Public Goods and Challenges). Under this same section related to social inclusion, most EU actions towards persons with disabilities and IP related to non-discrimination, social protection, employment and culture could be included. Moreover, IP organisations could also benefit from civil society organisations and local authorities (CSO-LA) allocations. However, failing to mention specific groups, such as persons with disabilities and IP in terms of financial allocation, can jeopardise accountability of actions related to these specific groups. In this review, the EIDHR and the GPGC programmes will be further analysed, since they are the ones from which ICwD could see the most benefit. CSOLA would also be important instruments for IPwD, although less so for ICwD.

It is important to note that most projects which could benefit ICwD are funded through geographical programmes and EU Delegations in third countries. In that sense, the EU's Development Cooperation Instrument and the European Development Fund (EDF) could support country-specific projects on education, culture, access to basic services, etc., that are also relevant for ICwD. Nonetheless, the 2015 Council Regulation on the implementation of the 11th EDF (Council of the European Union, 2015b) for example, makes no references to IP. However, it does encourage paying special attention to children's perspectives when programming for countries and regions in crisis, post-crisis or fragility situations (Article 6), which may include indigenous territories, although it does not give specifics in this sense. The regulation also states that the UNCRPD should be one of the international instruments to provide the policy framework to guide the programming and implementation of the 11th EDF, although this is not developed throughout the document.

Overall, identifying the targeting of ICwD through EU development funds is not easy. According to the European Commission services, the 'Internal database on support to child rights since 2009 shows 286 recurrences for children with disabilities as subtheme, with 8 projects containing the word "indigenous" and 154 for indigenous children as subtheme, with 15 projects containing the word "disabled". A work would then need to be done on cross-checking and strictly refining the list (degree of relevancy in the occurrence on the subtheme selected varies from 10 % to 100 % of the project)'.

5.2 The Multiannual Indicative Programme 2014–2017 for the Thematic Programme on 'Global Public Goods and Challenges' for the Period 2014–2020.

IP actions in this programme are mainly related to culture mainstreaming, healthy, productive and resilient ecosystems, the implementation of UNDRIP, biocultural heritage and social justice and inclusion. The key issues regarding children are health, education, knowledge, skills, employment, social protection, social inclusion programmes, child labour, child marriage and birth registration. Finally, disability is associated with poverty, environmental exposure and management of selected chemicals (which is mainly associated with a medical approach to disability) and vocational and educational training (VET).

The main problem is that the objectives, actions, expected results and proposed indicators do not take into account intersectionality, which means they do not attend to the specific needs of particular groups. For example, one of the indicators of the enhanced capacity of IP to protect their lands, culture and rights is the 'number of cases of correct application of the right to FPIC to extractive activities in indigenous peoples' ancestral domain, in line with the UNDRIP' (European Commission, 2014). However, even if the FPIC process is in line with UNDRIP requirements, children and persons with disabilities (and of course children with disabilities) are not taken into account.

In terms of actions targeting children, ICwD could benefit from a few of them, although no specific mention to them is made. The first action is to improve child birth registration which, as mentioned before, is crucial in order to monitor child mortality rates among ICwD, while also enhancing the access to specific social welfare programmes. The second action from which ICwD could benefit is the protection of children from violence and harmful traditional practices. These actions would include awareness-raising campaigns and changes in policy and legal environments. However, specific actions and budgets should be identified for ending violence against ICwD, with special focus on infanticide and sexual violence against indigenous girls with communicational and intellectual disabilities. For this, it is also paramount to reinforce intercultural and all child-friendly justice and healthcare systems.

However, multiannual indicative programmes are long-term strategies. Further objectives and indicators are then identified for each programme and project. For example, the Commission Implementing Decision on the 2015 Annual Action Programme, Part III, for the human development of the Thematic Programme on Global Public Goods and Challenges, to be financed from the general budget of the European Union (European Commission, 2015b), makes reference to three particular actions relevant for ICwD. The first one is entitled 'Towards Universal Birth Registration in Africa' and is intended to contribute to an increase in registration of children at birth in certain African countries over a three-year period. The second action is entitled 'Contribution to the UNICEF Global Programme to Accelerate Action to End Child Marriage' and seeks to end child marriage. The third is entitled 'Combating Unacceptable Forms of Work in the Thai Fishing and Seafood Industry' and seeks to bring an end to child labour. Regarding the rights of persons with disabilities, there is just one action covered, entitled 'Bridging the Gap: Inclusive policies and services for equal rights of persons with disabilities'. 68 This action seeks to generate strong international support to drive the disability inclusion agenda forward and support the inclusion of persons with disabilities in the post-2015 development framework and its related SDG targets and indicators. More specifically, this project aims to 'increase the technical capacity of development partners to include persons with disabilities in mainstream development cooperation, ensuring that work towards achieving the SDGs is consistent

⁶⁸ This project supports a four-year project entitled 'Bridging the Gap I: Human Rights indicators for the CRPD in support of a disability-inclusive 2030 Agenda for Sustainable Development' (European Union, 2017).

with the CRPD' and 'enhance the capacity of five partner governments in low and middle income countries to develop and implement disability-inclusive policies and services' (European Union, 2017). Although there are no actions targeting IP in the 2015 Commission Implementing Decision, ICwD could benefit from these four actions. ⁶⁹

5.3 The 2014–2017 EIDHR multiannual indicative programme

When addressing IP, persons with disabilities, children and young people, this programme specifically highlights the importance of meaningful participation, either through FPIC or the participation of a list of 'disadvantaged groups' in political institutions. However, it is noteworthy that the participation of children and young people in matters that affect them is not considered under this programme. Again, lack of intersectionality is an issue, since the inclusion or the special needs of persons with disabilities is not envisaged during FPIC processes. The Human Rights Defender programme is a very interesting mechanism from which IP can benefit, although no specific reserved space for IPwD or children and young people has so far been considered. This can pose another interesting question: have they failed to benefit before now because they are having trouble accessing the programme, or because they usually are not leaders of their communities? Either way, the EU could do much to improve the situation, improving access to EU-specific programmes for persons with disabilities or supporting leadership roles for IPwD and participation rights.

The European Commission has further developed the EIDHR Multiannual Indicative Programme through Commission Implementing Decisions. The 2015 Commission Implementing Decision for 2016 and 2017 for the EIDHR considers several actions in relation to the rights of IPs, the rights of PwD and the rights of children, although an intersectional approach is not applied in most actions. In the Action Document for supporting Human Rights Priorities (Annex 2), both the rights of IP and the rights of persons with disabilities are considered cross-cutting issues. Furthermore, the call for proposals for 2017 specifically targets the rights of IP as human rights defenders (Lot 1), the rights of persons with disabilities (Lot 4) and the rights of the children, in relation to child labour (Lot 3).⁷¹ In addition, there are specific implementation budgets for actions targeting specific groups. The action document aiming to develop indigenous networks and supporting the Technical Secretariat for IP representatives to UN organs, bodies and sessions in relation to human rights (DOCIP, Annex 9), 72 and to improve the access of IP to justice and development through community-based monitoring (Annex 10), 73 in fact funds part of the Indigenous Navigator project. In both programmes, the rights of children and the rights of persons with disabilities are considered a crosscutting issue but are not further mainstreamed throughout the documents. The 2015 Commission's Implementing Decision also developed a specific programme on children, particularly on supporting a global programme to improve the monitoring of places of detention in order to protect child migrants (Annex 11),74 where the rights of IP and the rights of PwD are considered cross-cutting issues but are not further mainstreamed either. The action document for supporting the deployment of international human rights Indicators (Annex 14) acknowledges the need for data disaggregation on education by sex, age and disability status and also on victims of physical, sexual or psychological violence, victim assistance or redress, but disability status is not considered. Finally, the action document for supporting human rights

⁶⁹ Other implementing documents such as the 2014 Commission Implementing Decisions for human development themes (European Commission, 2014a) or the 2015 Commission Implementing Decision for environment and climate change (European Commission, 2015a) make no reference to IP or PwD.

⁷⁰ Interview with DOCIP staff.

⁷¹ The total budget for 2017, including two additional amounts, was EUR 30,214,000,

⁷² The total budget for 2016 was EUR 2,000,000.

⁷³ This specific programme is intended to support ILO actions and had a total budget of EUR 1,200,000.

 $^{^{74}}$ This specific programme is intended to support UNHCHR actions and had a total budget of EUR 1,200,000 for 2016.

dialogues and their follow-up (Annex 15) acknowledges the need for including IP organisations and leaders in human rights dialogues, but children and youth organisations or organisations of PwD are not taken into account.

5.4 Relevant Council conclusions for IP

The 2015 Council's conclusions on the action plan for human rights and democracy (Council of the European Union, 2015a) consider IP, children and disability issues, although again not in an intersectional manner. Regarding IP, the action plan calls for the further development of EU policy in line with the UNDRIP and the outcome document of the 2014 World Conference on Indigenous Peoples, and protecting IP human rights defenders. Regarding PwD, the document calls for stepping up the promotion of the rights of PwD in the EU's external actions through the UNCRPD. In relation to children, it specifically addresses the situation of children in armed conflict zones and issues that also affect ICwD, such as child labour, child marriage and violence against children, albeit in general terms and not across specific groups of children.

The 2017 European Consensus on Development (Council of the European Union, 2017b) specifically considers disability in developing countries (paragraph 31) which is a big improvement in relation to the 2005 European Consensus on Development, which did not mention it at any point. The 2017 Consensus makes reference to IP on three occasions, the first including both IP and PwD in the list of 'disadvantaged, vulnerable, and marginalised situations' (paragraph 30). In the remaining instances, the 2017 Consensus mentions IP in relation to governance and sustainable management of resources and lands. However, neither IPwD nor ICWD are considered in this document.

The 2017 Council conclusions on IP (Council of the European Union, 2017a) and the 2016 Joint Staff Working Document on implementing EU external policy on IP (European Commission, 2016) recognise some degree of intersectionality, by considering that among IP, special attention should be paid to 'women, children, and young people, persons with disabilities' and other 'disadvantaged or vulnerable' groups. However, no specific target, activities or indicators are highlighted, especially in relation to persons with disabilities. The 2016 Joint Staff Working Document on implementing the policy (European Commission 2016) for example, includes references to two projects—one in Cameroon and another in Vietnam, specifically targeting indigenous children.

According to the European Commission, the main vehicle for taking into account the rights of IP will be the rights-based approach, in line with the 15 May 2017 Council Conclusions on IPs. This clear commitment to anchor IP rights into this approach is an important step. It ensures that these rights are addressed by being at the core of the operations through the rights-based approach methodology, which put emphasis on rights holders and duty bearers in the design and implementation of programmes. It was a way to ensure that these rights will be addressed by being at the core of the rights-based approach methodology (Council of the European Union, 2014b). Still, although the Commission Staff Working Document on a tool-box and rights-based approach, encompassing all human rights for EU development cooperation (Council of the European Union, 2014a) makes reference to the UNCRPD, and therefore to the rights of persons with disabilities, it does not include an intersectional approach nor does it refer to intersectionality.

5.5 Other relevant documents for EU external action on children and disability

In addition to the documents above, from all the EU policy documents potentially relevant to ICwD, two have been selected for further analysis: the 2008 Action Plan on Children's Rights in External Action, the

2003 Guidance Note on Disability and Development for EU Delegations and Services, and the 2012 Guidance Note on Disability-Inclusive Development Cooperation, which actually updates the 2003 Note.

The Action Plan on Children's Rights in External Action considers some degree of intersectionality by stating that 'there are groups of children and adolescents who have special needs and who are particularly at risk: children belonging to ethnic or other minorities, child migrants, displaced children or refugees, children affected by armed conflict, child soldiers, orphans and children without parental care, children affected by HIV/AIDS and children with disabilities, all warrant special attention. Girls are particularly vulnerable and face additional risks' (European Commission, 2008).

Both the Guidance Note on Disability and Development for EU Delegations and Services and the Note on Disability-Inclusive Development Cooperation make specific references to children with disabilities in developing contexts, which is the closest the EU has come to targeting ICwD, although the vocabulary used in this document, such as 'disabled people' or 'disabled children', carries negative connotations and is not appropriate. The Guidance Note on Disability and Development for EU Delegations and Services makes the most complete diagnosis of the situation, mentioning that 'many families of children with disabilities both fear for and are ashamed of them. They tend to hide children with disabilities and do not offer them any opportunities for development', and that 'disability is often perceived in a very negative way due to cultural factors, ignorance, superstitions and fear. In some places, disability is seen as a curse or punishment from God; people with disabilities are perceived as being sub-human and unfit to participate in society's mainstream activities. Where people with disabilities are not visible in society, advocacy for disability rights is made all the more difficult'. Both situations have been repeatedly confirmed in the interviews carried out for this study. The 2003 Guidance Note called for several changes: 1) the recognition of women and children with disabilities in programmes; 2) education projects aimed specifically at women and children with disabilities; 3) the strengthening of networks for women with disabilities and parents of children with disabilities; 4) specific programmes for children with disabilities in post-conflict societies (including rehabilitation of child soldiers)(European Commission, 2003).

5.6 Other EU human rights instruments

The EU has several instruments to promote human rights in its external relations, such as human rights dialogues, human rights guidelines and human rights country strategies. Although human rights guidelines are not legally binding, they represent the main human rights priorities for the EU, since they are adopted at the ministerial level. None of the eleven guidelines addresses the issue of ICwD but some of them relate to human rights that are relevant for them.⁷⁵ For example, in the EU Guideline on Children and Armed Conflict (Council of the European Union, 2008a) and the EU Guidelines on Violence against Women and Girls and Combating all Forms of Discrimination against Them (Council of the European Union, 2008b), indigenous status is not considered, although disability is mainstreamed together with other identity markers such as gender, age and sexual orientation, etc., especially in relation to the higher exposure to violence and sexual exploitation.

⁷⁵ For example, in most of these guidelines, the protection of IP rights are usually addressed as a human rights defenders' issue. This is the case for the 2008 EU Guideline on Human Rights Defenders (Council of the European Union, 2008a) and the 2009 EU Guideline on Human Rights and International Humanitarian Law (Council of the European Union, 2009). In addition, disability is absent in the former but intersected with gender and age in the latter. Similarly, in the EU Guidelines on the Promotion and Protection of Freedom of Religion or Belief (Council of the European Union, 2013b), indigenous status is considered but disability status is not. In the EU Guidelines on Promoting and Protecting the Enjoyment of All Human Rights by Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Persons (Council of the European Union, 2013c) and the Guidelines on EU Policy towards Third Countries on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (Council of the European Union, 2013b) no references are made to IP or PwD, while in the EU Guideline on the Death Penalty (Council of the European Union, 2013a) IP are not mentioned but disability is mainstreamed.

However, it is worth conducting a separate analysis of the 2017 EU Guidelines on the Promotion and Protection of the Rights of the Child. ICwD are not considered in these guidelines, and indigenous children are just mentioned in relation to equal access to education and vocational training, although several references to children belonging to ethnic minorities are made throughout the guidelines. In the 2017 guidelines, disability is further mainstreamed in relation to education, decent work, social and political inclusion, non-discrimination and data collection.

According to the Annual Report on Human Rights and Democracy (European Union, 2017), in 2016, the EU funded several projects on promoting the rights of PwD in 30 countries through EIDHR and the Instrument for Pre-accession Assistance (IPA). Furthermore, the EU has a specific project on CwD in the Republic of Armenia and the Republic of Guinea Bissau (European Union, 2017), where EU delegations also raised the issue of the rights of PwD. The rights of PwD are priorities of EU human rights strategies in the Republic of Moldova, Arab Republic of Egypt, Russian Federation, Republic of Mali, Republic of South Africa, Islamic Republic of Afghanistan, Vanuatu and the Republic of Cuba, and the issue of inhumane and degrading treatment of CwD in the Republic of Ghana has also been highlighted in the report (European Union, 2017). According to this report, the EU funded projects on IP rights in 15 countries, mainly through the EIDHR and the EDF. One of these projects aimed to improve access to government services for indigenous children in the Republic of Botswana (European Union, 2017). Furthermore, IP rights were identified as an EU priority in the Russian Federation, Namibia, the Commonwealth of Australia, the Argentine Republic, Belize, the Plurinational State of Bolivia, the Federative Republic of Brazil, the Republic of Chile, the Republic of Colombia, the Republic of Ecuador and the Republic of Peru.

5.7 European Parliament Resolutions

In order to assess the EP's attention to ICwD, selected resolutions of recent years focusing on the EU's general human rights and development priorities were analysed, as well as some resolutions dealing specifically with the rights of persons with disabilities and indigenous peoples. The 2017 Resolution on the EU's priorities for the UN Human Rights Council sessions in 2017 did not even mention IPs, although it did call for the EU to continue to promote children's rights, in particular by making efforts to ensuring children's access to water, sanitation, healthcare and education (including in conflict zones and refugee camps) and by eliminating child labour, recruitment of child soldiers, deprivation of liberty, torture, trafficking, underage and forced marriage, sexual exploitation and harmful practices such as female genital mutilation(European Parliament, 2017a). It also called for UN members to 'address more effectively the impact of conflict and post-conflict situations on women and girls', although no reference was made to the impacts on CwD. In fact, this resolution does not mainstream disability at all, except in the case of refugees with disabilities, and does not condemn or express concern over human rights violations of PwD.

The 2017 Resolution on the revision of the European Consensus on Development calls for 'specific EU development strategies to better target, protect and support vulnerable and marginalised groups' including women and children, persons with disabilities and IP (European Parliament, 2014a), but disability is again not further mainstreamed and the rights of IP are merely referenced in relation to trade and natural resources. However, the rights of children are further developed, with a significant emphasis placed on education and eliminating all forms of violence and exploitation against children, although only gender is mainstreamed.

The 2016 Resolution on the implementation of the UN Convention on the Rights of Persons with Disabilities, with special regard to the Concluding Observations of the UNCRPD (European Parliament, 2016d) although not specifically mentioning ICwD, addresses several topics that are relevant to them. Firstly, it has an intersectional perspective, recognising multiple forms and layers of discrimination and oppression based on age and gender (European Parliament, 2016d), but not on indigenous or other ethnic

origin. Another interesting feature of this resolution is that it calls for the systematic mainstreaming of the rights of PwD in all EU international cooperation policies and programmes(European Parliament, 2016d) and calls on the EU to address disability issues in dialogues with partner countries and support and engage in strategic cooperation with the partner country disability NGOs, and address disability issues in dialogues with partner countries and support and engage in strategic cooperation with the partner country disability NGOs (European Parliament, 2016d).

In the 2016 Resolution on the annual report on human rights and democracy in the world, and the EU's policy on the matter in 2015, the European Parliament 'reiterates its call for a strengthened EU policy and diplomacy that should aim to eradicate all forms of discrimination [including those based on race, colour, gender, language, culture, social origin, age, disability among other status], and to use every opportunity to express its grave concern over such discriminations; urges, furthermore, that the EU continues to promote the ratification and full implementation of all relevant UN conventions' (European Parliament, 2016b). This Resolution includes a section on the rights of IP (paragraphs 125–127), and another on the rights of PwD (paragraphs 98–101). In the former section, the European Parliament express its concerns over IP human rights violations and calls on the EU delegations to strengthen the dialogue with IP on the ground further in order to identify and prevent human rights violations, and urges the Commission to follow the implementation of provisions protecting the rights of persons belonging to minorities closely throughout the enlargement process.

In the latter section, multiple forms of discrimination are acknowledged throughout the Resolution, especially for women and children with disabilities. In this section, the European Parliament calls on the Commission to ensure that implementation of the UNCRPD is raised systematically in human rights dialogues with third countries, urges the mainstreaming of the human rights of PwD in all EU external policies and actions, supports the recommendation to mainstream a gender perspective in all the EU's disability strategies (including its external policies and action), encourages the VP/HR to continue to support the process of ratification and implementation of the UNCRPD by those countries that have not ratified or implemented it as yet, notes that the EU should lead by example through the domestic effective implementation of the UNCRPD and calls for the EU to take a leading role in the implementation of an inclusive 2030 Agenda for Sustainable Development.

The 2016 Resolution on the situation of the Guarani-Kaiowá in the Brazilian state of Mato Grosso do Sul (European Parliament, 2016c) makes three references to indigenous children, mainly related to malnutrition, lack of access to basic services such as healthcare and education, and high rates of mortality, although there is no reference to IP or CwD. The 2017 Resolution on an integrated European Union policy for the Arctic, which aims to create a framework for protecting the region, makes several references to the rights of IP, FPIC, indigenous knowledge, right to education, etc. However, the impact of climate change and economic activities on children and on PwD is not considered in this Resolution. Similarly, the 2017 European Parliament Resolution on the Situation of Human Rights and Democracy in Nicaragua – The Case of Francisca Ramirez (European Parliament, 2017b) makes a few references to IP rights and FPIC but does not mention the situation of human rights of children or persons with disabilities.

The 2014 Resolution on the EU and the global development framework after 2015 makes no reference to IP, although it 'underlines the importance of respecting and promoting the rights of disabled people in the new framework' (European Parliament, 2014b). It also mainstreams the rights of the children in the following priority areas: post-conflict recovery, food security, health and education, the empowerment and elimination of all forms of violence against women and children and the elimination of child labour.

6. Recommendations to the EU and the European Parliament

Since 2012, the issue of the rights of IPwD is getting more attention within the international arena. However, IPwD do not constitute a homogenous group. Specific subsets of persons based on gender, age, degree and type of disability may face multiple levels and sources of discrimination, which in turn can jeopardise their human rights. ICwD rights related to life, dignity and physical and mental integrity, full participation, education and access to intercultural services are seriously at risk due to poverty, cultural barriers and stigma, remoteness and exposure to natural hazards and conflicts in their territories.

The UNCRPD is the first human rights convention to which the EU has become a party. In the light of this juncture, the European Parliament has an opportunity to a) promote the rights of every child with a disability, including ICwD; b) support the current international and national efforts in defending these rights; and c) champion the rights of ICwD in multiple international arenas where the EU is present. The following recommendations constitute specific proposals of action for the EU and the European Parliament, backed by the UNPFII and the IPwDGN, and checked in terms of their feasibility and suitability.

6.1 Improving data collection

- In continuation of previous efforts, notably through the promotion and implementation of SDG 17 of the 2030 Agenda, and in line with articles 31–33 of the UNCRPD, the EU should:
 - continue the promotion of data collection in all countries and the inclusion of questions regarding ethnic self-identification and the WG list of questions in all censuses and population surveys, disaggregating by age and sex;
 - commission in-depth studies in targeted countries, working together with the regional focal
 persons of the IPwDGN and their networks in the field. These studies can also be commissioned
 in countries were the EU is currently funding projects both on IP rights and PwD rights such as
 the Russian Federation, the Republic of India and the Republic of Paraguay;
 - conduct consultations with ICwD, whenever possible in line with international guidance tools (Plan International, 2016; WHO, 2007).
- Although the task of disaggregated data collection is enormous, efforts on technical capacity building at the national level could be promoted in the contexts of human rights dialogues and funded through bilateral programmes on statistics and thematic budgets. Since data scarcity is an issue in Small Island Developing States in the Pacific, where the majority of the population is indigenous, these third countries could be good targets for starting the process of improving data collection on ICwD.
- In view of the next multiannual programming exercise and the renewal of the Indigenous Navigator Initiative, the EU should:
 - explore ways of institutionalising this initiative during the negotiations over the new regulations (EIDHR or DCI-GPGC) and use the indigenous navigator for improving the life of ICwD and IPwD as a unique community-based framework for monitoring IP rights;
 - in particular, with regard to ICwD, during future questionnaire revisions, include questions, such as the WG short set of questions or items on school attendance, participation in social life and main daily activities of the child in order to identify examples of social inclusion/exclusion, child labour and exploitation, etc.

- In line with the 2017 Council Conclusions on IP, the EU should apply the rights-based approach methodology in all future projects aiming to collect data on IP and disability, and:
 - include environmental and social indicators when studying disabilities, such as economic and cultural factors, as well as accessibility to schools, playgrounds, intercultural justice and health care services;
 - focus on the rights of ICwD rather than the causes of disability. Priority should be given to life free from any kind of violence or exploitation, freedom of movement, education, nondiscrimination and participation (interaction with other children, participation in the social life of the community) and the right and access to basic intercultural services;
 - promote intersectionality and gender mainstreaming, paying particular attention to the specific needs, vulnerabilities, strengths and opportunities of indigenous girls with disabilities. Further research is needed in terms of infanticide and forced sterilisation and sexual violence committed against indigenous girls with disabilities;
 - ensure EU delegations on the ground are systematically implementing the rights-based approach, through continuous training and skill development for EU staff in third countries. This is already foreseen in the Bridging the Gap Project (see above), but continuous efforts are needed due to the high mobility rate of EU delegation staff.

6.2 Improving legal frameworks

- Through political and human rights dialogues between the EU and third countries, the EU should:
 - encourage states to ratify the ILO Convention I169, the UNCRC and UNCRPD and adopt their optional protocols; as well as to uphold the UNDRIP;
 - include information on ICwD in all dialogues concerning IP and children and persons with disabilities.
- The EU should urge member states to make serious commitments to including ICwD in all policies, actions and programmes related to international cooperation and external relations;
- The EU should include ICwD in future revisions of relevant EU guidelines, such as the EU Guidelines on Children and Armed Conflict, EU Guidelines on Ending Violence against Women and Girls and Combating all Forms of Discrimination against Them, EU Guidelines on the Promotion and Protection of LGBTI Persons, EU Guidelines on Preventing Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and, more importantly, the EU Guideline on the Rights of the Child;
- Based on its experience and previous work promoting the UNCRPD and the UNDRIP, and notably through its extensive work with and support for the Human Rights Council, the European Parliament could adopt resolutions calling for:
 - ensuring intersectionality between indigenous and disability status in international legal frameworks, going beyond the inclusion of the 'list of "vulnerable" groups';
 - ensuring international frameworks on development and DRR, torture, inhumane and cruel treatment (including harmful traditional practices), access to justice and death penalty, and FPIC pay attention to the situation, rights, needs and opportunities of IPwD and notably ICwD;
 - support for UN efforts on developing an SDG framework for disaggregated data collection;
 - the development of specific guidelines and criteria for applying FPIC process that are inclusive of PwD and children and young people. This will ensure indigenous women, young people and persons with disabilities are included in every consultation process that affects them.

 The EU should make sure that the FPIC of people with disabilities living in indigenous communities is taken into account in any EU development project concerning IP, by ensuring information and documentation about any project sponsored or funded by the EU on indigenous territories is accessible to IPwD.

6.3 Targeted actions

- The EU should ensure participation of IPwD in EU human rights dialogues, international conferences and forums (at least 15 % of indigenous representatives should be PwD). This can be done by continuing particular actions funded by the EIDHR, the GPGC or the CSO-LA programmes;
- Based on its experience and previous work promoting the UNCRPD and the UNDRIP, and notably through its extensive work with and support for the Human Rights Council, the EU should:
 - ensure that the ICwD agenda is considered in international debates on the rights of women and girls, IP, disabilities and children, as a way to improve intersectionality;
 - assist the IPwDGN and Disability Caucus in promoting the principles of non-discrimination and equality. Funds for this action can be allocated under EIDHR, the GPGC or the CSOLA programmes;
 - call on the CRPD for monitoring the situation of ICwD by addressing the issue in its lists of issues for state parties.
- The should should call on EU member states with indigenous populations to provide regular information on the situation and rights of ICwD in their territories;
- The EU should ensure the inclusion of intersectionality between indigenous and disability status in EU cooperation policies goes beyond the inclusion of the 'list of "vulnerable" groups';
- The EU should (i) fund projects and actions within the framework of the EIDHR multi and GPGC multiannual indicative programmes, and (ii) earmark funds within country programmes for projects and actions under the development cooperation instrument and the EDF, taking into account the respective added value of each of the instruments, to:
 - promote the right to leisure time and full development of ICwD, so that children with disabilities can also fully participate in their societies according to their age;
 - improve access to intercultural education, justice, social protection and health care systems for indigenous children, and specially ICwD;
 - support specific programmes for teacher training which focus on children with disabilities in IP communities and intercultural schools;
 - adopt the principles of universal design and universal access while creating all-user friendly environments in all cooperation projects the EU is funding (schools, playgrounds, justice and health care centres);
 - support organisations of IPwD on the ground and specific awareness-raising activities and studies on disabilities they are carrying out;
 - conduct intercultural awareness-raising campaigns on the rights, strengths and opportunities of children with disabilities and more specifically ICwD;
 - support organisations of parents of ICwD;
 - continue to support improvements in birth registration systems, especially for indigenous children.

- In terms of monitoring initiatives and supervising budgets of programmes on human rights and development, the European Parliament should take action in the following areas:
 - ensuring and supervising that budget allocation of EU programmes on ICwD effectively target children who already live with a disability. Prevention of disabilities is based on a medical approach and takes resources away from ICwD;
 - working together with the European Commission and member states to support the creation of an OECD Development Assistance Committee Code on Disability to better supervise what is being done in terms of projects and budget allocations, especially though geographical programmes and EU delegations.
- The EP should call on EU partners in the private and public sector to provide complete and accessible information on human rights violations that have been frequently associated with and documented in relation to extractive industries or certain development projects (such as increased cases of sexual violence against indigenous women and children, including indigenous women and children with disabilities, extra-judicial killings, land degradation and pollution of water sources and land) as well as information on processes of relocation and characteristics of alternative resettlements, etc. This is paramount for ensuring informed consent on the different projects;
- The EP should call on the EU to pursue its work with a view to finding ways and putting in place processes to remove barriers and improve access to remedies. In particular, it should call on the European Commission to mandate the European Union Agency for Fundamental Rights (FRA) to collect information on judicial and non-judicial mechanisms in member states concerning access to remedy for victims of business related violations, including ICwD, as a follow-up of the April 2017 FRA opinion on 'improving access to remedy in the area of business and human rights at the EU level' (FRA, 2017);
- The EP should call on the European Commission to launch the EU Action Plan on Responsible Business Conduct, the Commission's intention having been welcomed by the Council in its Conclusions of June 2016 (Council of the European Union, 2016). This action plan should address the implementation of the UN guiding principles on business and human rights, including with regard to due diligence and access to remedy, and provide an overall policy framework.

Bibliography

- Afonso, H., Projeto de Lei Nº 1057/2007 Dispõe Sobre O Combate a Práticas Tradicionais Nocivas E À Proteção Dos Direitos Fundamentais de Crianças Indígenas, Bem Como Pertencentes a Outras Sociedades Ditas Não Tradicionais, Câmara dos Deputados do Brazil, Brazil, 2007.
- Amnesty International, 'We Are Not Animals To Be Hunted or Sold' Violence and Discrimination Against People with Albinism in Malawi', London, 2016. https://www.amnesty.org/en/documents/afr36/4126/2016/en/ (last accessed: 16/10/2017).
- Anaya, J., Report of the Special Rapporteur on the Situation of Human Rights and Fundamental Freedoms of Indigenous People, UN, 2009. https://documents-dds-ny.un.org/doc/UNDOC/GEN/N09/502/81/PDF/N0950281.pdf?OpenElement (last accessed: 16/10/2017).
- Austin, L. et al., *Disaster, Disability and Difference: A Study of the Challenges Faced by Persons with Disabilities* (*PwDs*) in *Post-Earthquake Nepal*, UNDP, Kathmandu, 2016. http://www.np.undp.org/content/nepal/en/home/library/crisis_prevention_and_recovery/disaster-disability-difference-PWDs-post-quake2016.html (last accessed: 16/10/2017).
- Beswick, S., 'If You Leave Your Country You Have No Life!' Rape, Suicide, and Violence: The Voices of Ethiopian, Somali, and Sudanese Female Refugees in Kenyan Refugee Camps', *Northeast African Studies*, No 8(3), 2001, pag. 69–98.
- Borges Oliveira, L.M., 'Pessoas Com Deficiências.' Cartila Do Censo 2010, Brasilia, 2010.
- Bouchard, J., Meyer-Bisch, P. 'Intersectionality and Interdependence of Human Rights: Same or Different?', *The Equal Rights Review*, No 16, 2016, pp. 186–203. http://www.equalrightstrust.org/ertdocumentbank/Intersectionality and Interdependence of Human Rights Same or Different.pdf (last accessed: 16/10/2017).
- CEPAL, Salud de La Población Joven Indígena En América Latina: Un Panorama General, Santiago de Chile, 2011. http://repositorio.cepal.org/bitstream/handle/11362/35357/1/S2011118_es.pdf (last accessed: 02/10/2017).
- Choo, H.Y., Myra, M.F., 'Practicing Intersectionality in Sociological Research: A Critical Analysis of Inclusions, Interactions, and Institutions in the Study of Inequalities.' *Sociological Theory* No 28, 2010, pp. 129–49.
- Chow, P.Y.S., 'Has Intersectionality Reached Its Limits? Intersectionality in the UN Human Rights Treaty Body Practice and the Issue of Ambivalence.', *Human Rights Law Review* No 16, 2016, pp. 453–81. https://academic.oup.com/hrlr/article-abstract/16/3/453/2452831/Has-Intersectionality-Reached-its-Limits?redirectedFrom=fulltext (last accessed: 16/10/2017).
- Committee on the Rights of Persons with Disabilities, *List of Issues in Relation to the Initial Report of Kenya*, United Nations, 2015. http://tbinternet.ohchr.org/Treaties/CRPD/Shared%20Documents/KEN/CRPD_C_KEN_Q_1_20292_E .doc (last accessed: 16/10/2017).
- Committee on the Rights of the Child, General Comment $n^\circ 11$: Indigenous Children and Their Rights under the Convention, United Nations, 2009. http://www.un.org/esa/socdev/unpfii/documents/GC_11_indigenous.pdf (last accesssed: 16/10/2017).
- Committee on the Rights of the Child, Concluding Observations on the Combined Second to Fourth Periodic Reports of Brazil, United Nations, 2015. http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhsjNHBu mcEd5TkNWJOjDFQeatJbyFs960qiwzXV0YO437juxmhfAMHNLV1o3vXd5Afw5LCD74G939ZexURikt e8xMCKphJkr44J4Oqu42m030 (last accessed: 16/10/2017).
- Council of Europe, *Human Rights: A Reality for All Council of Europe Disability Strategy*, Council of Europe, Strasbourg, 2007. https://rm.coe.int/16806c400c (last accessed: 16/10/2017).

- Council of the European Union, EU Guidelines on Children and Armed Conflict, Council of the European Union, Brussels, 2008(a).
- Council of the European Union, *EU Guidelines on Violence Against Women and Girls and Combating All Forms of Discrimination Against Them*, Council of the European Union, Brussels, 2008(b). https://eeas.europa.eu/sites/eeas/files/16173_08_en.pdf (last accessed: 13/11/2017).
- Council of the European Union, Note on the set up of the EU-level framework required by art. 33.2 of the UN Convention on the rights of persons with disabilities, Council of the European Union, Brussels, 2012.
- Council of the European Union, *A rights-based approach; encompassing all human rights for EU development cooperation*, Council of the European Union, Brussels, 2014(a). http://register.consilium.europa.eu/doc/srv?l=EN&f=ST 9489 2014 INIT. (last accessed: 16/10/2017).
- Council of the European Union, Council Conclusions on a Rights-Based Approach to Development Cooperation, Encompassing Al Human Rights, Council of the European Union, Brussels, 2014(b).
- Council of the European Union, *Council Conclusions on the Action Plan on Human Rights and Democracy 2015* 2019, Council of the European Union, Brussels, 2015(a). https://ec.europa.eu/anti-trafficking/sites/antitrafficking/files/action-plan-on-human-rights-and-democracy-2015-2019 en.pdf. (last accessed: 13/11/2017).
- Council of the European Union, Council Regulation (EU) 2015/322 of 2 March 2015 on the Implementation of the 11th European Development Fund, Council of the European Union, Brussels, 2015(b). http://eurlex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32015R0322 (last accessed: 13/11/2017).
- Council of the European Union, *Council Conclusions on Business and Human Rights*, Council of the European Union, Brussels, 2016. http://data.consilium.europa.eu/doc/document/ST-10254-2016-INIT/en/pdf ((last accessed: 13/11/2017).
- Council of the European Union, *Council Conclusions on Indigenous People*, Council of the European Union, Brussels, 2017(a). http://data.consilium.europa.eu/doc/document/ST-8814-2017-INIT/en/pdf (last accessed: 16/10/2017).
- Council of the European Union, *The new European consensus on development 'our world, our dignity, our future'*, Council of the European Union, Brussels, 2017(b). https://ec.europa.eu/europeaid/sites/devco/files/european-consensus-on-development-final-20170626_en.pdf. (last accessed: 16/10/2017)
- Crenshaw, K., 'Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics.', *University of Chicago Legal Forum*, Vol: 1989(1), Chicago, 1989. http://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8 (last accessed: 02/10/2017).
- Crenshaw, K., 'Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color.' *Stanford Law Review* No 43, 1991, pp. 1241–99. http://multipleidentitieslgbtq.wiki.westga.edu/file/view/Crenshaw1991.pdf (last accessed: 16/10/2017).
- Cultural Survival. 2015. 'Nothing About Us, Without Us Indigenous Persons with Disabilities Demand Action.', *Cultural Survival Quarterly Magazine* No 39, 2015. https://www.culturalsurvival.org/publications/cultural-survival-quarterly/39-3-nothing-about-us-without-us-indigenous-persons (last accessed: 02/10/2017).
- Davaki, K. et al., *Discrimination Generated by the Intersection of Gender and Disability*, European Parliament, Brussels, 2013.
- Davis, A.N., 'Intersectionality and International Law: Recognizing Complex Identities on the Global Stage', School of Oriental and African Studies Harvard Human Rights Journal, No 28, 2013. http://harvardhrj.com/wp-content/uploads/2009/09/intersectionality-and-international-law-recognizing-complex-identities-on-the-global-stage.pdf. (last accessed: 16/10/2017.

- Deemas, D., 'We Want to Change That Stigma', *Cultural Survival Quarterly Magazine* No 39, 2015. https://www.culturalsurvival.org/publications/cultural-survival-quarterly/we-want-chage-stigma (last accessed: 02/10/2017).
- Devandas, C., Sexual and Reproductive Health and Rights of Girls and Young Women with Disabilities Report of the Special Rapporteur on the Rights of Persons with Disabilities, United Nations, 2017. https://digitallibrary.un.org/record/1301518?ln=es (last accessed: 13/11/2017).
- Di Giacomo, M. et al., 'Childhood Disability in Aboriginal and Torres Strait Islander Peoples: A Literature Review', *International Journal for Equity in Health* No 12, 2013, BioMed Central, pp. 1–18.
- Ero, I. Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, United Nations, Human Rights Council, 2017. http://www.refworld.org/docid/58b00c124.html (last accessed: 13/11/2017).
- European Commission, Guidance Note on Disability and Development for EU Delegations and Services, European Commission, Brussels, 2003. https://ec.europa.eu/europeaid/sites/devco/files/methodology-guide-on-disability-development-for-ec-delegations-services-200303_en_2.pdf (last accessed: 16/10/2017).
- European Commission, *The European Union's Action Plan on Children's Rights in External Action*, European Commission, Brussels, 2008. http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52008SC0136 (last accessed: 16/10/2017).
- European Commission, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe, European Commission, Brussels, 2010. http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52010DC0636 (last accessed: 16/10/2017).
- European Commission, Commission Proposal on the setting-up at EU level of the framework reauired by art. 33.2 of the UN Convention on the Rights of Persons with Disabilities, European Commission, Brussels, 2012. http://ec.europa.eu/social/main.jsp?catld=1189&langld=en (last accessed: 16/10/2017).
- European Commission, Commission Implementing Decision on the Annual Action Programme 2014, 2015 and 2016 for the 'Human Development' Theme of the Global Public Goods and Challenges Programme to Be Financed from the General Budget of the European Union, European Commission, Brussels, 2014(a). https://ec.europa.eu/europeaid/sites/devco/files/commission-implementing-decision-c-2014-7887_en.pdf (last accessed: 13/11/2017).
- European Commission, Multiannual Indicative Programme 2014-2017 for the Thematic Programme on 'Global Public Goods and Challenges' for the Period 2014-2020, European Commission, Brussels, 2014(b). http://ec.europa.eu/europeaid/commission-implementing-decision-adopting-multiannual-indicative-programme-thematic-programme-global_en. (last accessed: 02/10/2017).
- European Commission, Commission Implementing Decision on the Annual Action Programme 2015 for Environment and Climate Change under the Global Public Goods and Challenges Thematic Programme, to Be Financed from the General Budget of the European Union, European Commission, Brussels, 2015(a). https://ec.europa.eu/europeaid/sites/devco/files/aap-gpgc-2015-c20155973-commission-decision-20150811_en.pdf (last accessed: 13/11/2017).
- European Commission, Commission Implementing Decision on the Annual Action Programme 2015 Part III for Theme Human Development of the Global Public Goods and Challenges Programme to Be Financed from the General Budget of the European Union, European Commission, Brussels, 2015(b). https://ec.europa.eu/europeaid/sites/devco/files/commission-implementing-decision_c2015-8571 en 0.pdf (last accessed: 13/11/2017).
- European Commission, *Implementing EU External Policy on Indigenous Peoples*, European Commission, Brussels, 2016. http://www.un.org/esa/socdev/unpfii/documents/2016/Docs-updates/JOINT STAFF WORKING PAPER EN V2 P1 865982.pdf (last accessed: 16/10/2017).
- European Parliament, European Parliament Resolution of 14 February 2017 on the Revision of the European Consensus on Development P8 TA(2017)0026, European Parliament, Brussels, 2014(a).

- http://www.europarl.europa.eu/sides/getDoc.do?type=TA&language=EN&reference=P8-TA-2017-0026 (last accessed: 13/11/2017).
- European Parliament, European Parliament Resolution of 25 November 2014 on the EU and the Global Development Framework after 2015 P8_TA(2014)0059, European Parliament, Brussels, 2014(b). http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2014-0059+0+DOC+XML+V0//EN (last accessed: 13/11/2017).
- European Parliament, EU Implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) EU Implementation Assessment, European Parliament; Brussels, 2016(a). http://www.europarl.europa.eu/RegData/etudes/IDAN/2016/536347/EPRS_IDA(2016)536347_EN.pd f (last accessed: 16/10/2017).
- European Parliament, European Parliament Resolution of 14 December 2016 on the Annual Report on Human Rights and Democracy in the World and the European Union's Policy on the Matter 2015 P8_TA(2016)0502, European Parliament, Brussels, 2016(b). http://www.europarl.europa.eu/sides/getDoc.do?type=TA&language=EN&reference=P8-TA-2016-0502 (last accessed: 13/11/2017).
- European Parliament, European Parliament Resolution of 24 November 2016 on the Situation of the GuaraniKaiowá in the Brazilian State of Mato Grosso Do Sul (2016/2991(RSP)), European Parliament, Brussels, 2016(c). http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//NONSGML+TA+P8-TA-2016-0445+0+DOC+PDF+V0//EN (last accessed: 13/11/2017).
- European Parliament, European Parliament Resolution of 7 July 2016 on the Implementation of the UN Convention on the Rights of Persons with Disabilities, with Special Regard to the Concluding Observations of the UN CRPD Committee (2015/2258(INI)), European Parliament, Brussels, 2016(d). http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//NONSGML+TA+P8-TA-2016-0318+0+DOC+PDF+V0//EN (last accessed: 13/11/2017).
- European Parliament, European Parliament Resolution of 16 March 2017 on EU Priorities for the UN Human Rights Council Sessions in 2017, European Parliament, Brussels, 2017(a). http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+MOTION+P8-RC-2017-0183+0+DOC+XML+V0//EN (last accessed: 13/11/2017).
- European Parliament, European Parliament Resolution on the Situation of Human Rights and Democracy in Nicaragua the Case of Francisca Ramirez (2017/2563(RSP)), European Parliament, Brussels, 2017(b). http://www.europarl.europa.eu/sides/getDoc.do?type=TA&reference=P8-TA-2017-0043&format=XML&language=EN (last accessed: 28/11/2017).
- European Parliament and Council of the European Union, 'Regulation (EU) No 233/2014 of the European Parliament and of the Council of 11 March 2014 Establishing a Financing Instrument for Development Cooperation for the Period 2014-2020', Official Journal of the European Union, no. 233: L77/44, Brussels, 2015.https://eeas.europa.eu/sites/eeas/files/regulation_eu_no_2332014_of_the_ep_and_the_coun cil_establishing_a_financing_instrument_for_development_cooperation_2014-2020_0.pdf (last accessed: 13/11/2017).
- European Union, Consideration of Reports Submitted by States Parties under Article 35 of the Convention, United Nations, 2014. http://www.refworld.org/pdfid/55c872c04.pdf (last accessed: 16/10/2017).
- European Union, EU Framework to Promote, Protect and Monitor the Implementation of UN CRPD Work Programme 2015 2016, Euroepan Union, 2015. http://cms.horus.be/files/99909/MediaArchive/Work%20Programme%20EU%20%20Framework%2 02015-2016.doc (last accessed: 16/10/2017).
- European Union, *Annual Report on Human Rights and Democracy in the World in 2016*, European Union, 2017. https://eeas.europa.eu/headquarters/headQuarters-homepage/33993/annual-report-human-rights-and-democracy-world-2016_en (last accessed: 13/11/2017).
- European Union Agency for Fundamental Rights (FRA), Developing Indicators for the Protection, Respect and

- Promotion of the Rights of the Child in the European Union, European Union, 2009. http://fra.europa.eu/en/publication/2012/developing-indicators-protection-respect-and-promotion-rights-child-european-unio-0 (last accessed: 02/10/2017).
- European Union Agency For Fundamental Rights (FRA), *Inequalities and Multiple Discrimination in Access to and Quality of Healthcare. Equality*, European Union, Luxembourg, 2013. http://fra.europa.eu/en/publication/2013/inequalities-discrimination-healthcare (last accessed: 16/10/2017).
- European Union Agency for Fundamental Rights (FRA), *Violence against Children with Disabilities: Legislation, Policies and Programmes in the EU*, European Union Agency for Fundamental Rights, Wien, 2015. http://fra.europa.eu/en/publication/2015/violence-children-disabilities-eu (last accessed: 13/11/2017).
- European Union Agency for Fundamental Rights (FRA), *Opinion on Improving Access to Remedy in the Area of Business and Human Rights at the EU Level*, European Union Agency for Fundamental Rights, Wien, 2017. http://fra.europa.eu/en/opinion/2017/business-human-rights (last accessed: 13/11/2017).
- Expert Mechanism on the Rights of Indigenous Peoples, Access to Justice in the Promotion and Protection of the Rights of Indigenous Peoples: Restorative Justice, Indigenous Juridical Systems and Access to Justice for Indigenous Women, Children and Youth, and Persons with Disabilities, Expert Mechanism on the Rights of Indigenous Peoples, 2014.
- Expert Mechanism on the Rights of Indigenous Peoples, Right to Health and Indigenous Peoples with a Focus on Children and Youth, Expert Mechanism on the Rights of Indigenous People, 2016.
- Frohmader, C., Dehumanised: The Forced Sterilisation of Women and Girls with Disabilities in Australia, 2013. http://tbinternet.ohchr.org/Treaties/CAT/Shared Documents/AUS/INT_CAT_NGO_AUS_18673_E.pdf (last accessed: 16/10/2017).
- Garcia Bruno et al., 'Discourses and Practices in the Inclusion of Deaf Indians in Differentiated Indigenous Schools', *Educação & Realidade*, No 41(3), 2016, pp. 681–93.
- Gilroy, J. et al., 'Conceptual Framework for Policy and Research Development with Indigenous People with Disabilities', *Australian Aboriginal Studies*, No 2, 2013, pp. 42–58. http://web.b.ebscohost.com.recursos.uloyola.es/ehost/pdfviewer/pdfviewer?vid=1&sid=660eaed8-e015-47b4-9ef5-deba7a755039%40sessionmgr101. (last accessed: 16/10/2017).
- Goldberg, C., 'Is Intersectionality a Disabled Framework? PWIVID: In/Visibility and Variability as Intracategorical Interventions', *Critical Disability Discourses*, No 7, 2015, pp. 55–88. https://scholar.google.es/scholar?hl=es&as_sdt=0%2C5&q=.+ls+Intersectionality+a+Disabled+Framework%3F+Presenting+PWIVID%3A+In%2FVisibility+and+Variability+as+Intracategorical+Interventions.+&btnG= (last accessed: 16/10/2017).
- Government of Brazil, Replies of Brazil to the List of Issues of the Committee on the Rights of Persons with Disabilities, United Nations, 2015. https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/158/50/PDF/G1515850.pdf?OpenElement (last accessed: 16/10/2017).
- Government of Brazil, *Voluntary National Review on the Sustainable Development Goals*, United Nations, 2017. https://sustainabledevelopment.un.org/content/documents/15806Brazil_English.pdf (last accessed: 13/11/2017).
- Government of Kenya, *Replies of Kenya to the List of Issues in Relation to the Initial Report of Kenya*, United Nations, 2015. https://documents-dds-ny.un.org/doc/UNDOC/GEN/G15/152/68/PDF/G1515268.pdf?OpenElement (last accessed: 16/10/2017).
- Government of Nepal, *National Review of Sustainable Development Goals*, Government of Nepal, National Planning Commission, Kathmandu, 2017. http://www.npc.gov.np/images/category/reviewSDG.pdf (last accessed: 13/11/2017).

- Henriksen, J.B., *Key Principles in Implementing ILO Convention No. 169.*, ILO, 2008. http://www.ilo.org/wcmsp5/groups/public/@ed_norm/@normes/documents/publication/wcms_11 8120.pdf (last accessed: 16/10/2017).
- Hickey, H., 'Indigenous People with Disabilities: The Missing Link' *Human Rights and Disability Advocacy*, Philadelphia, 2014, pp. 157–69.
- Hollinsworth, D., 'Decolonizing Indigenous Disability in Australia', *Disability and Society*, 2012, pp. 1–15.
- Human Rights Watch, *Futures Stolen: Barriers to Education for Children with Disabilities in Nepal*, Human Rights Watch, New York, 2011. https://www.hrw.org/report/2011/08/24/futures-stolen/barriers-education-children-disabilities-nepal (last accessed: 16/10/2017).
- Human Rights Watch, Living in Hell: Abuses against People with Psychosocial Disabilities in Indonesia, Human Rights Watch, New York, 2016. https://www.hrw.org/node/287537/ (last accessed: 02/10/2017)
- International Labour Organisation, *Indigenous and Tribal Peoples Convention (Convention No. 169)*, ILO, 1989. http://ilo.org/dyn/normlex/en/f?p=NORMLEXPUB:12100:0::NO::P12100_ILO_CODE:C169 (last accessed: 16/10/2017)
- Indigenous Navigator, 'Long Community Questionnaire', 2007. http://indigenousnavigator.org/images/documents-english/tools/questionnaires/Long-community-questionnaire-sep2017-en.pdf (last accessed: 16/10/2017).
- Inguanzo, I., Reconocimiento de Los Derechos de Los Pueblos Indígenas En El Sudeste Asiático: Un Análisis Comparado, Centro de Investigaciones Sociológicas, Madrid, 2016.
- International Disability Alliance, IDA Report on IDA Activities, International Disability Alliance, 2016.
- Johnson, S., 'Jordan's Principle and Indigenous Children with Disabilities in Canada: Jurisdiction, Advocacy, and Research', *Journal of Social Work in Disability & Rehabilitation*, No 14(3–4), 2015, pp. 233–244.
- Kenya National Commission on Human Rights, *Compendium on Submissions to CRPD 2016*, Nairobi, 2016. http://www.knchr.org/Portals/0/InternationalObligationsReports/CRPD REPORT A4.pdf?ver=2016-08-17-114343-847 (last accessed: 02/10/2017).
- Kingsbury, B., "Indigenous Peoples' in International Law: A Constructivist Approach to the Asian Controversy', *American Journal of International Law* No 92, 1998, pp. 414–57. http://www.jstor.org/stable/2997916 (last accessed: 02/10/2017).
- Lewis, J. et al., 'Environmental Exposures to Metals in Native Communities and Implications for Child Development: Basis for the Navajo Birth Cohort Study', *Journal of Social Work in Disability & Rehabilitation* No 14, Routledge, 2015, pp. 245–69.
- Martínez Cobo, J., Study of the Problem of Discrimination against Indigenous Populations, United Nations, 1986.
- National Coordinating Agency for Population and Development, *Kenya National Survey for Persons with Disabilities*, Nairobi, 2008. http://www.ilo.org/surveydata/index.php/catalog/927/download/6118 (last accessed: 02/10/2017).
- Parliament of Kenya, 'The Children's Act (No. 8 of 2001)', Kenya, 2001.
- Pereira de Souza, V., Moraes Garcia Bruno, M., 'As Crianças Indígenas Guarani E Kaiowá Com Deficiência: Ausências E emergências Para a Efetivaçao Das Políticas Públicas de Saúde E Educaçao', *Educaçao, Diversidade E Fronteiras Da In/Exclusão*, Universidade Federal da Grande Dourados, Dourados, 2012. http://200.129.209.183/arquivos/arquivos/78/EDITORA/catalogo/educacao-diversidade-e-fronteiras-da-in-exclusao-marilda-garcia-bruno-e-renato-suttana-orgs.pdf (last accessed: 02/10/2017).
- Petrolewska, A., 'Simply, Real Consultation: Indigenous Persons with Disabilities Demand Action', *Cultural Survival Quarterly Magazine* No 39, 2015.
- Plan International, Guidelines for Consulting with Children & Young People with Disabilities 'Nothing about

- *Us , without Us ': The Importance of Consulting with Children and Young People with Disabilities,* Plan International, 2016. https://plan-international.org/publications/guidelines-consulting-children-and-young-people-disabilities (last accessed: 02/10/2017).
- Schiek, D., Lawson, A., European Union Non-Discrimination Law and Intersectionality: Investigating the Triangle of the Racial, Gender and Disability Discrimination, Routledge, New York, 2011.
- Scully, D., Understanding Sexual Violence: A Study of Convicted Rapist, Routledge, London, 2013.
- Shakespeare, T., Watson, N., 'The Social Model of Disability: An Outdated Ideology?', *Research in Social Science and Disability*, No 2, 2002, pp. 9–28. http://disability-studies.leeds.ac.uk/files/library/Shakespeare-social-model-of-disability.pdf. (last accessed: 16/10/2017).
- Stang A., María F., Las Personas Con Discapacidad En América Latina: Del Reconocimiento Jurídico a La Desigualdad Real, Santiago de Chile, 2011.
- Stark, L., Alastair A., 'A Systematic Review of Prevalence Studies of Gender Based Violence in Complex Emergencies', *Trauma, Violence and Abuse* No 12, 2011, pp. 127–34.
- Subba, C. et al., A Study on the Socio-Economic Status of Indigenous Peoples in Nepal, LAHURNIP & IWGIA, Kathmandu, 2014. http://www.iwgia.org/iwgia_files_publications_files/0712_social-economic-status-of-indigenous-peoples-of-nepal.pdf. (16/10/2017).
- Thornton, W., Voigt L., 'Disaster Rape: Vulnerability of Women to Sexual Assaults during Hurricane Katrina', Journal of Public Management and Social Policy, No 13, 2007, pp. 23–49.
- United Nations, *Convention on the Rights of the Child*, United Nations, 1989. http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx (last access: 16/10/2017).
- United Nations, *The Convention on the Rights of Persons with Disabilities and Its Optional Protocol*, United Nations, 2006. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html (last accessed: 16/10/2017).
- United Nations, Thematic Study on the Issue of Violence against Women and Girls and Disability, United Nations,
 2012. http://www.ohchr.org/Documents/Issues/Disability/ThematicStudyViolenceAgainstWomenGirls.pdf (last accessed: 16/10/2017).
- United Nations, Study on the Right to Participation of Indigenous Youth in the Nordic Countries in Decision-Making Processes, 2013(a). http://www.un.org/Docs/journal/asp/ws.asp?m=E/C.19/2013/8 (last accessed: 16/10/2017).
- United Nations, Study on the Situation of Indigenous Persons with Disabilities, with a Particular Focus on Challenges Faced with Regard to the Full Enjoyment of Human Rights and Inclusion in Development, 2013(b). http://www.un.org/Docs/journal/asp/ws.asp?m=E/C.19/2013/6 (last accessed: 16/10/2017).
- United Nation, Outcome Document of the High-Level Plenary Meeting of the General Assembly Known as World Conference on Indigenous Peoples, United Nations General Assembly, 2014. http://www.un.org/esa/socdev/unpfii/documents/wc/AdoptedAlta_outcomedoc_EN.pdf (last accessed: 16/10/2017).
- United Nations Children's Fund (UNICEF), Breaking the Silence on Violence against Indigenous Girls, Adolescents and Young Women A Call to Action Based on an Overview of Existing Evidence from Africa, Asia Pacific and Latin America, UNICEF, New York, 2013(a). https://www.unicef.org/protection/files/Violence_study_summary_report.pdf (last accessed: 16/10/2017).
- United Nations Children's Fund (UNICEF), *Children and Young People with Disabilities*, UNICEF, New York, 2013(b). https://www.unicef.org/disabilities/files/Factsheet_A5__Web_NEW.pdf. (last accessed: 16/10/2017).
- United Nations Children's Fund (UNICEF), The Convention on the Rights of the Child. Guiding Principles:

- *General Requirements for All Rights*, UNICEF, 2014. https://www.unicef.org/crc/index_30177.html. (last accessed: 16/10/2017).
- United Nations Educational, Scientific and Cultural Organization (UNESCO), *Education For All: National Review Report 2001-2015*, Kathmandu, 2015. http://unesdoc.unesco.org/images/0023/002327/232769E.pdf (last accessed: 02/10/2017).
- United Nations Population Fund, A Deeper Silence: The Unheard Experiences of Women with Disabilities Sexual and Reproductive Health and Violence against Women in Kiribati, Solomon Islands and Tonga, United Nations, 2013. http://pacific.unfpa.org. (last accessed: 13/11/2017).
- WHO, WHO Ethical and Safety Recommendations for Researching, Documenting and Monitoring Sexual Violence in Emergencies, 2007. http://www.who.int/gender/documents/OMS_Ethics&Safety10Aug07.pdf (last accessed: 02/10/2017).
- Yeo, R., Moore K., 'Including Disabled People in Poverty Reduction Work: 'Nothing About Us, Without Us, World Development No 31, 2003, pp. 571–90.

Appendix1: Interviewees

Organisation	Interviewees	Indigenous Person	IPwD	Gender	Country-based
IPwDGN	Olga Montúfar	Yes	Yes	Female	Mexico
IPwDGN	ManaseNtutu	Yes	Yes	Male	Kenya
IPwDGN	SetarekiMecanawi	Yes	Yes	Male	Fiji
IPwDGN	Pratima Gurung	Yes	Yes	Female	Nepal
PDNK	Christine Kandie	Yes	Yes	Female	Kenya
Laguna and Acoma Coalition for a Safe Environment (LACSE)	Petuuche Gilbert	Yes	Yes	Male	United States of America
IDA	TchaureaFleury	No	No	Female	Switzerland
ILO	Martin Oelz	No	No	Male	Switzerland
ILO	Stefan Tromel	No	No	Male	Switzerland
DOCIP	Amalia Rodríguez	No	No	Female	Belgium
DOCIP	MathiasWuidur	No	No	Male	Belgium
ACHIPR	SoyataMaiga	No	No	Female	Mali
IPACC /UNIPROBA	Vital Bambanze	Yes	No	Male	Burundi
IPACC / PIDPP	MochireDiel	Yes	No	Male	DemocraticRepublic of Congo
JOAS/AIPP	JannieLasimbang	Yes	No	Female	Malaysia
DIHR	SilleStiedsen	No	No	Female	Denmark
CHIRAPAQ	Raquel García	No	No	Female	Peru

Appendix 2: English version of the questionnaire for IP organisations

Chara	ctoristics	of w	our or	ganisation
Ciiaia	icteristics	OI V	our or	uaiiisatioii

2. What is the name of your people?

1. What is the name of your organisation?

3. In which country is your organisation based?

4. Which countries does your organisation cover?
5. How many disabled men and women are on the board of your organisation?
Prevalence of disabilities among indigenous children
6. Do any children within your community have any difficulty seeing?
 Yes
o No
If yes, how many?
7. Are there any children within your community who cannot see at all?
 Yes
o No
f yes, how many?
8. Do any children within your community have any difficulty hearing music or people's voices?
o Yes
o No
Any further details:
9. Do they have hearing assistance?
o Yes
o No
f yes, how many?
10. Are there any children within your community who cannot hear music or people's voices at all
o Yes
o No
f yes, how many?
11. Do any children within your community have any difficulty walking?
o Yes
o No

Any fu	ırther details:
12. Do	they have special equipment for walking such as crutches or a wheelchair?
0	Yes
0	No
If yes,	how many?
13. Do	any children within your community have any difficulty communicating with other people?
0	Yes
0	No
14. Ar	e people within the community able to understand what the child wants to say?
0	Yes
0	No
The si	tuation of indigenous children with disabilities
you sa 'not a	you answered 'yes' to any of the previous questions, on a scale of 1 to 5, to what extent would by that the indigenous children within your community are discriminated against, with 1 being t all ' and 5 being 'very '?
1	
Not at	all
16. Ho	ow accessible are primary school facilities for the children of your community/people?
0	Immediately and universally accessible (within short walking distance, with no physical barriers; all children, including those living with disabilities, have unrestricted access to school facilities)
0	Immediately accessible but not universally accessible (within short walking distance, although with some physical barriers; most children have unrestricted access to school facilities)
0	Accessible (within reasonable walking distance and/or affordable transport is provided; with limited effort, all children can access school facilities)
0	Moderately inaccessible (walking distance and/or costs of transport constitute a challenge; distance to schools facilities limit the school attendance of some children)
0	Not accessible (children who attend school have to live outside the community)
	oes the school/do the schools in your community/communities have adapted infrastructure naterials for students with disabilities?
0	Yes
0	No

18. Is your indigenous language taught in the school(s) of your community?

o Yes

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o No

19. If your indigenous language is taught in school, is the teaching of your language adapted to
children with disabilities (sign language, Braille, etc.) ?

- Yes
- o No

20. In your community, do children with any difficulties attend any special school for children with disabilities?

21. Do the children with the following difficulties regularly attend school to the same extent as other children within your community?

	Yes	No
Children with visual disabilities		
Children with hearing disabilities		
Children with physical disabilities		
Children with intellectual disabilities		
Children with communicational disabilities		

22.	Would you say that in your	community,	children with	difficulties	seeing,	hearing,	walking	or
con	nmunicating have trouble ma	king friends	of their age?					

- Yes
- o No

23. Would you say that in your community, the main activities of children with difficulties seeing, hearing, walking or communicating are (mark more than one answer if appropriate):

- o Staying at home
- o Helping family
- o Going to school
- o Playing with other children

The situation of indigenous persons with disabilities

24. How many disabled men and women have land titles?

	Men	Women
None of them		
A few of them		
Some of them		
Most of them		

25.	Do persons	with	disabilities	from y	our	community	have	access t	o your	religious	and	cultura
site	s?											

- Yes
- o No

26. Is there any extractive industry close to your community?

- Yes
- o No

27. When consultations are undertaken with your community/communities before the approval of projects or other measure that may affect you, are those consultations:

	Yes	No
In line with free, prior and informed consent criteria		
Held in your indigenous language		
Indigenous young people participate		
Indigenous persons with disabilities participate		
Documentation and information is adapted to people with disabilities		

28. If, since 2008, your people/community experienced displacement or relocation, were the special needs of disabled persons taken into account?

- Yes
- o No
- o There was no relocation or displacement

29. If, since 2008, your people/community experienced displacement or relocation, have the disabled men and women of your community received the same extent of redress, restitution and/or compensation?

_	Vac
()	1 11

o No

o Nobody received redress, restitution and/or compensation

Other relevant rights of indigenous children with disabilities

30. As far as you know, was there any incident of violence against any children with disabilities in your community?

- o Sexual violence committed by a family member
- o Sexual violence committed by a community member
- o Sexual violence committed by a non-community member
- o Harmful traditional practice resulting in death or severe harm
- o I am not aware of any episode of violence against indigenous children with disabilities

31. What kind of disability does the child live with?

- Visual disability
- o Hearing disability
- o Physical disability
- o Intellectual disability
- Communicational disability

32.	Was	the	child	а	airl	or	а	boy	ι?
<i></i>	1145		CIIII	u	9	•	u	~~;	, .

- o Girl
- o Boy

33.	How	old	was	the	child?	
-----	-----	-----	-----	-----	--------	--

34. How many disabled and non-disabled children in your community are NOT registered?

	Boys	Girls	Boys with disabilities	Girls with disabilities
None of them				
A few of them				
Most of them				
All of them				

Any further details:

35. As far as you know, do any children from your community receive any social support, aid or benefits from the government?

- Yes
- o No

36. Please provide any information, comments or suggestions that you consider might be useful for this study							
De	mo	graphics					
37	. Se	:					
	0	Man					
	0	Woman					
	0	Prefer not to disclose					
38	. Do	you live with any disability?					
	0	Yes					
	0	No					
39	. If y	es, what kind?					
	0	Visual disability					
	0	Hearing disability					
	0	Physical disability					
	0	Intellectual disability					
	0	Communicational disability					
40	. Ag	e:					
	0	Below 18 years old					
	0	18–24 years old					
	0	25–34 years old					
	0	35–64 years old					
	0	Over 65 years old					

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