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**Expert Group Meeting**

**on Indigenous Persons with Disabilities**

7-8 July 2016 **| ILO Headquarters | Geneva**

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Summary:

*“Now we are at the table neither as indigenous peoples, nor as disabled, but as indigenous persons with disabilities. That changes everything” --* Setareki Macanawai (Fiji)

On 7 and 8 July 2016, leaders from organizations of persons with disabilities, indigenous peoples and indigenous persons with disabilities, United Nations and other international experts, and academics[[1]](#footnote-1) participated in the first **Expert Group Meeting (EGM) on indigenous persons with disabilities**.

The *Special Rapporteur on the rights of persons with disabilities* Ms. Catalina Devandas-Aguilar and the *Special Rapporteur on the rights of indigenous peoples* Ms. Victoria Tauli Corpuz, co-hosted the meeting, in cooperation with the *Expert Mechanism on the Rights of Indigenous Peoples (EMRIP)* and the *UN Permanent Forum on Indigenous Issues (UNPFII).*  The EGM was organizedthanks to the support of the Government of Finland, the Office of the High Commissioner for Human Rights (OHCHR), the International Labour Organization (ILO), the UN Department of Economic and Social Affairs (DESA), and the International Disability Alliance (IDA).

The EGM aimed to explore the synergies and complementarities between the most relevant international human rights instruments for indigenous persons with disabilities: the UN Declaration on the Rights of Indigenous Peoples (UNDRIP), the ILO Convention 169 and the UN Convention on the Rights of Persons with Disabilities (CRPD). The meeting also assessed the need for further efforts to ensure that the different UN mechanisms and initiatives fully include the rights of indigenous persons with disabilities, including the EMRIP, the UNPFII, the Special Rapporteurs, the Committee on the rights of persons with disabilities, and the 2030 Agenda, among others.

The outcomes pursued were three-fold:

1. ***Generate knowledge and recommendations*** to promote and protect the rights of indigenous persons with disabilities;
2. ***Inform the Panel discussion on the situation of indigenous persons with disabilities of the EMRIP that took place on 12 July 2016***. In this regard, the EGM provided a common framework of discussion , with an agenda of themes to put forward during the EMRIP, including access to social services, access to justice, and the identification of safeguards to avoid assimilation, preserve the autonomy and self-determination of indigenous persons with disabilities;
3. ***Create an informal network of experts on the issue of indigenous persons with disabilities***, which could potentially support UN work to improve understanding of the intersectionality between the disability and indigenous sectors.

The prevalence of collective rights in the UNDRIP was highlighted as potentially contrasting with the individual rights-based focus of the CRPD. However, experts cautioned against seeing them as a dichotomy, and rather argued for understanding individual and collective rights as two aspects of the same body of entitlements. In this regard, *community-based approaches* were identified as a point of convergence between both instruments, due to their collective and individual rights-based dimensions. Experts agreed that these approaches for the delivery of support services are key to promote the inclusion of indigenous persons with disabilities, while preventing cultural assimilation and subsequent loss of identity.

Other issues discussed in depth included the impact that the “*indigenous”* and “*disability”* identity terms have in determining eligibility for social services and State support, and how being considered “*vulnerable”* often implies a burden, a subject of charity rather than a rights-holder. Experts indicated that by categorizing a person in narrow identity siloes hampers their chances to participate in decision-making, resulting in inadequate services and interactions with State institutions. In this regard, exploring synergies with other communities such as persons with disabilities is of strategic importance.

**Main challenges:**

Sessions tapped into the knowledge and experience of participants to identify common trends and challenges faced by indigenous persons with disabilities in different communities, key issues to focus, and reviewed existing practices around them. Participants identified the following key challenges:

* ***Knowledge gap at grassroots level:*** Participants acknowledged thatmost indigenous persons with disabilities are not aware of their human rights, thus the need for capacity building and increased efforts by States to enhance their skills.
* ***Risk of cultural and social assimilation*** in certain models of inclusion, particularly in States’ approaches to service delivery. Disability-specific services are often planned centrally and located in urban areas, which forces indigenous persons with disabilities to choose between access to services and maintaining their lives, identity and place in their communities.
* ***Social perceptions of disability among different indigenous communities***. Participants provided examples of cases in which language plays a positive role in promoting inclusion, and others where language used to describe disability reinforces stigma, discrimination and social exclusion.
* ***Situation of indigenous women and girls with disabilities***: Gender was described in almost all cases as an aggravating factor in terms of exclusion and discrimination. The lack of women in leadership roles and their widespread marginalization in the community were among the concerns around women and girls with disabilities in many indigenous communities worldwide.
* ***Lack of access to services and support in most areas***, including justice, education, health and political participation.
* ***Insufficient statistical information on indigenous persons with disabilities and the need to invest in disaggregated data.*** Experts called States and international cooperation agencies to support research efforts to fill important knowledge gaps. Suggestions ranged from advocating for United Nations treaty bodies and other international monitoring instruments to commission more specific studies, to assessing the adequacy of incorporating indigenous-specific variables into the short set of questions of the Washington Group on Disability Statistics. Experts identified data collection as a key advocacy instrument, as long as mechanisms to produce statistical data include the direct participation of rights-holders and are respectful of their rights.

**Key recommendations:**

Participants agreed on the following recommendations:

* Advocate with the Committee on the rights of persons with disabilities for the **development of a General Comment on indigenous persons with disabilities**, to guide States on how to adequately implement the CRPD among indigenous communities (e.g., on issues such as personal assistance services in the community in a way that prevents assimilation or situations of forced migration);
* Include the **promotion and protection of the rights of indigenous persons with disabilities and their access to services in National Action Plans**. Bolivia’s national plan for persons with disabilities, which has a special focus on indigenous peoples’, was mentioned as an example on how public policy can work to connect these two agendas;
* **Recommend EMRIP to review of the situation of indigenous person with disability to date**, in the framework of the 10th anniversary of the adoption of the Declaration in 2017.
* Adopt a **System-wide Wide Action Plan that is inclusive of persons with disabilities and indigenous peoples** to enhance coordination among UN agencies, including at the field level, to ensure that disability and indigenous peoples factors are mainstreamed in all UN programmes, and that indicators and benchmarks are identified in monitoring the implementation of the SDGs.
* Bridge the information gap on indigenous persons with disabilities, by **adapting the set of questions of the Washington Group on Disability Statistics to disaggregate data on indigenous persons with disabilities at national level**.
* **Strengthen the capacity of organizations of indigenous persons with disabilities and the Indigenous Persons with Disabilities Global Network,** with the support from States, donor and international cooperation partners.
* **Raise the awareness of the media** on the issue of indigenous persons with disabilities.

**Outstanding issues requiring further discussion:**

* **Climate change and humanitarian issues**: how can we look at the SDGs, for instance, through the lens of the rights of indigenous persons with disabilities in a more specific ways.
* **Prevention of disability from an indigenous perspective**: many disabilities are the direct result of violations of the rights of indigenous peoples to self-determination and over their lands.
* **Psychosocial disabilities** among indigenous communities: how to address the issue of legal capacity and support in decision-making in indigenous communities?
* How to **support indigenous persons with disabilities and respect their autonomy** in a way that is culturally sensitive? How to translate these concepts in practice?.
* The need for **clearer definitions on social services for indigenous persons with disabilities,** in light of the need to avoid the risk of assimilation.

Opening remarks:

***Chief of the Gender Equality and Diversity Branch, ILO, Ms. Shauna Olney:*** “When we talk about the 2030 sustainable Development Agenda, we always use the phrase "Leave no one behind." Today, we want to give that phrase real meaning. This meeting will give us much needed space to exchange, discuss and reflect.”

***Ambassador of Finland, H.E. Ms. Päivi Kairamo:*** “Finland is pleased to support the organization of this event, as it focuses on two groups that are of great importance to the Finnish Human Rights policy. The Finnish ratification of the Convention and its Optional Protocol last June makes it legally binding, strengthens the protection of the rights of persons with disabilities, and reinforces the State's responsibility to guarantee the realization of these rights. Finland has been actively engaged in the promotion of a human rights-based approach to sustainable development, particularly in ensuring that the principle of non-discrimination is applied throughout decision-making and actions to implement the 2030 Agenda.

The inclusion of people with disabilities is a key priority in Finland's humanitarian policy. We pay special attention to the empowerment of women and girls with disabilities, and are very pleased to be part of the coalition that prepared the Charter on inclusion of persons with disabilities into humanitarian action launched in Istanbul.

The Working Group on discrimination against women in law and practice recently made an important recommendation in its report to the Human Rights Council. It emphasized that States need to ensure the accessibility of health services, including sexual health and reproductive rights for women with disabilities. It also recommended guaranteeing these women their autonomy in decision-making, including in relation to their sexuality and reproduction. I hope we will be able to cover these questions during this meeting as well.”

***Special Rapporteur on the rights of persons with disabilities, Ms. Catalina Devandas-Aguilar:*** “Groups of indigenous persons with disabilities are often not included in the mainstream work on disability and the rights of persons with disabilities. Consequently, we are not being responsive enough to their needs or cultural settings. It is important for me to learn about how I can promote the rights of indigenous persons with disabilities in a way that is respectful and sensitive. Today, we will learn to read the Declaration on the rights of indigenous peoples from a disability perspective, and the CRPD from an indigenous peoples’ perspective.

***Special Rapporteur on the rights of indigenous peoples, Ms. Victoria Tauli Corpuz:*** “The Declaration on the rights of indigenous peoples was negotiated at the same time when the CRPD was adopted. These two main international instruments followed similar paths, with the direct involvement of the rights-holders themselves. There is ever since increasing awareness about the rights of indigenous persons with disabilities, and new possibilities to share their experiences in international forums and mechanisms.

Situations of armed conflict and disaster, exploitation of land resources, the environmental crisis – climate change in particular – affect indigenous peoples disproportionately. In Honduras, for instance, indigenous deep-sea divers have no access to health services if they acquire a disability, because they are not registered at birth. In Brazil, Amazonian children acquire a disability due the extensive mercury poisoning from illegal gold mining. In the Philippines, no relief reached many indigenous communities affected by the typhoons, because they are in remote areas that are difficult to access.

We must discuss the relationship between collective and individual rights: at the end of the day, the ones that take care of persons with disabilities are the family and the community, before any hospital or governmental agency. We must also pay attention to children with disabilities. They depend on actions taken by the adults to survive in this world. I believe your worth as a person depends on how you take care of the weakest, the most vulnerable; I believe that's what human rights are ultimately about.”

***Chair of the Indigenous Persons with Disabilities Global Network, Ms. Doreen Demas:*** “As indigenous peoples with disabilities, we must ensure that our expertise, our experiences and our voices are part of the solution, part of what needs to be done. We come from many different cultures, languages, customs and traditions, so the dialogue here today will be interesting because the complexities are varied. There is no easy solution to our problems, nor one thing that fits everything.”

**Session II**

**Setting the scene: what has been done so far to include indigenous persons with disabilities?**

*The Convention on the Rights of Persons with Disabilities (CRPD), the ILO Convention No. 169 and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)* *are the three most relevant international instruments for indigenous persons with disabilities.*

**Summary:** Participants provided an overview of the international human rights treaties and mechanisms that address the issue of indigenous persons with disabilities, and introduced some key issues for discussion going forward, such as access to justice and education. In addition to a preliminary exploration of the specific mechanisms--EMRIP, UNDRIP, ILO convention 169, CRPD—participants questioned how to insert the agenda of indigenous persons with disabilities within broader processes, such as the SDGs. The Bolivian National Action Plan is an example of successful integration.

Human rights instruments and mechanisms**:**

The issue of indigenous persons with disabilities was discussed for the first time at the 3rd session of the **UNPFII** in 2004, with a recommendation to recognize indigenous persons with disabilities within indigenous communities. Almost a decade later, in 2013, the UNPFII produced a **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**, (E/C.19/2013/6). The study called for the Special Rapporteur on the rights of indigenous peoples, the mechanisms on the rights of indigenous people, and the ILO to continue exploring how to pursue research and strengthen this relationship. In the report of its 15th session (2016), the UNPFII recommended a qualitative study on indigenous persons with disabilities in all seven regions of the world.

The **Convention on the rights of persons with disabilities** was acknowledged for having transformed the lives of persons with disabilities in many countries. However, indigenous persons with disabilities appear to be marginalized and almost utterly forgotten by the mainstream disability movement.

In 2013, the Human Rights Council requested **EMRIP**, which serves as its advisory body on the rights of indigenous peoples, to conduct a Study on ***access to justice*** ***in the protection and promotion of the rights of indigenous people*** *(*A/HRC/24/50*)*, which did not do adequately reflect the situation of indigenous persons with disabilities, among other groups. Therefore, in 2014 EMRIP prepared a ***follow-up Study on access to justice with a focus on restorative justice, indigenous juridical systems and access to justice for indigenous women, children and youth, and persons with disabilities*** (A/HRC/27/65)

The study revealed that indigenous persons with disabilities are disproportionately at risk of experiencing all forms of violence and neglect, compounded by discrimination based on race, gender, identity and sexual orientation, and face high rates of incarceration.

Key issues raised in the discussions:

Discussion focused on access to justice, with participants stressing the need for human rights educationfor the justice community, increased access to legal counsel for persons with disabilities and greater support for their families.

It was noted that the CRPD does not address the issue of measures to prevent disability, for instance due to environmental pollution. These are central to indigenous communities and their rights frameworks. It was pointed however that any preventive effort must avoid to further discriminate or stereotype persons with disabilities.

Moreover, participants identified the **lack of statistics and disaggregated data** as a main challenge, particularly with regard to children with disabilities, while acknowledging some progress within the European Union framework.

**Session III**

**Framing the discussion: the intersectionality between ethnicity and disability in the UN international human rights framework**

***“We have an aspiration for our rights for cultural inclusion as indigenous people, and for social inclusion as persons with disabilities; that should be a strong statement up front.”***

**Summary:** Participants pointed at the challenge to determine where they fit as persons with disabilities and as indigenous peoples simultaneously. They elaborated on the notion of intersectionality to include not only indigenous origin and disability, but also other grounds such as gender and socio-economic aspects (like being from an high-income versus a lower-income country). When taking into account a holistic view towards identity, indigenous persons with disabilities find themselves usually excluded. In this regard, avoiding silos *approaches was seen as highly important to prevent further marginalization* in all development processes and mechanisms.

Intersections**:**

**With sports:**  Sports are a strategic space for the inclusion of persons with disabilities, particularly in indigenous communities. While the Olympic Games and other international competitions run separate games for persons with and without disabilities (e.g., Paralympics), the World Indigenous Games do not separate among these population groups, and athletes with and without disabilities compete at the same time.

**With natural disasters and the climate change agenda:** Indigenous peoples live in fragile ecosystems, which are directly affected by natural disasters like typhoons, hurricanes or Tsunamis Relocation and evacuation plans, such as in the case of small islands, need to consider rights-based approaches that are inclusive of the needs of indigenous persons with disabilities.

**With armed conflict situations:** This is directly related to the suggestion for including prevention in the agenda.Conflicts like those that took place in the Philippines, Colombia, or Cambodia resulted in high numbers of persons with disabilities due to landmines and other conflict-related circumstances.

Participants acknowledged the need for a **positive common and overarching message to recognize the value and contribution of indigenous persons with disabilities** to their culture and society, to be framed around the notion of *embracing diversity*.

**Session IV**

**Inclusion versus assimilation**

***There is a need for a better integration of indigenous persons with disabilities in society. However, this integration must respect the cultural background of indigenous peoples. Often, legislation and policies designed to include persons with disabilities in mainstream society leads to cultural assimilation when applied to indigenous persons with disabilities, threatening their languages, ways of life and identities.***

**Summary:** Experts noted the insufficient availability of services for indigenous persons with disabilities in their communities. As support services are often centralized in larger urban areas, in order to access them, they must relocate to those areas, thus becoming disconnected from their communities. Experts discussed how to provide access to indigenous persons with disabilities within the existing services, without exposing them to assimilation and cultural alienation. There is a parallel between this discussion and the debate on “integration vs. inclusion” in the disability context, whereas assimilation overlapped with the integrationist approach.

Participants agreed that further discussion is required on service implementation, to define how to design specific services from an indigenous perspective, and which mainstream services they can benefit from without risking assimilation.

Key issues raised in the discussions**:**

In the Latin American context, “***assimilation”*** means colonization. Preventing assimilation is a collective right that applies to the community as a whole, regardless of disability.

Indigenous peoples in isolated and rural areas live under their traditional systems. The risk of assimilation exists mainly in their access to services. Assimilation of indigenous peoples becomes a problem in urban areas, because services do not respond to their traditional ways of dealing with health and education. Moreover, indigenous persons with disabilities face challenges to access these services, due to discrimination, language and other communications barriers. For instance, to be eligible for disability pensions, indigenous persons with disabilities in remote areas are often required to be using mainstream medical services, rather than their traditional ones.

In relation to the term ***vulnerability***, many experts cautioned that, should indigenous peoples remain part of the broader “vulnerable populations” group (together with women, children, youth, elders and persons with disabilities), they would be diluted by means of inclusion. Indigenous people reject being labeled as vulnerable, and prefer to pursue a stand-alone agenda as it is strategically better option.

Similarly, some cautioned that the frequent association between poverty and indigeneity turns poverty as part of their identity, a problem shared by persons with disabilities. The post 2015 Agenda implies that indigenous peoples are always poor. Others flagged that this may be something that indigenous communities need to accept as part of the “political game”, in order to be included in the development agenda.

Lessons from national experiences**:**

In some schools in Australia, attendance and other output levels were positively affected through inclusive experiences, where teaching methods and environments were adapted to accommodate visual, acoustic and mobility impairments. On the other hand, other schools adopted direct instruction methods which were not culturally sensitive nor responsive of either indigenous culture nor disabilities. They reminded policy makers that ***resourcing is only part of it. The rest is adapting practices to become more inclusive***.

In **Canada**, the *Canadian Indian Act* establishes jurisdictional aspects of access to services that are at the basis of the systemic discrimination against indigenous persons with disabilities. Indigenous persons with disabilities cannot access and enjoy the same services as other persons with disabilities, because the First Nations’ People fall under the responsibility of the Federal government, and therefore, service providers and administration are different.

State programmes for indigenous persons with disabilities in **Mexico** seem to be poorly coordinated and continue to promote special education. While there are materials for children with disabilities, often schools do not know about them, and teachers are often non-native speakers, which contributes to non-inclusive environments.

Experts also pointed that, as indigenous persons with disabilities are often considered mainly a health issue, services, support or benefits require the approval of a medical authority. This implies a problem, by not being recognized as persons with equal rights. However, experts also cautioned that health issues need to be nevertheless a central consideration, considering the incidence of diabetes, hypertension, or cardiac illnesses among others, in acquiring disabilities.

**Session V**

**Individual rights vs. collective rights; Identity and self-identification**

*While most international human rights instruments reflect an individualistic concept of rights and of rights-holders, the UNDRIP holds the collective rights of indigenous peoples at its core. Indigenous peoples’ individual identity is inseparably connected to the group/community to which an individual belongs. This is one of the reasons why they have been demanding for the protection of their collective rights as a group.*

**Summary:** Participants reflected on the relationship between collective and individual rights, the synergies between existing international instruments that guarantee them, and their practical implementation. They also discussed the role of self-identification in the construction of identity and the impact identity has in the determination of eligibility to access social services, as well as in the disaggregation of data utilized to define those services and other relevant policies.

From a human rights perspective, this dichotomy is rather artificial. For example, in the UNDRIP and the Inter American Convention on Human Rights, the right to property does not only include individual rights, but also the right to collective property. Similarly, the right to freedom of association is presented as an individual right that is exercised collectively.

Individual and collective rights

Experts explained that the rights contained in international human rights treaties and standards are in fact collective rights from which individuals benefit. Therefore, it is not a matter of one set of rights against the other, but rather as two complementary aspects of the same body of rights.

Indigenous peoples should not be forced to make choices between accessing services and preserving their identity, but should be able to receive services and operate them in their communities. There should be no dichotomy between individual and collective rights for indigenous persons with disabilities.

Ensuring that indigenous persons with disabilities are part of the collective requires their free and informed consent. Experts made a case point on their right to inherit land, to ensure their participation in collective land rights and the control over natural resources.

Regarding the tension between individual and collective rights, experts agreed that solutions cannot be prescriptive, but rather contextualized. As approximately 80 percent of persons with disabilities reside in developing countries, solutions cannot rely solely on State programmes, but also on the wide variety of responses and world views of indigenous peoples in relation to indigenous persons with disabilities.

Lessons at national level on self-identification:

In **Latin America** self-identification of disability is resisted, and families sometimes do not accept their members with disabilities. Disaggregation therefore requires different types of instruments. In Paraguay, questionnaires for population census combine individual with communal questions to identify persons with disabilities and find out about their situation. Interviewers ask how many persons with disability there are in each community, and the types of disabilities they have.

In remote Western **Australia**, there are experiences of personalization that produced good outcomes in the access to services. They rely on looking at the person in all of its complexity, whereas gender, cultural background, a person’s role in the family and disability are considered alongside other social determinants, such as vocation or work experience. Complexity translates in the participation of the person in multiple communities. One should look at inclusion in those multiple communities of interaction.

In **Canada**, racism and discrimination make it harder for indigenous peoples to access health services, despite laws granting universal access. The case of an indigenous homeless man with a disability who died of a bladder infection after waiting for 34 hours unattended at the Emergency room illustrates how the collective identity of being indigenous hampered access to rights that are granted as individuals.

**Session VI**

**Social perceptions of disability within indigenous communities: challenges faced by indigenous women and girls with disabilities**

**Summary:** Participants discussed the way indigenous languages portray disability, which tends to have a descriptive, functional perspective. On the one hand, it was noted that this lead to non-recognition and invisibility. On the other hand, the worthiness of the person isn’t questioned in this functional descriptions, which arguably makes many of these language references fit within the social model towards disability.

Experts pointed at the differences between traditional indigenous understandings of mental illness and mainstream Western psychiatry; and how indigenous approaches could provide useful frameworks to adopt more broadly, across cultures. This was exemplified by the historical appreciation of the ability to “see beyond the visible” or to have visions as wisdom among many indigenous cultures, which are commonly regarded as mental illnesses in Western mental health practice.

On women and girls with disabilities, participants agreed that gender is a factor for further marginalization and discrimination, and highlighted their lack of representation and disempowerment, as well as the need for improving access to information and education at the community level. Article 8 of the CRPD could be used to combat stigma and common stereotypes against women and girls with disabilities.

Terminology issues:

Some indigenous languages do not have concepts or words to describe disability. Indigenous languages sometimes do not lend to an easy recognition of the situation of indigenous persons with disabilities, which at times results in hiding and hurting these members of the community through the use of discriminatory language (e.g. in Nigeria persons with disabilities are referred with a term which means “hopeless”).

Even in the absence of an overarching concept of disability, t indigenous communities often describe persons with disabilities as wheelchair users, blind persons, someone who does not walk very well. This view of disability is closer to the “social model of disability” defined by the disability movement, which implies recognition of the role that person with disability plays in the community, rather than focusing on their impairment. This concept is worth highlighting and promoting in the broader disability movement.

Lessons at national level on indigenous women and girls with disabilities:

In **Mexico,** when a girl with a disability is born, the lack of information on the availability of support services makes it hard for the family to make an informed decision about the child’s upbringing. Moreover, existing beliefs that the parents must have done some wrongdoing to have a child with disability further contributes to stigma, lack of participation in decision-making, and overall disempowerment in adulthood.

In **Australia**, gender-based stigma placesindigenous mothers at heightened risk of having their child removed if s/he has a disability. The diagnosis of Fetal Alcohol Syndrome in some cases of birth of indigenous children with disabilities resulted in the stigmatization of their mothers after giving birth. Mothers feel ashamed, fearing that the diagnosis may be related to personal lifestyle, particularly in rural and remote communities in Australia. These problems are closely connected to insufficient access to sexual and reproductive health faced by indigenous women and girls with disabilities.

To fight stigma and discrimination, experts agreed on the need to raise awareness of sexual and reproductive rights, and the laws that guarantee them, in ways that are culturally relevant to indigenous peoples. The adaptation of the American with Disabilities Act into some First Nation languages is as an example of this practice.

**Session VII**

**Moving forward: interpreting the CRPD from an indigenous perspective**

*The CRPD is a legally binding treaty adopted by the UN General Assembly in December 2006: Its purpose is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”[[2]](#footnote-2)*

**Summary:** Participants discussed how the concepts of Community-based Rehabilitation (CBR) and Community-based Inclusive Development (CBID) contribute to interpret the CRPD from an indigenous perspective. Article 19 on living independently and being included in the community appears to be the most relevant article of the Convention to frame the discussion. Additionally, articles 24 (education), 25 (health) and 27 (work and employment) are also very relevant. Indigenous peoples’ experiences on intercultural education and community-based practices in the areas of health, work and employment are relevant contributions from an indigenous perspective. Article 11 on situations of humanitarian risk and emergencies and article 31 on statistics and data collection are also highly relevant for indigenous peoples.

Context and definitions:

The original draft text of art icle19 of the CRPD had a strong focus onthe concept of living independently. However, as representatives from Arab countries and Latin America felt that this concept was not reflecting their own culture, the final text then combined living independently and being included in the community. The process did not include an indigenous perspective.

The key principle in the Convention that tackles all the regional or cultural differences is *“on an equal basis with other members of the community”*. The principle means that whatever is designed or established to support the participation of persons with disabilities must allow them to enjoy the same levels of autonomy and control of their lives than any other member of that particular community.

Different approaches exist in relation to **legal capacity**. Supported decision-making by appointment of a judge was defined as a Western approach, which doesn’t reflect supported decision-making structures that are network or community based, more common in the African and other contexts. Experts stressed the need for States to enact legislation and policies that are in line with the cultural and social contexts in which are applied.

Recommendations to move forward:

**Community-based Rehabilitation (CBR) and Community-Based Inclusive Development (CBID)** are examples of inclusive development at the community level that seem to avoid assimilation, and would require an in-depth assessment. In response to the lack of services, indigenous communities started to organize themselves to develop and provide services from within. This started primarily as rehabilitation, but then extended to other services that were not initially available.

**Suggest that the CRPD Committee develop a general comment on indigenous persons with disabilities**, following the model ofgeneral comment no. 11 on indigenous children to the Convention on the Rights of the Child. A general comment could serve as an evidence-based, devising tool to assist Member States in solving questions of implementation rather than establishing new standards. One expert suggested that the general comment provides guidelines for *personal assistance services* to live in the community, in a way that does not force indigenous persons with disabilities out of their communities’ culture.

**Raise the awareness of the media:** experts indicated that the media are not covering enough stories of indigenous persons with disabilities, thus the need to sensitize them and provide them information and key messages emanating from experts’ thematic reports.

**Suggest that the Washington Group on Disability Statistics adapt its short set of questions on disability statistics to capture data on indigenous persons with disabilities.** Data collection and disaggregation continues to be a long-standing challenge. Experts pointed at States’ resistance to provide disaggregated data, under the argument of avoiding the propagation of discrimination. Article 31 of the CRPD needs to be analyzed from an indigenous peoples’ lens to highlight practices to collect data that are discriminatory against persons with disabilities within their communities. Experts criticized the approach by personnel conducting data collection exercises in communities who create false expectations with persons with disabilities and their families about the possibility of change.Communities must be informed about the purpose of data collection exercises and the process in a transparent manner, to avoid reluctance among the communities, and how the research findings are used to identify community actions that help alleviate disparities.

Research methods must be participatory and empower indigenous persons with disabilities, both through participatory methodologies and through outcomes in terms of policy change.

**Session VIII**

**Moving forward: interpreting the UNDRIP from a disability perspective**

*UNDRIP is one of the first international human rights instruments that that is implementation-oriented and recognizes collective rights. It is based on four key principles: 1)* **Equality***: Ensuring indigenous people have equal access to and enjoy all human rights on an equal basis; 2) Self-determination, which entails the right to be consulted, 3)* **Land***, without which indigenous people wouldn't have a cultural identity; 4) several provisions that provide for how* ***indigenous community interrelate with other State institutions regional authorities, and other institutions.*** *.*

**Summary:** UNDRIP is not a legally binding document as the CRPD, but has an outcome document resulting from the 2014 World Conference on Indigenous People, which recommends how States, civil society, the private sector and other stakeholders should contribute to the implementation of the Declaration. Articles 21 and 22 of UNDRIP refer to persons with disability. The Declaration does not mention the concept of vulnerability, as it never aimed at the rehabilitation of “vulnerable groups”, but rather to ensure that all sectors of the community become key actors in their own development.

The *Inter-Agency Support Group on Indigenous Peoples’ Issues* plays an important role to encourage United Nations agencies, funds and the programmes to become more sensitive to the situations of indigenous persons with disabilities.

In developing National Action Plans, States could include a section related to indigenous persons with disabilities. Conditional cash transfer programmes were mentioned as a model targeting indigenous persons with disabilities to be evaluated.

Another document considered relevant by the experts for a framework on indigenous persons with disabilities was the ***draft protocol on persons with disabilities, by the*** *African Commission on Human and Peoples’ rights*, released in February 2016.

Opportunities:

In order to obtain more data and information about indigenous persons with disabilities, experts suggested the following:

* Include case studies covering community-based approaches and indigenous persons with disabilities in Latin America in a regional study to be undertaken by the Pan-American Health Organization on the social determinant and health in 14 countries in Latin America.
* Include specific questions on the promotion and protection of the rights of indigenous persons with disabilities in the annual questionnaire of the EMRIP, which seeks the views of States and indigenous peoples regarding measures and implementation strategies to achieve the goals set out in the UNDRIP.
* Review and draft a paper on indigenous persons with disabilities for the Ruggie principles on business and human rights[[3]](#footnote-3).
* Ensure that UNDP’s independent evaluation office, which initiated a global thematic evaluation on UNDP's contribution to disability-inclusive development, also covers indigenous persons with disabilities.

Lessons at national level:

In **Australia**, the government expressed support for the UNDRIP (after its initial rejection in 2007); however, this seems to have hardly had any influence on domestic policy. As a way of example, only one indigenous woman has been elected in Parliament in over a 100 years.

In **Norway**, on the other hand, the entry into force of the CRPD and the ILO Convention 169 seem to have contributed to strengthen the indigenous perspective.

*At the grass-roots level, when we go to communities and talk with indigenous persons with disabilities, we realize that they do not know the CRPD, UNDRIP or WCIP. They are not even aware of having human rights.”* –**Pratima Gurung (Nepal)**

Similarly, in **Sweden**, a recommendation from the Committee on the rights of persons with disabilities to collect data on the situation of the Sami people prompted the Swedish government to allocate resources and to conduct a study at municipal level to assess whether services are provided in a culturally-sensitive manner, including disability-specific services. The results of the study were used to advocate for more action by the State.

Issues for further elaboration:

Evidence in several countries indicates that **indigenous persons with psychosocial disabilities** face high rates of incarceration, as a psychosocial disability among indigenous peoples is highly criminalized.

Experts indicated that the **definition of self-determination** should be a addressed in a general comment on indigenous persons with disabilities. States need to be assured that self-determination in the context of disability does not have the same political connotation that it has in the indigenous context, but rather refers to the ability to make their own decisions as individuals, on disability-related services and all aspects of their lives.

In relation to **social protection** and paternalism, it is important to move away from approaches that view persons with disabilities as mere recipients of care and assistance in social protection schemes. This challenge doubles when it comes to indigenous persons with disabilities.

**Session IX**

**Increasing the focus on indigenous persons with disabilities in all relevant processes, including the 2030 Agenda**

**Summary:** Participants discuss entry points and actions that could mutually reinforce the advocacy work of indigenous peoples and persons with disabilities. They agreed on the need for increased attention to the situation of indigenous persons with disabilities by the different disability and indigenous-specific United Nations mechanisms (UNPFII, EMRIP, CRPD Committee, the two Special Rapporteurs), as well as by the mainstream mechanisms and treaty bodies, including the Special Procedures of the Human Rights Council and the Universal Periodic Review, and in other processes such as the 2030 Agenda.

Learning from the experience of the Millennium Development Goals, where indigenous and disability communities have been excluded from the MDGs due to the lack of direct participation, the situation has been reversed with the SDGs. In fact, persons with disability are mentioned at least six times in the preamble and in some of the goals of the 2030 Agenda for Sustainable Development. Several indicators require States to disaggregate data by disability, although there are no disability-specific indicators. The 2030 Agenda mentions indigenous peoples at least four times, and has a specific indicator on land related with goal two.The indigenous community has been involved in the area of science, technology and innovation to implement the SDG. In the first Forum on science, technology and innovation in June 2016, discussions included the issue of traditional knowledge as a way to contribute to the implementation of the SDGs.

Suggested next steps:

Experts expressed the need for representative organizations of indigenous persons with disabilities to **participate as members of the UNPFII, and at the EMRIP**. Using the framework of improving health outcomes, the UNPFII could ensure the rights of indigenous persons with disabilities in upcoming agendas.

As 2017 marks the 10th anniversary of the adoption of the Declaration and the UN Permanent Forum will discuss the agenda for the next ten years, experts suggested presenting a **review of the situation of indigenous person with disability to date**, which could be commissioned by EMRIP.

**Organizations of indigenous persons with disabilities and the Global Network of indigenous persons with disabilities must be strengthened** with the support from States, donor and international cooperation partners. They should also be encouraged to prepare **shadow reports on countries under review by the CRPD Committee**, a practice that the disability community has conducted quite successfully.

*“We need to learn from our experience with the MDGs, and the missed opportunity that was for us. Our lack of direct and effective participation meant for us to be unaccounted for in their implementation.”****--Catalina Devandas Aguilar***

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Advocate that during countries reviews in the context of the **Universal Periodic Review**, States ask questions about measures taken to improve the human rights situation of indigenous persons with disabilities.

Advocate with States to ensure that **National Development Plans include indigenous persons with disabilities,** and that they measure and disaggregate data on indigenous peoples and disability at the national and sub national levels, with the participation of civil society.

*“If we’re absent from the dialogue, we will be left out in the outcomes, and our interests will remain neglected”—****Victoria Tauli-Corpuz***

**Envisage a System-Wide Action Plan that is inclusive of persons with disabilities and indigenous peoples**, to enhance the coordination between UN agencies and with field offices on disability and to ensure it is mainstreamed in all programmes. This is particularly important in the context of the implementation of the SDGs, and the role the UN system in it.

**Session X**

**Exchange with Permanent Missions: enhancing attention on the rights of indigenous persons with disabilities.**

***Ambassador of Australia, H.E. Mr. John Quinn:*** “In the UN system, too often we don't connect the pieces of the puzzle, so it is a very good idea to join these dots (Indigeneity and disability). We can't afford not to be taking advantage of synergies. The timing for this meeting is excellent for a number of reasons: the special session on this topic at the Human Rights Council, the SDGs, and the recent adoption of a new Charter on persons with disabilities during the World Humanitarian Summit in Istanbul.

“Australia has focused on a strategy for mainstreaming indigenous people and disability issues. Our National Disability Strategy includes an important insurance scheme and specific programs for indigenous peoples. However, indigenous people are not sufficiently taking advantage of these programmes, so we have to increase our mainstreaming efforts. Our domestic data suggests that indigenous peoples are almost twice as likely to become disabled, and face specific barriers to access to services. But we need to strengthen our monitoring and evaluation system, to know whether we're making progress.

“Internationally, we have supported the participation of indigenous peoples and persons with disabilities in various UN processes. We support a bottom-up approach in terms of advocacy, for which we need to see more human rights institutions in these discussions, as their role is essential in terms of follow up to treaty body work.”

***Representative of the Permanent Mission of Mexico, Mr. Raúl Vargas Juárez:***

Mexico faces enormous challenges in relation to access to justice for indigenous peoples. Those were illustrated by the case of Valentina, a young indigenous woman victim of sexual violence seeking justice and reparations, in a legal and institutional system that was not prepared to provide her guarantees. The case, which went to the Inter-American Court for Human Rights, shows remaining challenges that Mexico and the whole region still face in relation to access to justice for indigenous peoples.

Mexico believes that the 2030 agenda is an excellent opportunity to advance on many of these issues. This agenda is indivisible and should be achieved across the board in its 169 targets, some of which touch on these issues.

This is a very important year at the Human Rights Council with regard to indigenous people’s rights, as we have the opportunity to review the mandate of the EMRIP. Together with Guatemala, we will try to provide the EMRIP with the necessary tools to carry out its work as best as possible and to empower the Special Rapporteur on the rights of indigenous peoples to enhance cooperation.

Finally, in October 2016, the Social Forum of the Human Rights Council will address the issue of persons with disabilities. We should use that opportunity to cover relevant matters for both groups, as representatives of indigenous peoples’ and persons with disabilities will be present in the room. The Mexican mission is open to the possibility of holding an open dialogue with all partners involved in this process.”

***Deputy Permanent Representative and Chargé d’affaires a.i. of New Zealand, Mr. Carl Allan Reaich:***

“The promotion and protection of indigenous peoples and disability rights are two of New Zealand’s fundamental human rights priorities, through four interrelated elements: 1) Public engagement: The New Zealand Office for Disability Issues leads our public engagement process to inform and revise the New Zealand Disability Strategy. In the 1st phase, we have been holding focus group discussions with Maori persons with disabilities. 2) Active consultations: New Zealand has a Maori Disability Action Plan for 2012-2017 that aims to ensure the access of Maori indigenous peoples of New Zealand to disability-related services. which was developed with the involvement of disabled Maori--the and their families, among other key stakeholders such as the Disability Leadership Group. 3) Policy development: quantitative and qualitative data obtained through the previous processes and the participation of beneficiaries ensures that the policy design responds to their needs. 4) Ensuring coherence: New Zealand tries to ensure that its domestic agencies are joining the dots between the Statistical Office, the Maori Health Strategy, the Office for Disability Issues, and all other Ministries.

Concerning the UN, we need to ensure coherence and coordination, as well as the participation of all UN agencies – including the World Trade Organization - in relation to the Sustainable Development Goals. There are many aspects where trade might make a contribution, and the indigenous and disability rights agendas can definitely impact positively in the trading regulations.

Finally, the Maori Disability Action Plan, which frames interactions with tribal groups, with persons with disabilities and their families could be a useful experience to inform this reflection going forward.”

***Representative of the Permanent Mission of Ecuador, Mr. Juan Pablo Cadena:***

“Vulnerabilities must be acknowledged, whether it is in accessing justice, health, education, or by their systemic inclusion in society; and it doesn't necessarily need to be perceived as something negative. They are important when it comes to designing policies targeted to those groups, which need to take into account that concepts of development differ among minority ethnic groups.

Statistics are also fundamental. Ecuador has made interesting efforts in this regard. The rights of indigenous peoples and of persons with disabilities are priorities for us. A few years ago, Ecuador launched the Manuel Espejo solidarity programme, which included a study to identify and register all persons with disabilities at the national scale. By 2014, we identified 410,000 people with disabilities in Ecuador, disaggregated by type of impairment and ethnic origin.

When we submitted our national report to the Committee of the CRPD in 2014 the Committee recommended that we improve the way we disaggregated data. Since then, Ecuador has launched different programmes, for example to follow-up on pregnancies and other programmes to prevent disability in the newborns. We have also increased assistance to families so that they can care for their relatives with disabilities at home, so that indigenous peoples can continue to live in their communities.

Ecuador is committed to supporting international actions as well as national plans and policies to improve the lives of indigenous peoples and persons with disabilities living in our country.”

**Annex | List of Experts**

Ms. Catalina DEVANDAS AGUILAR, Special Rapporteur on the rights of persons with disabilities (Costa Rica)

Ms. Victoria TAULI CORPUZ, Special Rapporteur on the rights of indigenous peoples (Philippines)

Mr. Scott AVERY, Policy and research Director, First Peoples Disability (Australia)

Mr. Danlami BASHARU, UN Expert, Committee on the rights of persons with disabilities (Nigeria)

Mr. Albert BARUME, UN Expert, Expert Mechanism on the Rights of Indigenous Peoples (EMRIP) (Kenya)

Mr. Ulises CARDENAS, Representative, Indigenous community Atacameña de Chunchuri (Chile)

Ms. Mirna CUNNINGHAM, President, Association for Women's Rights in Development and indigenous rights activist (Nicaragua)

Ms. Anna DAHLBERG, Project Manager Sami people with disabilities, Nordic Centre for Welfare and Social Issues (Sweden)

Mr. Binota Moy DHAMAI, Representative, Asia Indigenous Peoples Pact (Bangladesh)

Ms. Doreen DEMAS, Chair, Indigenous Persons with Disabilities Global Network (Canada)

Mr. John GILROY, Lecturer, Faculty of Health Science, University of Sydney (Koori from the Yuin Nation, Australia)

Ms. Pratima GURUNG, Nepal Indigenous Disabled Association and member of the Indigenous Persons with Disabilities Global Network (Nepal)

Mr. Wilton LITTLECHILD, Independent Expert, Expert Mechanism on the Rights of Indigenous Peoples (EMRIP) (Canada)

Ms. Hannah MGGLADE, Senior Indigenous Fellow (OHCHR) (Australia)

Mr. Setareki MACANAWAI, Chief Executive Officer, Pacific Disability Forum and member of the Indigenous Persons with Disabilities Global Network (Fiji)

Ms. Olga MONTÚFAR CONTRERAS, Representative, Paso a Paso Foundation for indigenous persons with disabilities (Mexico)

Mr. Martin OELZ, Senior Specialist on Equality and Non-Discrimination, ILO (Austria)

Ms. Karen SOLDATIC, Faculty Member, Institute for Culture and Society, Western Sydney University (Australia)

Mr. Piera Jovnna SOMBY, Sami person with disability (Norway)

Mr. Stefan TROMEL, Senior Disability Specialist, ILO (Spain)

Mr. Alexey TSYKAREV, Chair, Expert Mechanism on the Rights of Indigenous Peoples (EMRIP) (Russian Federation)

**Agenda**

**Thursday 7 July 2016**

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| **Time** | **Session** | **Moderator** |
| 09.00-09.40 | **Opening and welcome remarks**   * Ambassador of Finland, H.E. Ms. Päivi Kairamo * UN Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas Aguilar * UN Special Rapporteur on the Rights of Indigenous Peoples, Ms. Victoria Tauli Carpuz * International Labour Organisation * Indigenous Persons with Disabilities Global Network |  |
| 10.00-10.30 | **Setting the scene: what has been done so far to include indigenous persons with disabilities?**   * CRPD Committee * EMRIP * UNPFII * Indigenous Persons with Disabilities Global Network | Victoria Tauli Corpuz, Special Rapporteur |
| 11.00-12.30 | **Framing the discussion: how is the intersectionality between ethnicity and disability considered in the UN international human rights framework?**   * Presentation of the background document (P. Gurung and S. Macanawai) * Mapping of gaps and potential areas of conflict * General discussion | Stefan Tromel, Senior Disability Expert, ILO |
| 14.00-14.45 | **Inclusion vs. assimilation** | Alexey Tsykarev, Chair EMRIP |
| 14.45-15.30 | **Individual rights vs. collective rights**  **Identity and self-identification** | Alexey Tsykarev, Chair EMRIP |
| 16:00-17:15 | **Social perceptions of disability within indigenous communities**  **Challenges faced by indigenous women and girls with disabilities** | Martin Oelz, Equality and Non-Discrimination Specialist, ILO |

**Friday 8 July 2016**

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| **Time** | **Session** | **Moderator** |
| 09.00-10.30 | **Moving forward: Interpreting the CRPD from an indigenous perspective** | Danlami Basharu, Expert, CRPD Committee |
| 11.00-12.30 | **Moving forward: Interpreting the UNDRIP from a disability perspective** | Albert Barume, Member, EMRIP |
| 14.00-15.30 | **Increasing the focus on indigenous persons with disabilities in all relevant processes, including the 2030 Agenda**   * Disaggregated indicators and statistics * UN human rights machinery: Treaty bodies, Special Procedures, Universal Periodic Review * The work of the United Nations | Mirna Cunningham, Association for Women's Rights in Development |
| 16:00-17:15 | **Exchange with Permanent Missions on how to enhance attention on the rights of indigenous persons with disabilities within the UN human rights machinery**   * Exchange with representatives of selected PM | Victoria Tauli Carpuz  Catalina Devandas |
| 17:15-17:30 | **Closing remarks**   * Ambassador of Australia, H.E. Mr. John Quinn * Special Rapporteur on the Rights of Indigenous Peoples * Special Rapporteur on the Rights of Persons with Disabilities |  |

1. For a complete list of participants, please see the Annex. [↑](#footnote-ref-1)
2. CRPD, Article 1. [↑](#footnote-ref-2)
3. See Publication *Guiding Principles on Business and Human Rights*: <http://www.ohchr.org/Documents/Publications/GuidingPrinciplesBusinessHR_EN.pdf> [↑](#footnote-ref-3)