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Human Rights

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 development²

Pursuant to a decision of the Permanent Forum on Indigenous Issues at its eleventh session (see E/2012/43, para 103), Mirna Cunningham and Paul Kanyinke Sena³, members of the Forum, conducted study on the situation of indigenous persons with disabilities, with a particular focus on challenges faced

¹ E/C.19/2012/1

² The Department of Economic and Social Affairs bears no responsibility for the views and recommendations in this report.

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with respect to the full enjoyment of human rights and inclusion in development,
which is hereby submitted to the Forum at its twelfth session.

Summary

This report takes a first look at the situation of indigenous persons with disabilities in the enjoyment of their human rights. It looks at the main relevant legal standards, namely the U.N. Convention on the Rights of Persons with Disabilities and the U.N. Declaration on the Rights of Indigenous Peoples, and how these interact to protect relevant rights. It examines some areas in which, according to indigenous persons with disabilities, there is discrimination in the enjoyment of rights, for example, political participation, access to justice, education, language and culture, and issues specific to indigenous women and children with disabilities. The report concludes that more attention is needed to the rights of indigenous persons with disabilities. It makes recommendations to United Nations agencies and other relevant stakeholders on important ways to increase real inclusion and participation of indigenous persons with disabilities, as well as supporting the establishment and developing the capacity of organizations of indigenous persons with disabilities, and by allocating resources for building the capacity of indigenous peoples to address the needs of indigenous persons with disabilities in their communities. It recommends that the upcoming 2013 High Level Meeting on Disability and Development and 2014 World Conference on Indigenous Peoples each be maximized to examine the realities of indigenous persons with disabilities and how they can benefit from the post-MDG framework.

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I. Introduction

1. This report was prepared in consultation with indigenous persons with disabilities. In particular, an expert meeting was held in Madrid on November 20 - 21, which brought together indigenous persons with disabilities from different regions, as well as other experts, including from the United Nations, working in the areas of indigenous peoples and persons with disabilities.

2. The 2011 World Report on Disability produced by the World Health Organization and the World Bank estimates that 15% of the world population has a disability, of whom 3% have a severe disability. Applying this percentage to the estimated 360 million indigenous persons, the number of indigenous persons with disabilities is approximately 54 million persons.

3. The lack of reliable data is a problem both for indigenous peoples and for persons with disabilities as very few countries have statistics on indigenous persons with disabilities. Data from Latin America and Australia provide a diverse picture, ranging from countries in which the prevalence of disability among indigenous persons with disabilities is lower than in the general population and statistics which show a much higher prevalence.

4. In Latin America, available statistics for seven countries (Brazil, Colombia, Costa Rica, Ecuador, Mexico, Panama, and Uruguay) show that there

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is a higher rate of disability among indigenous persons as compared to the rest of the population, although for Brazil and Colombia, the rate is lower among indigenous children. For ages 19 and older there are more indigenous persons with disabilities than non-indigenous for all seven countries, with more sizeable gaps in Costa Rica and Uruguay.

5. In Australia, about 50% of indigenous adults reported a disability in 2008,⁴ as compared to a national figure of 18.5% (2009)⁵. In New Zealand, statistics were published in 2006 on disability and Maori. The 2006 Disability Survey found, after adjusting for the different age structures of the two populations, that the age-standardized disability rate for Maori was 19% and 13% for non-Maori. More Maori persons with disabilities are living in poverty or have no educational achievements, as compared to non-Maori persons with disabilities.⁶

6. In Canada, some statistics have been provided on Aboriginal persons with disabilities by state and by indigenous peoples. In 2000, the observer for Canada informed the Working Group on Indigenous Populations that Aboriginal children were three times more likely than non-indigenous children to have physical

⁴ Australian Bureau of Statistics (2010) **The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples, Oct 2010**. Canberra: Australian Bureau of Statistics, cited at <http://www.healthinfonet.ecu.edu.au/health-facts/overviews/disability>.

⁵ Results of Survey of Disability, Ageing and Carers (SDAC) 2009.

⁶ Office for Disability Issues and Statistics New Zealand (2010). *Disability and Māori in New Zealand in 2006: Results from the New Zealand Disability Survey*. Wellington: Statistics New Zealand.

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disabilities.⁷ A First Nations Regional Longitudinal Health Survey (RHS) 2002/3 provides some information about prevalence, employment, education, income, health status, and recommendations.⁸ This survey showed that about 22.9% of persons 18 and over (On-reserve) have disabilities.

7. A number of reasons seem to indicate that the prevalence of disability among indigenous peoples would be higher than in the general population including higher levels of poverty, increased exposure to environmental degradation, impact of large projects such as dams or mining projects and higher risk of being victims of violence. The 2009 State of the World's Indigenous Peoples Report mentions in particular mental health issues and the prevalence of diabetes among indigenous persons.⁹

8. While data on the prevalence of disability among indigenous peoples is important, it is even more important to have information on their actual well-being and their inclusion. Therefore, the situation of indigenous persons with disabilities must be taken into account in the efforts to develop new statistical tools that will reflect the situation of indigenous peoples in a culturally-sensitive way, as outlined in the 2009 State of the World's Indigenous Peoples.

⁷ Human rights of indigenous peoples, Report of the Working Group on Indigenous Populations on its eighteenth session, E/CN.4/Sub.2/2000/24 at para 34.

⁸ First Nations Information Governance Committee. First Nations Regional Longitudinal Health Survey 2002-03; Results for Adults, Youth and Children Living in First Nations Communities. Assembly of First Nations (November 2005).

⁹ UN DESA, State of the World's Indigenous Peoples (ST/ESA/328) 2009 at 163 and 169-172.

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The legal framework

9. Two international instruments provide the main legal but also conceptual and political framework on how the rights of indigenous persons with disabilities are to be protected and promoted. Two articles (21 and 22) of the United Declaration on the Rights of Indigenous Peoples (UNDRIP) include a specific reference to persons with disabilities. The Convention on the Rights of Persons with Disabilities (CRPD), which entered into force in 2008 and has now been adopted by 126 Parties, includes a sole reference to indigenous peoples in its preamble.

10. The CRPD, as other human rights treaties, takes a primary focus on individual rights, but has also a number of provisions of a more collective nature. The approach of the UNDRIP is primarily collective, but also includes references that provide individual rights. Both instruments have in common their comprehensive nature and while both would have benefitted from some more explicit references to indigenous persons with disabilities, read together, they provide useful guidance to States, indigenous peoples, and other stakeholders.

11. The CRPD gives detailed guidance on how States are to promote and protect the rights of persons with disabilities and this clearly includes indigenous persons with disabilities. Implementing the CRPD in a way that respects also the UNDRIP means that, whenever relevant, the measures that are foreseen in the CRPD will need to be applied in a way that is sensitive to the culture and world

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vision of indigenous peoples in order to best protect the rights of indigenous persons with disabilities.

12. While the legislation and policies designed for persons with disabilities often have as an objective to ensure their full inclusion in mainstream society, indigenous peoples tend to be wary of any form of mainstreaming that may lead to assimilation, threatening their languages, ways of life and identities. For indigenous persons with disabilities, whether living in their communities, and/or in urban settings, where indigenous institutions may be located, this “tension” should result in ensuring that indigenous persons with disabilities are supported to fully take part in the life of their communities.

13. Another important instrument is the ILO Convention concerning Indigenous and Tribal peoples in Independent Countries (ILO Convention 169)¹⁰, recognizing the need to remove the assimilationist orientation of earlier standards¹¹ and other important developments such as the rights to culture and land. Implementing Convention 169 includes consultations, respect for customs and also agreement with international human rights law.¹²

¹⁰ Adopted by the International Labour Conference on 26 June 1989, entered into force 5 September 1991.

¹¹ Preambular para. 4, ILO Convention 169.

¹² See ILO, Research on Best Practices for the Implementation of the Principles of ILO Convention No. 169, Case Study 7, Key Principles in Implementing ILO Convention No. 169, authored by John Henriksen (2008), at 19 and 56-57.

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14. There seems to be little awareness among indigenous persons with disabilities of the UNDRIP and the CRPD. While the UNDRIP is available in a number of indigenous languages, translations of the CRPD into indigenous languages are lacking. Translation and dissemination as well as a process of appropriation by indigenous peoples of the CRPD is needed.

(The purposeful absence of) Prevention of disability in the CRPD

15. The negotiators of the CRPD purposely did not include the issue of prevention of disability except in the right to health, where the text mentions prevention of secondary disability for persons who already have a disability. This is because the Convention deals with *persons with disabilities* – in other words, persons who already have disabilities. Following from this, legislation and policies targeting the rights of persons with disabilities should avoid addressing the issue of prevention of disability. In addition, discussions around prevention often perpetuate negative, discriminatory and harmful stereotypes about disability. However, the greater chances in some indigenous communities of acquiring a disability (including those more closely linked with poverty, environmental contamination or working conditions), can be discussed under the auspices of other relevant frameworks and not when discussing the rights of persons with disabilities (and keeping in mind the need to avoid harmful stereotypes about disability). If there are disproportionately more persons with disabilities among indigenous peoples, as compared to others, this could be relevant in evaluating whether and how well any necessary services and supports

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for persons with disabilities are provided by relevant parties. For these reasons, and using the CRPD as a reference, prevention is not included in this report, which focuses on *indigenous persons with disabilities*.

II. Attention by the UN to indigenous persons with disabilities

16. Indigenous persons with disabilities have been largely invisible in the work of the different UN entities that address the rights and situation of indigenous peoples and persons with disabilities. The 2011 World Report on Disability includes very little information on indigenous persons with disabilities¹³, and the State of the World's Indigenous Peoples only reports that indigenous persons are more likely to have a disability¹⁴, including mental health issues leading to higher suicide rates. The Expert Mechanism on the rights of indigenous persons and the UN Special Rapporteur on the Rights of Indigenous Peoples have so far not addressed the specific situation of indigenous persons with disabilities.

17. Ten of the twenty-seven States that have submitted their first periodic reports to the CRPD Committee so far have mentioned indigenous peoples - Argentina, Australia, Cook Islands, Costa Rica, Denmark, Kenya, Mexico, New Zealand, Paraguay, and Peru. Some references to indigenous peoples are incidental and general (and not very meaningful) while others are more specific

¹³ See page 104.

¹⁴ See page 161.

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about the actual situation of indigenous persons with disabilities. Indigenous persons with disabilities are mentioned in the CRPD Committee's concluding observations for two countries reviewed so far¹⁵: Argentina and Peru. Both focused mainly on statistics and education. Argentina was also asked to adopt specific policies and programs for indigenous persons with disabilities under article 5 CRPD (equality and non discrimination).

III. Perceptions of disability among indigenous peoples

18. Persons with disabilities are faced with a number of attitudinal barriers in most societies, including stigma, fear, prejudice, low expectations, paternalism, or failure to be informed. The CRPD seeks to tackle these attitudinal barriers through various provisions. A key guiding principle of the CRPD is in its article 3, stating that disability is part of human diversity, no different from other features that distinguish one person from another.

19. In some indigenous languages, there is no translation of the term "persons with disabilities" and sometimes there are terms which are pejorative or covering only certain types of disability. In pre-colonial Maori culture, persons with disabilities may have been well supported and valued but this may have been withdrawn in harder times or if sickness or impairment was believed to be due to an infringement of *tapu* (sacred rules), *atua* affliction (from a supernatural being

¹⁵ Tunisia, Spain, China, Peru, Argentina, and Hungary. Sessions of the CRPD Committee can be found at: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Sessions.aspx>.

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or ancestor), or *makutu* (spiritual powers, witchcraft or magic).¹⁶ There are also indigenous languages that have used very positive terms for persons with certain disabilities, often linked to the fact that they were seen as having special gifts (for instance from the Creator), each person having a special role in their community, and where impairment is seen as difference rather than a “deficiency”.¹⁷

20. It also seems to be the case that, in a number of indigenous societies that used to have a more respectful attitude to persons with disabilities, the impact of colonialism and the Western model of development may have led to a more negative attitude. This shift has often also been increased by the application of the (now outmoded) medical model of disability, which has focused on “correcting” the individual instead of taking a more holistic approach, as would also better reflect the earlier culture of indigenous peoples. In some places, the perception of what was once seen as a gift, source of wisdom or as a welcome contact with the spirits or the spiritual or philosophical life has changed because of the rupture of social systems resulting from a western model of development. Strengthening of indigenous institutions is extremely important to regain or build this inclusion. Just as disability is an evolving concept, indigenous cultures and

¹⁶ See Office for Disability Issues and Statistics New Zealand (2010). *Disability and Māori in New Zealand in 2006: Results from the New Zealand Disability Survey*. Wellington: Statistics New Zealand. At 9.

¹⁷ Canada Human Resources and Skills Canada, Aboriginal Affairs Directorate. *Where the River Flows: Aboriginal People with Disability, A Literature Review: Focus on Employment* (October 2006) at 31-32.

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world views are also not static, and can affect persons with disabilities in positive or negative ways.

IV. Key issues for indigenous persons with disabilities

A. Self Determination

21. The right of indigenous peoples to self-determination needs to be at the heart of any policy that seeks to promote and protect the rights of indigenous persons with disabilities. Indigenous persons with disabilities have the same right to benefit from self-determination as other members of indigenous peoples, and this collective right must be taken into consideration in elaborating all policies and designing and delivering needed services. The right of indigenous peoples to determine their political / organizational systems should include and respect its members with disabilities, and should be exercised with the active participation of indigenous persons with disabilities. An increased understanding and concern for broader self-determination and jurisdictional issues is needed in this regard.¹⁸

22. The CRPD seeks to provide to persons with disabilities the same rights as their peers who do not have disabilities living in their same State Party. This same notion shall also apply to indigenous peoples. Indigenous persons with disabilities should benefit from the same rights and opportunities as other indigenous persons from their same community.

¹⁸ Evidence given by Wendall Nicholas [member of the Maliseet Nation at Tobique], 37th Parliament, 1st session, Sub-Committee on the Status of Persons with Disabilities of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities, 19 March 2002.

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B. Participation in decision-making and consultation

23. The right to participate in decision-making processes is protected in both instruments. Both contain articles on participating in decisions affecting their lives¹⁹, the right to participate in political and public life²⁰, and article 20 of UNDRIP states the right of indigenous peoples “to maintain and develop their political, economic and social systems or institutions”.

24. For indigenous persons with disabilities living outside of their communities, it is important that general organizations of persons with disabilities include them as members, learn how to make their demands in a culturally-appropriate way, and exchange knowledge and experience.

25. There is little evidence on the participation of indigenous persons with disabilities in consultation processes in place in their communities or national States. The formation of organizations of persons with disabilities can be an important factor or step to facilitate consultation and meaningful participation in decision-making, as has been done in Australia (the First Peoples Disability Network), or the Miskitu divers with disabilities who have formed organizations (in Nicaragua/Honduras). Additional support for and consultations with such organizations are needed.

¹⁹ Art. 4 (3) and 29 CRPD, and arts. 18-19 UNDRIP. See also art. 33 (3) CRPD.

²⁰ See, e.g., art. 29 CRPD, preambular para 7, and, arts. 5 (referring to a dual approach of own institutions, and state institutions) and 11 UNDRIP.

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26. The level of inclusion of indigenous persons with disabilities in indigenous institutions has not yet been sufficiently examined and most available evidence is anecdotal. Some indigenous persons with disabilities do not participate in decision-making processes or community planning, because of mobility limitations or because meetings are conducted in inaccessible places, depriving them of their right to political participation. Furthermore often indigenous persons with disabilities are largely ignored and also lack the very basic means needed to participate. A recent study, for example, found that none of the Navajo Nation's public buildings is fully accessible to the estimated 40,000 persons with disabilities living on the Navajo Nation reservation.²¹

27. The Miskitu people have two parliaments in the two autonomous regions (Región Autónoma del Atlántico Norte (RAAN) (capital Puerto Cabezas) and Región Autónoma del Atlántico Sur (RAAS, capital in Bluefields), but these lack members of parliament with disabilities. The deputy mayor of RAAN's regional capital is a woman with a disability.

28. It is the responsibility of States at all levels and indigenous peoples, to ensure that indigenous persons with disabilities are not discriminated against because of their disability, and the right to participation in decision-making and consultations are fundamental to achieving this.

²¹ DAILY TIMES [Farmington], Report: Navajo Nation Fails to Provide Disability Access, 28 Dec. 2011,

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Political advocacy for inclusive development in the Brunca region in Costa**Rica**

Within the framework of the Policy on Human Rights and Equal Opportunities for Persons with Disabilities of the Legislative Assembly of Costa Rica, a project is being undertaken which focused on access to inclusive development for disadvantaged groups such as indigenous persons with disabilities, who number 14,000. Since 2007, work has been done to train indigenous leaders and representatives of organizations of persons with disabilities and public institutions for self training in advocacy and social auditing on the rights of persons with disabilities.

C. Discrimination (double/multiple discrimination)

29. Indigenous peoples face regular and systematic discrimination in many aspects of life and discrimination experienced by persons with disabilities is very similar to this and takes diverse forms, including direct and indirect discrimination. This is why combatting discrimination on the ground of disability is one of the main objectives and central elements of the CRPD, similar to UNDRIP's non-discrimination provisions and rationale.

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30. For indigenous persons with disabilities, a major issue is discrimination in the availability and quality of services as compared to other persons with disabilities, as well as discrimination in their societies (being seen “lower” than others), and lack of prioritization of their needs, unique capabilities and potential contributions to the development of their communities. Indigenous persons with disabilities may also experience the combined effect of discrimination against different aspects of their identities. For example, an indigenous child may be unable to attend school if its facilities are not accessible and also if instruction is not available in his or her indigenous language.

D. Access to justice

31. Similar to the mistrust that indigenous peoples often have towards the formal justice system, the experience of persons with disabilities is also often negative, due to a justice system that has been designed without consideration of their needs. Indigenous peoples who have their own traditional justice systems will need to ensure their accessibility to indigenous persons with disabilities. This would include, for instance, ensuring that deaf indigenous persons can communicate in sign language, that the premises are accessible and that information is available in alternative formats.

32. There is a common experience of indigenous women and of women with disabilities that victims of rape are faced with indifference and inaction, often leading to non-reporting of these cases, or, in some instances, to forced marriage.

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There is a common experience of far-reaching impunity faced by indigenous peoples and persons with disabilities which puts them especially in risk of experiencing situations of violence. Furthermore, the general justice system needs to be accessible to persons with disabilities and also sensitive to indigenous persons with disabilities. Disability awareness training, with rights based and intercultural approaches, for staff in charge of the administration of justice needs to be provided.

33. Indigenous peoples and persons with disabilities (in particular, persons with intellectual and psychosocial disabilities) are usually overrepresented in correctional institutions and other types of detention centers, a situation that can be linked to the inaccessibility of the justice. More research would be required on the specific situation of indigenous persons with disabilities in this specific context.

E. Education, language and culture

34. The CRPD (art. 24) sets forth extensive obligations on education of persons with disabilities while the UNDRIP contains a range of relevant articles²² and sets forth a dual approach mentioning the right of indigenous peoples to establish and have their own educational systems and institutions and in culturally appropriate methods, and also provides that “indigenous individuals,

²² See position paper of International Disability Alliance on education (July 2011) (available at <http://www.internationaldisabilityalliance.org/sites/disalliance.e-presentaciones.net/files/public/files/IDA-Position-Paper-The-right-to-education-14-June-11.doc>), and see EMRIP study on education.

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particularly children, have the right to all levels and forms of education of the State without discrimination”. In addition to the same challenges that indigenous children face in accessing appropriate education in their communities, indigenous children with disabilities face additional barriers.

35. Specifically, there is a lack of prioritization of education of children with disabilities by their parents, resulting from the lack of awareness and support provided by States. This was identified as the single most important issue facing indigenous children with disabilities in the Philippines. Although there is a lack of empirical data, anecdotal evidence suggests that a disproportionately high number of indigenous children with disabilities may be out of school altogether. In New Zealand, in 2006 42% of Maori persons with disabilities had no educational qualifications, compared to 34% of non-Maori persons with disabilities.²³ It may also be the case that when indigenous children with disabilities are able to access education, special education is the main option.

36. The CRPD clearly establishes that all children with disabilities have the right to be part of the general education system, which requires that children with disabilities be provided with the necessary reasonable accommodations. For indigenous children with disabilities who live in their communities, this will require that the indigenous education system provides indigenous children with disabilities with the required support.

²³ Office for Disability Issues and Statistics New Zealand (2010). *Disability and Māori in New Zealand in 2006: Results from the New Zealand Disability Survey*. Wellington: Statistics New Zealand. At 31 and Appendix Table 39.

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Sign languages

Sign languages are languages in their own right and in some countries have been recognized in the national constitution or other legislation as one of the official national languages. Sign languages and linguistic rights are protected in the CRPD. Signed language has been documented at least among North American, South American and Australian indigenous peoples.²⁴ Signed language was used in varying degrees as an independent communication within most of language families indigenous to North America. There is a difference between signed language used as alternative communication by hearing persons, and that used by deaf people as a first language in deaf communities and which are separate languages unto themselves. In some places both the deaf and hearing members of indigenous peoples have used signed language. For some deaf persons around the world today, the primary means of communication are home signs, which have been described as signs developed when deaf persons are isolated from other deaf persons and need to communicate with hearing people around them. Home signs are the primary means of communication of deaf indigenous peoples in Australia. There is lack of consultation with indigenous deaf persons there on their language preferences. Several North American indigenous peoples

²⁴ e.g., the Chican traditional Yucatec Maya people in Yucatan, Mexico, Providence Island east of Nicaragua, the K'iche' and Kaqchikel of Guatemala, and the Urubu in Maranhao, Brazil. Jeffrey Davis, "Evidence of a historical signed lingua franca among North American Indians", *Deaf Worlds* 21(3): 47-72 (2005).

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incorporate traditional signed language into their language and education programs. Contact with a larger sign language or the spreading out of the deaf community can lead to endangerment or loss of traditional sign language. Sign languages are also usually not included in the work on endangered languages.

F. Access to health

37. Disability has often been incorrectly seen as mainly a health issue. The right to health is one of the many rights mentioned in the CRPD, but it is not more relevant than the right to education, participation in public and political life, or employment, to cite just a few. Nevertheless, the World Report on Disability highlights that persons with disabilities face serious challenges in accessing health services, leading to decreased life expectancy. This includes both disability-related health issues as well as health issues not related to the disability. The State of the World's Indigenous Peoples Report highlights the fact that indigenous peoples have lower level of access to health and greater unmet needs than the general population and subsequently their health outcomes and life expectancies are poorer.

38. In the design of intercultural health systems, it will be important to ensure that full (physical and communicational) accessibility to persons with disabilities is part of the design, which would be consistent with the prerequisite that these systems respect human rights as codified in international human rights instruments and international law. Furthermore, the right to self-determination with respect to health implies creating conditions for the full and effective participation of indigenous peoples in the design and management of health systems and this will require adequate attention to the situation of indigenous persons with disabilities. The commitment to building the human resources

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necessary for the participation of indigenous peoples in health policy and management, as well as training non-indigenous health professionals in the cultures and languages of indigenous peoples should also include disability awareness training, including the issue of how to obtain prior and informed consent to any health intervention. The right to health must be linked not only to the recognition of cultural, ethnic and linguistic diversity of indigenous peoples but also to their right to live in healthy habitats and land rights.

39. The CRPD includes a separate article 26 on habilitation and rehabilitation, which, while including health-related rehabilitation, goes well beyond health services. The article which stresses that (re)habilitation is voluntary, indicates that (re)habilitation should be provided at the community level, a concept that is known in the disability community as Community Based Rehabilitation (CBR). In the specific context of indigenous peoples, article 26 of the CRPD should lead to CBR initiatives which promote the participation and inclusion of indigenous persons with disabilities and are designed in a culturally-appropriate way by indigenous peoples and with the active involvement of indigenous persons with disabilities.

Intergenerational trauma

Indigenous peoples across the world suffer from an intergenerational or historical trauma resulting from forced assimilation, displacement, and children being removed from parents and institutionalized, which resulted in many psychosocial disabilities and unresolved grief. In addition, indigenous peoples were often removed from their lands and placed onto “missions” or “reservations”. In Canada, some 150,000 Aboriginal children were removed and separated from their families and communities to attend residential schools. Two primary objectives of the Residential Schools system were to remove and isolate children

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from the influence of their homes, families, traditions and cultures, and to assimilate them into the dominant culture. While most Indian Residential Schools ceased to operate by the mid-1970s, the last federally-run school closed in 1997 and it was only in 2010 that Canada announced that it would repeal the parts of the Indian Act that allowed for the establishment of the residential schools. Advocates were eventually able to achieve a settlement, apology, and Truth and Reconciliation Commission. As part of the settlement in Canada, some mental health and healing services are being made available to survivors. In the United States, Native children were put in boarding schools from 1869 to the 1960s where, in addition to traumas associated with forced separation from their families and forced assimilation, many experienced physical and sexual abuse. The mental health side of such history and abuses is not always well known. In Australia, experience of abuse and neglect in institutions were reported, and post-traumatic stress disorder and anxiety were some health consequences identified in the experience of indigenous persons with disabilities but that is not widely known. A residual and legitimate fear of assessment of indigenous persons with disabilities in some communities seems to pose a major challenge, which can be mitigated by training and involvement of indigenous peoples as key workers and additional steps to address past wrongs.

G. Adequate standard of living

40. Many indigenous persons with disabilities live in poverty and in some cases because of a development model that causes poverty. There is a vicious cycle between disability and poverty and for indigenous persons with disabilities the situation is worse. Living on mainly rural areas also has a significant impact

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on poverty and persons with disabilities. They are often lacking the basics such as food, clothing, hygienic system (sanitation), support for the basic necessities of life, assistive devices, mobility aids and health and rehabilitation services. Also lacking are clinics, disability skills training, and disability workers, as well as employment programs, job skills training, and transition to employment programs, resulting often in indigenous persons with disabilities lacking the skills required to earn their income.

41. Many times, indigenous persons with disabilities are not aware of or do not avail themselves of disability support pensions available to persons with disabilities. For indigenous persons with physical disabilities, there are usually many obstacles for moving around in the environment of their communities, leading to dependence and poverty. Even when technical aids are available, moving around in a wheelchair is mostly impossible, resulting in people either staying in their homes or forced to leave their community towards urban settings. Individual autonomy, however, is a general principle of the CRPD²⁵ and is closely related to the rights to liberty and security of the person, personal mobility, and others. More efforts need to be made to ensure that access to land and natural resources, but also access to capital are equally accessible for indigenous persons with disabilities and paying special attention to indigenous women with disabilities.

²⁵ Preamble, para (n) and art. 3 CRPD.

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H. Living in the community

42. Article 19 of the CRPD guarantees the right of persons with disabilities to live independently and be included in the community. In many countries, there is a widespread lack of state action to provide services and support in the community designed in consultation with persons with disabilities, often resulting in bad practices of state and private institutionalization of persons with disabilities.

43. While there are jurisdictional and user consultation issues related to service provision for many persons with disabilities around the world, the contexts are even more specific for indigenous peoples. The different relationship to state services and jurisdictional and cultural issues play key roles. Where there are State services available to indigenous persons with disabilities, service providers rarely include indigenous professionals who would have the same cultural understanding as the indigenous person with disabilities²⁶ and non-indigenous providers may lack training or awareness on relevant cultural approaches or issues. There is also a lack of supports or services within many indigenous communities. Support available to indigenous persons with disabilities must therefore be analyzed both for its compliance with the CRPD and its respect of indigenous cultures, institutions and organizations.

²⁶ National Council on Disability [U.S.], *Understanding Disability In American Indian & Alaska Native Communities* (2003).

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45. In some cases, indigenous persons with disabilities, due to the lack of adequate support services in their community, live in group home settings, far away from their communities where they are not supported to participate in community events and where staff is not supported to develop culturally competent skills to facilitate this. The repercussions of previous practices of separation from their communities still affect many indigenous persons with disabilities today whether directly or indirectly. Indigenous persons with disabilities in New South Wales, Australia have expressed fear that living in government owned or run accommodation, away from their family and country is akin to the historical removal of Aboriginal people from their communities.²⁷

46. Public resources need to be allocated by States to build the capacity of indigenous peoples, and at the community and organization levels, so that indigenous peoples can implement the CRPD in a culturally appropriate way. States should give resources for capacity building and development of such new initiatives.

I. Indigenous children with disabilities

47. There is much evidence that the lack of support and services to families of indigenous children with disabilities has led to the displacement of families from their communities and often even to the separation of children from their

²⁷ Telling it Like it Is, New South Wales survey 2004-2005, at 21.

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families and communities. In many societies where indigenous peoples suffer the intergenerational trauma that included forced assimilation and the removal of children from their families, indigenous children with disabilities continue to be at a high risk of being separated from their families, and being placed in institutions or with non-indigenous families.

48. The design of support services to indigenous families of children with disabilities needs to be done in a culturally-sensitive way and particular attention will need to be given not to use an approach that might replicate to some extent the practices of the past that have created these traumas. This will also comply with the principle of best interest of the child as indicated by the Convention on the Rights of the Child and reiterated by the CRPD.

49. Articles 7 and 10 of the CRPD protect the right to life of children with disabilities. Customs must be respected but only insofar as they do not violate international human rights law, meaning that any practices of infanticide of children with disabilities would be contrary to these provisions and other international human rights law.²⁸ Article 18 of the CRPD mandates States to ensure that all children with disabilities are registered at birth. There is some evidence that children with disabilities, including indigenous children with disabilities, are overrepresented among non registered children. There are an increasing number of indigenous institutions which are officially recognized to

²⁸ See ILO / John Henriksen study on good practices in implementing ILO Convention No. 169, *cited supra* at n. 10, at 57.

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have the responsibility of birth registration and it needs to be ensured that these do not discriminate against children with disabilities.

Indigenous-led service delivery systems

In some places, such as North America, there are efforts to have indigenous-led service delivery systems. In Canada, First Nations indigenous persons with disabilities in Manitoba and their allies have proposed a service delivery model, which was tabled at an All Chiefs Assembly in Manitoba in 2007.²⁹ It identified that the government needs to provide adequate services and funding to have a First Nations driven and controlled service delivery system which will then give children a more balanced and equal service delivery system. The model entails a First Nations Disability Resources Centre, regional centres, mobile therapy units, community based support, resources and equipment, and training and capacity building of First Nations in cooperation with local universities. It entails a phased approach, gradually increasing delivery by the First Nations as they gain the resources and capacity. For indigenous children in these communities and their families, this would make a concrete difference in their lives and in the life of the community. Indigenous children with disabilities would not have to leave their home or be separated from families in order to access services (which are not covered for them, anyway), but instead can be part of families, keep the culture,

²⁹ Making a Difference. Addressing Gaps in Services for First Nations Children with Disabilities and their Families: A Service Delivery Model. Assembly of Manitoba Chiefs, October 10, 2007.

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and, especially for those up north, maintain their language. At the present time it remains a model plan and has not yet been implemented.

J. Indigenous women with disabilities

50. Available evidence shows that girls and women with disabilities are at higher risk of violence than girls and women without disabilities,³⁰ and that indigenous women are disproportionately victims of sexual violence.³¹ Violence against girls and women with disabilities happens at home, but also in schools, residential institutions and in disability services. The definition of “violence” is broad and includes specific forms of violence against women with disabilities. Articles 14-17 and 25 of the CRPD mandate States to have policies in place to tackle this problem.

51. The situation of indigenous women with disabilities varies between communities. Indigenous women with disabilities experience challenges that other indigenous women also face, such as lack of representation in government, including in indigenous parliaments, lack of good hospital networks, lack of consultation, multiple forms of discrimination, poor access to education, health care and ancestral lands, high rates of poverty, increased risk of violence and

³⁰ Thematic study on the Issue of Violence against Women and Girls and Disability : Report of the Office of the United Nations High Commissioner for Human Rights - A/HRC/20/5 (30 March 2012).

³¹ Amnesty International, *Maze of Injustice* (2007).

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sexual abuse, including trafficking. Empowerment of indigenous women is sometimes portrayed as an imposition of western values. Indigenous women with disabilities often experience additional discrimination such as more restrictions on their legal capacity, and lack of an accessible legal system.

52. As with other women with disabilities, some indigenous women with disabilities are not seen as capable of raising children, and there are barriers to marriage. A number of studies have shown that indigenous women and women with disabilities are at particular risk of involuntary sterilization programmes as an instrument of population control, often inspired by eugenic ideas. To be effective, all policies and measures targeting indigenous women and girls with disabilities need to be designed in a culturally-appropriate way.

K. Emergency situations and disaster risk reduction

53 Article 11 of the CRPD highlights that persons with disabilities are especially vulnerable and must be assisted and protected in situations of natural as well as man-made emergencies. The exposure of indigenous persons with disabilities to such emergencies may be elevated because indigenous peoples often live in areas of special risk related to climate change (Africa, Coastal zones, Pacific, and Arctic), militarization and armed conflict, and the impact of extractive industries.

54. Initiatives that seek to make indigenous peoples more resilient to these challenges need to be undertaken in a disability-inclusive and fully participatory

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way.³² Protocols that are to be established, including those that foresee displacement of the community need to foresee actions targeting and involving indigenous persons with disabilities. Any resettlement must have the full, free, prior and informed consent of indigenous peoples, or because of natural disaster or other emergency, needs to be disability-inclusive. Similarly, all emergency and disaster risk reduction efforts should address the situation of indigenous persons with disabilities. In this regard, the Hyogo Framework for Action, which also refers to the disabled (sic) states clearly that the “information should incorporate relevant traditional and indigenous knowledge and culture heritage and be tailored to different target audiences, taking into account cultural and social factors.”

V. Conclusions

55. The available information on indigenous persons with disabilities shows a serious gap in the implementation and enjoyment of a wide range of rights, ranging from peoples’ self-determination and individual autonomy to access to justice, education, language, culture, and integrity of the person, among others. There is a large amount of unmet needs and rights that are not being addressed. Gaps in access to health, life expectancy, educational qualifications, income, safety of person, and participation in decision making are just a few examples.

³² See Declaration of DPOs annexed to the Yogyakarta Declaration on disaster risk reduction (October 2012).

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56. Urgent action is required by Member States, the United Nations, indigenous peoples, both indigenous peoples' organizations and organizations of persons with disabilities, and others, to take immediate steps to improve the situation of indigenous persons with disabilities, to consult with them, enable them to be heard, and to ensure that they are empowered to claim their rights as set forth in the two main legal standards, the CRPD and the UNDRIP, for which there exist major implementation gaps for this group. More attention, including research, needs to be given to this group by all stakeholders, in particular indigenous peoples and organizations of persons with disabilities. States need to allocate public resources to build the capacity of indigenous peoples, and at the community and organization levels, so that indigenous peoples can implement the CRPD in a culturally appropriate way. Involvement of indigenous persons with disabilities in the design of policies and services, in order for these to be culturally-sensitive/relevant, is needed and the unique experiences and knowledge of indigenous persons with disabilities need to be universally respected.

VI. Recommendations

A. Main recommendations

57. Relevant United Nations agencies dealing with indigenous peoples' issues should take action on the inclusion of indigenous persons with disabilities in all of its activities, make its website accessible to persons with disabilities, promote increased participation of indigenous persons with disabilities in its

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annual sessions and consider having an expert session on indigenous persons with disabilities.

58. The President of the General Assembly should ensure that the 2013 General Assembly High-Level Meeting on disability and Development and the 2014 World Conference on Indigenous Peoples, and their preparatory processes, are inclusive of and accessible to indigenous persons with disabilities, and take place with their full and effective participation, and that their views and interests are reflected in the agenda and the background papers.

59. Indigenous organizations should become more proactively inclusive of indigenous persons with disabilities, by ensuring a barrier-free environment and by recognizing the existence and value of indigenous persons with disabilities as full members of indigenous peoples.

60. Organizations of persons with disabilities (DPOs) should include indigenous persons with disabilities' perspectives, voices and participation.

61. UN entities, including the United Nations Development Programme (UNDP), United Nations Children's Fund (UNICEF), UN-WOMEN, United Nations Population Fund (UNFPA), World Health Organization (WHO), United Nations International Strategy for Disaster Reduction (UNISDR), and the regional commissions should include indigenous persons with disabilities in their work, to support the establishment of and develop the capacity of organizations of indigenous persons with disabilities and specifically report on their work in

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these areas in their dialogues with the United Nations Permanent Forum on Indigenous Issues (Permanent Forum).

62. States should include information on the rights of indigenous persons with disabilities when they present reports to the Permanent Forum, the CRPD Committee, other relevant treaty bodies and to the Universal Periodic Review, and, States should allocate funding resources for capacity building of indigenous peoples to provide culturally adequate services, as well as for the establishment and development of the capacity of organizations of indigenous persons with disabilities, including a focus on indigenous women with disabilities.

63. States should further support the participation of indigenous persons with disabilities in consultations regarding the post-2015 development agenda and ensure that the needs and perspectives of indigenous persons with disabilities are included in the resulting framework.

B. Other relevant recommendations:

Recommendations to indigenous peoples

64. Indigenous peoples are requested to include indigenous persons with disabilities who are familiar with their own rights in their negotiating teams in the standards currently being elaborated at the Organization of American States level.

Recommendations to States

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65. Help to guarantee the right to life of indigenous person with disabilities, by ensuring children with disabilities are registered at birth, and take measures to ensure that infanticide of children with disabilities does not occur.

66. Make sign language education available for deaf indigenous persons with disabilities and respect relevant cultural rights in the CRPD and the UNDRIP. Consult deaf indigenous persons on their issues, needs and preferences. Pay attention to the unique contribution that deaf indigenous persons make to cultural heritage of indigenous peoples and of the world.

67. Create high-level government task forces that meaningfully include persons with disabilities, indigenous peoples and their representative organizations, to review existing government programs and policies and to prepare comprehensive plans for the implementation of the CRPD and the UNDRIP, respectively.

68. Donors and development partners are encouraged to implement article 32 of the CRPD inclusively of indigenous persons with disabilities.

Recommendations to the UN system

69. The Special Rapporteurs on the Rights of Indigenous Peoples and on Disability should include meetings with indigenous persons with disabilities in their country visits, and request to the UN country team and to others providing

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support for organizing meetings with government and civil society, that meetings take place in venues accessible to persons with disabilities.

70. DESA should prepare a series of briefing notes relating to the rights of indigenous persons with disabilities, similar to the work that has been done to mainstream gender in the Permanent Forum, and a publication that identifies synergies and complementarity of obligations and implementation, and both of these should be done in cooperation with persons with disabilities and indigenous peoples and their representative organizations.

71. DESA should work with Member States and relevant UN bodies including UN regional commissions to improve the collection and dissemination of disaggregated data, statistics (as required by article 31 CRPD), information and knowledge and the use of the information regarding the situation of indigenous persons with disabilities.

72. The Inter-agency Support Group on the rights of indigenous peoples and the CRPD should explore synergies and opportunities to advance their work in relation to indigenous persons with disabilities, including through the use of the UNDG guidelines on indigenous peoples and on persons with disabilities.

73. EMRIP should include the rights of indigenous persons with disabilities in their work as a crosscutting issue, consistent with the CRPD and the UNDRIP, support efforts to make the voices of indigenous persons with disabilities heard,

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and consult with indigenous persons with disabilities and their representative organizations in the preparation of EMRIP studies.

74. The CRPD Committee should consider making recommendations to States Parties to the CRPD concerning the situation of indigenous persons with disabilities.

75. Relevant UN mechanisms and funds, including the UN Partnership on the Rights of Persons with Disabilities, the multi-donor trust fund on indigenous peoples, and the fund on indigenous women, should include indigenous persons with disabilities in the projects at the country level in cooperation with indigenous persons/women with disabilities and their representative organizations.

76. The ILO should increase its work to advance the rights of indigenous persons with disabilities, in keeping with ILO Convention 169, including the country reports on their implementation of the Convention, as well as the CRPD and the UNDRIP, and ensure that indigenous persons with disabilities are included in efforts to implement the new ILO recommendation on national social protection floors.

77. OHCHR should ensure the accessibility for persons with disabilities of the reports of the Special Rapporteur, EMRIP, and related websites, in line with relevant standards such as the WAI WCAG web accessibility standards, in

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cooperation with UN-wide initiatives to improve accessibility of reports and websites.

78. OHCHR should proactively reach out to indigenous persons with disabilities and encourage their participation in its Indigenous Fellowship Programme.

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