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Recommendations to Improve Public Policies and the Delivery of Public Services for Persons with Disabilities Belonging to Minority and Indigenous Communities in Ecuador

23 January 2020

On 26 and 27 November 2019, Minority Rights Group International (MRG) and the Latin American Network of Non-Governmental Organisations of Persons with Disabilities and their Families (RIADIS) with the support of the Swedish International Cooperation Agency for Development (SIDA) and the participation of the Indigenous Persons with Disabilities Global Network (IPWDGN), hosted a coalition building meeting in Quito on the intersectional discrimination and stigma experienced by persons with disabilities belonging to minority and indigenous communities. During the meeting, indigenous persons and Afro-descendants with disabilities shared some concerns with representatives of the Ecuadorian government, including the National Commission for Equality in Disability – CONADIS, the Ministry of Economic and Social Inclusion – MIES, the Secretariat of Human Rights of Ecuador, the National Commission for Intergeneration Equality (CNII), as well as the Confederation of Indigenous Nationalities of Ecuador –CONAIE and the UN Refugee Agency. Based on these concerns and a field mission to visit indigenous persons with disabilities and their families in the Ecuadorian Amazon, MRG, RIADIS and IPWDGN have formulated a series of recommendations for the relevant entities of the Ecuadorian government to consider within the guidelines and action plans that should be implemented for the benefit of this group in finding solutions to problems presented.

RECOMMENDATIONS

(1) Adopt mechanisms to ensure that members of minority and indigenous communities with disabilities are able to participate effectively in decisions that affect them and their communities, particularly at the regional level.

- **Background:** Based on paragraph 13 of the Committee on the Rights of Persons with Disabilities' Concluding Observations on Ecuador, meeting participants expressed that there is a lack of representation and participation of members of minority and indigenous communities with disabilities and their families in decision-making, not only at the local level, but also at the national level in Ecuador. To ensure that public policies are adequately tailored to the group's needs



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and promote the full enjoyment of their rights it is essential to ensure their participation in decisions that affect them and their communities because they are the ones who best understand their reality, their needs and the shortcomings of existing policies. To do so, it is also critical to ensure that members of minority and indigenous communities with disabilities are able to access quality education on an equal basis to their non-disabled peers (see Recommendation 2).

(2) Take steps to ensure the inclusion of members of minority and indigenous communities with disabilities in their community schools on an equal basis to their non-disabled peers, training teachers at these schools to meet the needs of these children and adolescents both in terms of their disability and in their mother tongue. The government must ensure that tests, exams and other requirements imposed to complete basic and secondary education at these schools are accessible to members of minority and indigenous groups with disabilities and their families so that they have access to higher education and professional training in Ecuador. We also recommend that teachers run awareness workshops in their classrooms so that other students are able to understand and value the capabilities of their peers with disabilities. These workshops should respond to the cultural and linguistic context of each community, respecting the right to self-determination.

- Context: Participants at the coalition building meeting expressed that schools in indigenous communities are not accessible because of the lack of resources and trained teachers able to teach children with disabilities on an equal footing, enabling children with disabilities to study and educate themselves alongside their non-disabled peers. Participants also noted that examinations for persons with disabilities remain inaccessible and must be adapted to ensure access to education for people with disabilities (auditory, visual, intellectual, psychosocial, physical, etc.). Without access to the necessary training and schooling that allows members of this group to be educated on an equal basis to their non-disabled peers, members of indigenous and minority communities with disabilities and their families cannot fully enjoy their fundamental rights given that education is a right that has a multiplier effect, the key that opens the door to other fundamental rights both at an individual and collective level and deprives people of the enjoyment of many rights and freedoms when it is denied or abrogated (as for example, the right to participation, see Recommendation 1).

(3) Under the Convention on the Rights of Persons with Disabilities Ecuador has an obligation to provide health, habilitation and rehabilitation services and programmes “as close as possible to people’s own communities, including in rural areas” and ensure that persons with disabilities “attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of



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life”.¹ We therefore recommend that the Ecuadorian government adopt measures to ensure access to basic public services in minority and indigenous communities, particularly health, habilitation and rehabilitation services and programmes to meet the needs of members of this collective, ensuring access to the necessary treatments to achieve and maintain their maximum independence and quality of life, respecting and valuing the role of traditional medicine.

- Context: Participants at the coalition building meeting emphasised that public services do not reach their communities, much less indigenous persons with disabilities. In particular, access to quality health, habilitation and rehabilitation services and programmes – with the resources, personnel and specialised treatments required to treat the health conditions related to their disability – is almost non-existent even though it is essential to ensure their quality of life and to prevent their health from deteriorating. In general, members of this group must move to urban areas far from their communities to receive specialised treatments that they require without access to adequate public transportation. Beyond the physical and logistic barriers that these trips entail for indigenous persons with disabilities, members of this collective experience a high level of poverty and accordingly, they lack the economic resources that would allow them to travel the long distances many must travel to access the medical treatments they need.

(4) Ensuring access to safe, clean drinking water and sanitation as pollution, unsanitary living conditions and lack of safe drinking water contribute to the incidence of health conditions that cause disabilities among members of these communities.

- Context: We understand that in many indigenous communities in Ecuador there is a lack of access to safe drinking water and that there are risks of pollution stemming from oil extraction, the use of pesticides, lack of sewage, etc. It is worth emphasising that in Ecuador, most oil extraction and mining activities are carried out on indigenous territories and that these activities have polluted water and subsoil in their territories (see for example pollution caused by the extraction of oil in Sucumbíos by Chevron / Texaco described as one of the largest environmental disasters in the world, cottage extractive industries that dump mercury into rivers). Other sources of pollution include the so-called Plan Colombia that sprayed glyphosate for many years in and around the border areas of Colombia and Ecuador, polluting the environment. In many cases, oil and mining concessions have been granted and fumigation activities have been carried out without obtaining the affected communities’ free, prior and informed consent; as such, many members of

¹ See Articles 25 and 26 of the Convention on the Rights of Persons with Disabilities.



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these communities were unaware that their water contained harmful substances. Exposure to these types of pollutants entails serious health risks and increases the likelihood that members of communities exposed to pollutants will develop impairments (including visual and intellectual). To avoid the serious health risks associated with drinking contaminated water, the government must adopt immediate measures to ensure that the water consumed by indigenous communities is safe and free of contaminants.

(5) Provide funding to indigenous nations and minority communities so that the communities themselves can carry out a comprehensive survey to account for the actual number of people with disabilities in their communities, where they reside, as well as in what conditions they live. We also recommend that public servants entering communities to attend to the needs of this collective (such as, for example, the Las Manueles brigades and MIES technicians) are themselves members of the community. They are the people who best understand the situation, the terrain, where persons with disabilities within the community live and are best placed to coordinate with the community leaders involved.

- Context: We understand that members of minority and indigenous communities with disabilities are a group that is fairly invisible in Ecuador. Many are not listed in records accounting for persons with disabilities and do not even have birth certificates so many do not receive the assistance or support they require. Although representatives of the Ecuadorian government participating in the coalition building meeting mentioned the actions undertaken by Las Manueles brigades to register indigenous persons with disabilities, it is clear that many members of this group remain unaccounted for. According to participants at the coalition building meeting, Las Manueles brigades and MIES technicians do not reach the homes of many people with disabilities in indigenous communities and rural areas and if they do, they are not always diligent in registering people with disabilities in these communities. Therefore, there are many cases of people with disabilities in situations of vulnerability within these communities that are not registered and / or do not receive the pensions or benefits they are entitled to receive. The indigenous communities with which we have met recognise the lack of attention that members of this group experience but emphasise that there are no reliable figures on the number of persons with disabilities within their communities. Until there is an accurate record of the number of persons with disabilities in indigenous and minority communities and, in particular, where they reside and in what conditions they live, it will not be possible to design a public policy that guarantees the full enjoyment of their rights.



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(6) To adopt specialised programs with trained personnel – with an understanding of the cultural and linguistic context, as well as the terrain and the environment in which indigenous and Afro-descendent communities live – to provide technical assistance in these communities and rural areas, to ensure that minorities and indigenous persons with disabilities, particularly in rural areas that are difficult to access, receive the necessary technical assistance, adapted to their environment.

- Context: We understand that many members of this group do not receive the necessary technical assistance, much less adapted to their environment. By way of example, wheelchairs that would be needed in rural areas without access to paved streets are different from the wheelchairs that might be suited to an urban environment. In this context, it would be necessary first to ensure that members of indigenous and Afro-descendant communities receive appropriate technical assistance and secondly that the assessments carried out to determine the technical assistance they require take into account and are adapted to the person's lived environment, guaranteeing the full enjoyment of their rights.

(7) To raise awareness among parents and relatives of indigenous persons with disabilities so that they understand that their children and / or relatives with disabilities can contribute to their communities if they receive the support they need to help them develop their skills and capabilities. In particular, we recommend the creation of workshops that are adapted to the cultural and linguistic context of each community to empower parents and relatives of indigenous persons with disabilities to foster a favourable environment that will help indigenous persons with disabilities to develop their capabilities, promoting their self-determination and autonomy. In this context, it is critical for awareness raising activities and trainings not to come completely from outside of the community; they must also target leaders and active community members so that the awareness raising campaigns can be undertaken from within the community itself. We also recommend that teams coming from outside of the community to raise awareness and empower members of the community include members of minority and indigenous communities with disabilities that have been able to access the assistance and training that has allowed them to educate and develop themselves independently. Doing so will help overcome any stigmas about people with disabilities that may exist in the community.

- Context: We understand that stigmas about persons with disabilities persist in many indigenous communities and that therefore parents and / or relatives do not allow indigenous persons with disabilities to leave their homes, enrol in schools or receive the attention and training they need. It is important to overcome these stigmas to enable environments that foster the development of their capabilities and overcome barriers of access to education that indigenous persons with disabilities experience.



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(8) Recalling paragraphs 31 and 32 of the Committee on the Rights of Persons with Disabilities' Concluding Observations on Ecuador, we recommend that the State take special measures to ensure that members of minority and indigenous communities with disabilities who are victims of domestic violence and / or sexual abuse, particularly those living in situations of vulnerability in rural areas, can go to the relevant authorities to seek support and report their situation. In particular, we recommend undertaking capacity-building activities for community leaders so that the autonomous governments of indigenous communities can promote spaces from which to address the problem internally in the first instance. We also recommend that prosecutors' offices / other relevant bodies at the local level hire a disabled indigenous woman as a point of contact to meet any needs arising from the gender violence that members of this group experience. We also recommend the creation of community ombudsman offices to encourage leaders from within the community to address the issue of gender violence in the first instance. Lastly, we recommend that these ombudsman and prosecutors' offices hire indigenous languages and sign language interpreters.

- Context: Although participants in the coalition building meeting acknowledged that the government recently published a guide recently and that efforts have been made to train some community leaders in Ecuadorian provinces, it is still necessary to raise awareness and to publicise these issues within indigenous communities. To this end, we recommend translating the guide into indigenous languages and adopting initiatives to ensure that this knowledge reaches the local level. We also understand that in 2020, CONADIS plans to provide a training on this subject in educational institutions. We suggest that as part of this initiative, the issue of gender violence and reproductive health be included in school curricula.

(9) To adopt mechanisms and measures to ensure that the VIII Population and VII Housing censuses that will be carried out in 2020 contemplate adequate data collection, allowing national statistics to make ethnic minorities and indigenous persons with disabilities visible, as noted in paragraphs 55 and 56 of the Committee on the Rights of Persons with Disabilities' Concluding Observations on Ecuador. In the same vein, in order to guarantee mechanisms that prevent people from these communities from losing their benefits during the disability requalification or reassessment processes, we recommend that the visit of MIES technicians and the Manuelas Program be closely coordinated with the leaders of the indigenous or minority community. We also recommend that members of the community being audited / visited accompany Manuelas Program and MIES technicians to ensure that no person with disabilities in the community in question is left out.

- Context: Given that the government will be undertaking the VIII Population and VII Housing censuses in November 2020, we consider INEC's initiative to include



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the Washington Group's short set of questions on disability effective, allowing for reliable, measurable and comparable statistics at the regional level. Nevertheless, the participants in the coalition meeting have stated that there is a well-founded fear regarding the loss of entitlements under the Joaquín Gallegos Lara benefit² or other benefits for persons with disabilities from indigenous or minority communities who have obtained their disability card from the CONADIS or the Ministry of Public Health. They have emphasised that in the requalification process, many people are losing the rights and benefits to which they are entitled given that the requalification mechanisms and processes may reduce the degree of their disability, even though in practice their disability has not changed or reduced and their living conditions are still inadequate to guarantee their full inclusion in all areas of their lives. Moreover, this requalification may adversely affect the statistics that CONADIS manages, since the population with disabilities would only decrease in number counted but not in real life. Because peoples' disability persists in actual fact, so too the stigma and discrimination they face.

² An assessment tested disability benefit. Amount of entitlement depends on the severity of disability recorded in the assessment.