

'NOTHING ABOUT CRPD **MONITORING WITHOUT US':** A CASE STUDY ON THE INVOLVEMENT OF THE **DISABILITY MOVEMENT IN** POLICY-MAKING IN ZAMBIA

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Summary

Article 33 of the UN CRPD is the most comprehensive provision referring to national level implementation and monitoring ever included in an international human rights treaty. It requires states parties to establish a triangular mechanism comprising of government, an independent element and civil society, in particular organisations of persons with disabilities (DPOs), to handle and monitor the implementation of the Convention. Bearing in mind that the human rights model introduced in the CRPD shall be applied to a historically marginalised group, the fulfilment of this obligation is essential but also challenging. Nevertheless our knowledge is very limited on the criteria of effective involvement. This chapter intends to explore and identify some of the key factors of active and effective civil society participation in policy-making through the example of Zambia. The paper also discusses the financial challenges of a developing country when implementing and monitoring the UN CRPD. In Zambia the disability movement took the leading role and initiated the establishment of the Independent Monitoring Unit (IMU). Since the Human Rights Commission of Zambia – as the Paris Principle compliant independent body - does not actively participate in the work of the monitoring body, the Zambian solution to implement article 33 of the CRPD cannot be considered as a good practice. However, it is certainly an interesting case study on the empowerment and involvement of the organisations for persons with

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disabilities. It is important to consider how far we can take the principle 'Nothing about us without us!' to ensure the participation of the disability movement but also achieve compliance with the CRPD.

1 Introduction – article 33 and its implications at the national level

The UN Convention on the Rights of Persons with Disabilities (CRPD or the Convention) seeks to ensure the full and equal enjoyment of human rights for the estimated 650 million persons with disabilities in the world facing multiple discrimination. Approximately 80 per cent of them are living in developing countries. Since the existing human rights conventions were-theoretically inclusive of disability, but were insufficient in challenging national laws that excluded the rights of persons with disabilities, there was a strong need for the Convention addressing the human rights of persons with disabilities in particular. The Convention does not create any new rights, but intends to tailor general human rights to persons with disabilities under the overarching philosophy of nondiscrimination. The CRPD merges civil and political and socio-economic rights within an international human rights treaty. Most importantly, the CRPD represents a paradigm shift from the 'medical model' of disability to the human rights model. The new approach no longer considers persons with disabilities simply as beneficiaries of charity or welfare, but as holders of the same rights as anyone else in society. As Lewis points out, the CRPD has the potential to become a transformative international legal instrument, which innovates by driving a new politics of disability.

Article 33 of the CRPD is arguably the most comprehensive provision on national level implementation and monitoring ever included in an international human rights treaty.⁴ No other previous UN convention comprises such an explicit reference to domestic interpretation. The only partially comparable example to article 33 of the CRPD could be article 3 of the Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (OPCAT), which requires states parties to designate or maintain a 'national preventive mechanism'.5 As the report of the Mental Disability Advocacy Centre (MDAC) highlights, article 33 of the CRPD articulates the general

OM Arnardóttir & G Quinn (eds) The UN Convention on the Rights of Persons with

Disabilities: European and Scandinavian perspectives (2009).

OHCHR 'Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for human rights monitors' Professional Training series, no 17 (2010).

O Lewis 'The expressive, educational and proactive roles of human rights: An analysis of the United Nations Convention on the Rights of Persons with Disabilities' in B McSherry & P Weller (eds) *Rethinking rights-based mental health laws* (2010) 97-128. G de Beco 'Study on the implementation of article 33 of the UN Convention on the Rights of Persons with Disabilities in Europe' OHCHR study (2011) 4.

OPCAT, art 3.

principle of participation that runs throughout the treaty to ensure states parties involve persons with disabilities in interpreting and implementing CRPD rights (article 3 of the CRPD). Persons with disabilities and their representative organisations have actively participated in drafting the Convention. This momentum was the beginning of a long process to enable the disability movement to speak on its own behalf and fight for the realisation of human rights as equally acknowledged and respected members of society. The empowerment of the disability movement is probably the key element in understanding the CRPD.

This paper focuses on the Zambian solution to designate an article 33 monitoring framework. There is a very strong disability movement in Zambia, which intends to fully participate in the implementation of the CRPD. Since the government did not take any steps to designate an article 33 framework, some representative organisations of persons with disabilities initiated the establishment of the IMU. They believe that persons with disabilities should play the leading role themselves, in line with the Convention, when implementing the CRPD. Yet, the well-known slogan from the drafting process of the Convention – 'Nothing about us without us!' - raises some unanswered questions. We can certainly consider it as a way to correct past exclusions, as it guarantees that the voice of civil society is heard during policy-making. The question is how far to take this principle to ensure participation of persons with disabilities. but avoid the situation of civil society becoming the sole owner of policymaking? The CRPD does not intend to give the role of policy-maker to civil society, but wishes to empower persons with disabilities and their representative organisations to participate in a meaningful way in all decision-making processes relating to their lives.

Article 33(1) of the CRPD – focal point and coordination 1.1 mechanism

According to article 33(1) of the CRPD, states parties shall appoint one or more focal points within government for matters relating to the implementation of the Convention. Focal points are therefore an issue of internal public administration and have to be formally designated.⁸ Countries can choose, depending on the structure of the state to designate one focal point in the most relevant ministry for disability matters, or

Mental Disability Advocacy Centre 'Building the architecture for change: Guidelines on article 33 of the UN Convention on the Rights of Persons with Disabilities' (2011).

G Quinn 'The United Nations Convention on the Rights of Persons with Disabilities – What role for philanthropy?' International Human Rights Funders Group, San Francisco (2010).

A Hoefmans & G de Beco 'The UN Convention on the Rights of Persons with Disabilities: An integral and integrated approach to the implementation of disability rights' Study commissioned by the Belgian Federal Public Service Social Security

designate several focal points (sub-focal points) in different departments. Sub-focal points are often designated in federal states where responsibilities are shared between various layers of government. Gatjens provides a non-exhaustive list of requirements for the focal point. He highlights that, amongst other characteristics, the designated entity should be close to the central authority that issues policies and has an effect on the government departments. If the government has an in-depth understanding of the paradigm shift addressed in the CRPD neither the Ministry of Health nor the Ministry of Social Affairs would be appointed as article 33(1) bodies. It is very important that staff of the designated entity have a comprehensive knowledge about the social/human rights model of disability. Adequate resources and a stable budget are necessary for the focal point to effectively perform its duties around the CRPD implementation.

It is not an obligation but article 33(1) also mentions the establishment of a coordination mechanism, which aims to facilitate the co-operation between governmental bodies to avoid adopting isolated measures at different departments.

1.2 Article 33(2) – the independent monitoring framework

Article 33(2) requires states parties to:

[M]aintain, strengthen, designate or establish within the State Party, a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention. When designating or establishing such a mechanism, States Parties shall take into account the principles relating to the status and functioning of national institutions for protection and promotion of human rights.

Article 33(2) of the CRPD makes a clear distinction between three dimensions (promotion, protection and monitoring), where tasks need to be carried out in regard to the implementation of the CRPD. These activities are listed in the thematic study of the United Nations High Commissioner for Human Rights. 12 Promotion includes scrutiny of

^{9 &#}x27;Final report of the work forum on the implementation of article 33 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD)' Organised by the Belgian Presidency of the Council of the European Union and the European Commission, Brussels (2010).

LFA Gatjens 'Analysis' of article 33 of the UN Convention: The critical importance of national implementation and monitoring' (2011) 14 SUR International Journal on Human Rights 71.

Rights 71.

The Ministry of Health is not a good choice to be designated as focal point as it represents the old medical model by treating persons with disabilities as patients. The Ministry of Social Welfare tends to consider persons with disabilities as objects in the government welfare system and that often maintains their dependency instead of having a holistic approach towards disability rights.

¹² De Beco (n 4 above).

compliance of draft legislation to ensure consistency with the obligations under the Convention, scrutiny of existing legislation, regulations and practices, awareness raising, human rights education and research. Protection shall cover investigation and examination of individual and group complaints, litigation, conducting enquiries, issuing reports and filing amicus curiae briefs. Monitoring includes collecting data and information on human rights violations, developing indicators and benchmarks, assessing progress, visiting places where violations often occur and the contribution to State Reports to the UN Committee. The framework, established under article 33(2) of the CRPD shall include at least one independent mechanism that is compliant with the Paris Principles. As Waddington points out, unfortunately the High Commissioner's report does not specify whether this independent mechanism must play a role in all three tasks of the framework.

Article 33(3) – the participation of civil society in 1.3 monitoring the CRPD

According to article 33(3) of the CRPD, civil society, in particular persons with disabilities and their representative organisations shall be involved and participate fully in the monitoring process of the Convention. The word 'shall' leaves no doubt on the binding nature of this provision. As it was mentioned earlier, the concept of 'participation' runs throughout the whole Convention as a general principle. Article 4(3) of the CRPD refers to the importance of involving persons with disabilities in all policy and decision-making processes concerning their lives. Paragraph (o) of the Preamble to the CRPD also emphasises that persons with disabilities should be actively involved in decision-making processes, policies and programmes, including those directly concerning them. These articles of the Convention clearly present a paradigm shift from the medical to the human rights model. There is a clear reference that persons with disabilities are not objects of charity, care or pity anymore but rights holders and active citizens who may wish to participate in monitoring the fulfilment of their human rights.

The well-known mantra '[n]othing about us without us!' and the involvement of persons with disabilities should be considered as one of the key elements in the successful implementation of the CRPD. Considering the invisibility of persons with disabilities in the human rights system, this provision is an extremely important challenge in all states parties. However, the Convention does not give instructions on how to establish a

¹³ L Waddington 'Reflections on the establishment of a framework to promote, protect and monitor implementation of the UN Convention on the Rights of Persons with Disabilities (article 33(2) CRPD) by the European Union' Maastricht Faculty of Law Working Paper, 2011 6 http://dx.doi.org/10.2139/ssrn.1746866 (accessed 30 June

partnership between the disability movement and the governing bodies. Considering the conceptual complexity of 'participation', it is necessary to take a comprehensive look and define the critical success factors. The guidelines of the Mental Disability Advocacy Centre on article 33 of the CRPD present a set of requirements to achieve meaningful participation.¹⁴ First and foremost involvement should happen in a structured manner and cannot be fully realised through ad hoc methods. Meaningful participation of the organisations of persons with disabilities should be guaranteed by capacity building and obtaining necessary knowledge. Accessibility, transparency and the availability of multiple forms of involvement are other important assets.

Article 33 triangulation – dynamics and function

As Quinn points out, the triangulation articulated in article 33 requires a balance of power and functions between the government, the national human rights institution and civil society. ¹⁵ The government is deemed to be responsible to ensure and promote the full realisation of human rights and fundamental freedoms for all persons with disabilities in line with article 4 of the CRPD. Therefore they must coordinate the implementation of the Convention across and within different departments. In order to ensure the accountability of the state and guarantee that international law provisions become a reality, a framework shall be designated including one or more independent elements. Independence is understood according to the Paris Principles. The United Nations Paris Principles provide the benchmark for national human rights institutions (NHRI) to be accredited and define at which level they may participate in the work of national human rights institutions. ¹⁶ The NHRI is usually the human rights commission, the equality body or the office of the ombudsman. In addition to their fully independent status, they are expected to frame relevant domestic questions within the scope of international law and investigate in the field of equality and non-discrimination effectively. The third element of the triangulation makes article 33 truly innovative, by involving in the monitoring process the voice of civil society and in particular persons with disabilities. The independent body still has its function to perform but the activities are enriched with the duty of collaborating with civil society. The government also needs to consult with Disabled Persons Organisations

MDAC (n 6 above) 23-24.

New Zealand Parliament, presentation by G Quinn, 19 February 2009 http://www.nuigalway.ie/cdlp/documents/publications/GQ-190209.pdf (accessed 4 January

The International Coordinating Committee currently uses three levels of accreditation: 'A' status institutions demonstrate compliance with the Paris Principles. They can participate fully in the international and regional work and meetings of national institutions, as voting members. 'B' status institutions do not fully comply with the Paris Principles, therefore they can only participate as observers in the work of the national human rights institutions. 'C' status institutions do not comply with the Paris Principles, thus they do not have any rights of privileges with the ICC

(DPOs) when it comes to policy and decision making in line with article 4(3) of the CRPD. Presumably, this collaboration is a great challenge and requires some important structural and functional changes in the work of the NHRI and the governmental bodies. It is a fascinating time to explore the dynamic of these innovatory changes and the solutions countries choose to designate their article 33 mechanism.

Most states parties are still in the process of establishing their article 33(2) framework to 'promote, protect and monitor' the implementation of the CRPD. Therefore it is very important to ensure the participation of DPOs from the very first stage. Knowledge is still very limited on what kind of initiatives or good practices are taking place in states parties in order to provide realistic opportunities for active and effective involvement of persons with disabilities instead of the formal consultations that happened in the past.

2 Conceptualising the involvement of the disability movement

2.1 Defining 'civil society' and the role of NGOs in governance

It is essential to conceptualise the phenomenon 'civil society' before discussing civic participation of persons with disabilities in Zambia. Civil society is a theoretical concept and there is no universal definition in use. 17 According to the general definition by Meidinger, civil society has been characterised as a sphere of social life that is public but excludes government activities. 18 Bratton claims that there is a link between the democratisation process in Africa and the concept of civil society empowerment. 19 This may explain why there is a strong disability movement in Zambia actively participating in the implementation of the CRPD. Nevertheless, Cohen and Arato describe the participatory model of democracy in which both the governing elite and the citizens play an active role in forming opinions and develop a conception of civic virtue through political experiences.²

When discussing the key features of civil society, Charnovitz highlights the voluntary manner and the individual commitment.²¹ In his view, new political actors in particular non-governmental organisations

PJ Simmons 'Learning to live with NGOs' (Autumn, 1998) 112 Foreign Policy 82. E Meidinger 'Forest certification as environmental law making by global civil society' In E Meidinger et al (eds) Social and political dimensions of forest certification (2003) 293. M Bratton 'Civil society and political transition in Africa' (1994) 11 IDR Reports. JL Cohen & A Arato Civil society and political theory (1993) 7. S Charnovitz 'Nongovernmental organisations and international law' (2006) 100

American Journal of International Law 348.

could take a role in policy-making after globalisation has considerably weakened the power of ruling governments.²² Despite the involvement of non-governmental organisations (NGOs) being considered as a latetwentieth-century phenomenon, Charnovitz dates it back much earlier.²³ Due to the long-term marginalisation of persons with disabilities, the participation of disability NGOs is still a relatively new concept. Although in other disciplines, such as environment protection, the UN co-operated with the non-governmental sector as partners in implementing programs, the collaboration with DPOs has started very recently after the conclusion of the CRPD.²⁴

The role of civil society in governance can be described in five key areas: information collection and dissemination; policy development consultation; policy implementation; assessment and monitoring; and advocacy for [environmental] justice.²⁵ These categories may be great starting point to define how the organisations of persons with disabilities can participate in policy- and decision-making processes. Gemmill and Bamidele-Izu contend that existing structures do not enable civil society to perform the aforementioned roles effectively. 26 Drafters of the CRPD intentionally incorporated a legal obligation on states parties to ensure the active and critical role of the disability movement in the governance system. Furthermore, provisions of article 33 integrate the disability movement into the structured space of civilian actors. In order to achieve meaningful involvement of persons with disabilities, significant changes in the structure of the governance are necessary.

It is important to make a distinction between DPOs and other types of NGOs in the context of disability. The term 'non-governmental organisation' was first used by the United Nations in 1945 to specify the role of consultants that were not representing national governments.²⁷ NGOs can certainly work for the protection of the rights of persons with disabilities in several ways. They can focus on the rights of persons with disabilities in general or represent particular groups within the disability community for instance persons with Down Syndrome, or persons with visual impairment. They can also organise their work around thematic areas, such as employment or education. NGOs can offer services for persons with disabilities or do purely advocacy work. DPOs can be defined

Charnovitz (n 22 above) 183.

TG Weiss 'International NGOs, global governance and social policy in the UN system' (1999) GASPP Occasional Papers 3/1999 STAKES, Helsinki.

Gemmill & Bamidele-Izu (n 25 above) 78.

S Charnovitz 'Two centuries of participation: NGOs and international governance' (1996-1997) 18 Michigan Journal of International Law 183.

B Gemmill & A Bamidele-Izu 'The role of NGOs and civil society in global environmental governance' in DC Esty &MH Ivanova (eds) (2002) Global Environmental Governance: Options & Opportunities Yale School of Forestry & Environmental Studies

N Srinivas 'Against NGOs?: A critical perspective on nongovernmental action' (2009) 38 Nonprofit and Voluntary Sector Quarterly 614.

as a form of non-governmental organisation that is particular in terms of its composition and leadership: both the membership and the leaders are persons with disabilities themselves.

2.2 Public participation in the African context

With regard to the roots of a civil society movement in Africa, voluntary associations were first constructed as a response to the disruptive effect of market economy during the colonial period. ²⁸ According to Bratton, those organisations shortly became explicitly political. Despite aspirations of the ruling elite to eliminate these groups around the time of independence, most of them successfully proved to be a strong alternative institutional framework. In Zambia, associational life mostly started with mineworkers' unions which could provide a ground for formulating opposition, together with economic networks against post-colonial autocracy by the end of the 1980s. Responding to the popular protest of civic actors, African governments created political openings, which lead to a more favourable atmosphere for free expression and association. ²⁹ For instance, in Zambia a number of NGOs were created to monitor the government's performance on human rights since the 1980s. These associations were essential to educate people about citizenship and democracy.

In South Africa, the Constitution provides a framework to guarantee public participation in the legislative process.³⁰ As a consequence of the involvement of citizens in public life, the democratic system functions in a representative and participatory way at the same time. ³¹ As Nyati points out, it is a government's duty to facilitate meaningful participation of the public in the legislative process and guarantee that everyone's opinion is considered.³² The aspiration behind this provision is to avoid the continuation of any exclusive policies that deprived fundamental rights of people in past regimes. The Constitutional Court decision in *Doctors for Life International v Speaker of the National Assembly*³³ is a very important milestone in addressing the extent to which public participation in the legislative process is protected by the South African Constitution. The judgment set the standard of the constitutional obligation to facilitate public participation and to develop more accountable legislation.

In Kenya, the Endorois case is a very important source to illustrate the legal concept of people's participation as a duty of the state. ³⁴ The African

Bratton (n 19 above) 6.

Nyati (n 31 above) 104. (2006) 12 BCLR 1399 (CC).

Bratton (n 19 above) 5.

Secs 59 (1)(a), 72 (1)(a), & 118 (1)(a). L Nyati 'Public participation: What has the Constitutional Court given the public?' (2008) 12 Law, Democracy & Development 102.

SA Djoyou Kamga 'The right to development in the African human rights system: The Endorois case' (2011) 44 De Jure 381.

Commission on Human and Peoples' rights stated that the lack of meaningful participation of the Endorois community was a violation of the right to development. As Kamga's commentary explains, the right to development is binding in the African Charter on Human and People's Rights (ACHPR) and was first tested through this case. The court's decision highlights the state's role as a duty bearer to guarantee people's participation and clarifies the beneficiaries of the right to development. The right to development includes a number of elements, such as non-discrimination, participation, equity, accountability, and the threshold of people's participation. The right to development includes a number of elements, such as non-discrimination, participation, equity, accountability, and the threshold of people's participation.

2.3 Development of research terminology

As part of a preliminary study, interviews were conducted with members of the European disability movement to develop the conceptual frame of 'involvement' and 'participation' as both are required under article 33 of the CRPD.³⁷ First of all, it is important to distinguish 'involvement' from 'consultation'. Consultation means a somewhat passive role in which one can express his or her opinion without necessarily being considered in the whole decision-making process. The government often consults with civil society only at a later or the last stage of any negotiations, which does not ensure their participation from the very beginning and their contribution may remain tokenistic. If civil society has no other possibilities than commenting on drafts already put on the table by the government, they have very little influential input. Exclusion from meaningful participation is unacceptable, not only in the scope of the aforementioned South African case-law but in the scope of the CRPD as well.

One of the most important concepts developed for purposes of the study described here is the distinction made between 'active' and 'effective' participation. Active participation refers to the regular presence of disability organisations during high-level meetings and negotiations. Active involvement does not guarantee that any of the contributions offered by civil society will be considered by governing forces. Effective involvement occurs when the contribution of civil society – in this case most importantly, organisations of persons with disabilities – is reflected in laws and policies. Therefore, it is arguably important to examine if the participation of civil society through its various methods is not only active but also effective. As part of the intention to use inclusive research methods, interviewees in Zambia were asked for a feedback on whether they agreed or not with such a conceptual division between 'active' and

³⁵ Communication 276/2003, Centre for Minority Rights Development (Kenya) and Minority Rights Group International on behalf of Endorois Welfare Council v Kenya, See African Commission, 27th Activity Report, 2009.

³⁶ Kamga (n 34 above) 391.

³⁷ In total ten interviews have been conducted with leaders of European umbrella DPOs between March and July 2012.

'effective' participation. Since their reaction was positive, these terms will be used throughout the chapter.

3 An example of emerging promising practice: Zambia

In the following section, the Zambian solution to implement article 33 of the CRPD will be analysed, as a promising practice for influential involvement of the disability movement. Nevertheless, it is important to take a look at the functioning of the whole article 33(2) mechanism and evaluate the participation of civil society accordingly. Some remarks will be made on possible ways to improve the sustainability of the CRPD in Zambia.

The former British colony of Northern Rhodesia, became independent from the United Kingdom and was named Zambia in 1964. According to the Global Competitiveness Report, Zambia is ranked as 102 out of 144 countries, which looks at factors that affect economic growth.³⁸ The UN Human Development Index is a useful tool to get a glimpse of the social situation of certain countries. It represents a push for a broader definition of well-being and provides a composite measure of three basic dimensions of human development (health, education and income). According to the 2013 report, Zambia is ranked 163 out of 187 countries.³⁹ indicators, such as life expectancy at birth (about 49.4 years) or the GNI per capita (\$1358) are still very concerning.

3.1 The CRPD and Zambia

Zambia signed the CRPD on 9 May 2008 and ratified the Convention on 1 February 2010. It has also signed but not yet ratified the Optional Protocol of the Convention on 29 September 2008. Article 35 of the CRPD requires governments to submit a report to the UN Committee on the Rights of Persons with Disabilities on their progress towards implementing the treaty. The first report should be submitted within two years of the Convention coming into force. Since the CRPD entered into force in Zambia in March 2010, the government was due to submit its State Report by March 2012. A number of DPOs participating in the implementation process have highlighted that no report was sent to the UN by this deadline. Civil society is still planning to make its own shadow report on

^{&#}x27;The Global Competitiveness Report' http://www.weforum.org/reports (accessed 31

The 2013 UN Human Development Report 'The Rise of the South: Human Progress in a Diverse World' UNDP.

the implementation of the Convention and hopes to present it in front of the UN in a few years. 40

3.2 Background information on the empirical data collection

This paper presents the findings of the interviews that were conducted with 12 disability organisations in 2012 in Lusaka as part of a field trip. 41 It was agreed that anonymity be preserved for the interviewees before recording, therefore personal references to staff members who participated in the study will be avoided.

In this chapter, primarily the answers of representatives of the disability movement will be analysed when describing factors of effective involvement in policy and decision-making processes. A few interviewees are not self-advocates themselves, but working for an organisation that is involved in the work of the monitoring framework. The study is far from scientific in the sense that it comes from the ground-up, but it intends to offer a first glimpse at active and effective involvement of the disability sector in implementing the Convention. This chapter does not give a fully comprehensive picture on the key factors of effective participation, but wishes to define some important prerequisites.

Article 33 implementation in Zambia 3.3

Zambia initially chose to designate several focal persons in the relevant Ministries under article 33(1) of the CRPD to coordinate the implementation of the Convention. However, civil society representatives were not satisfied with the performance and level of collaboration of these bodies. The Zambian Federation of the Disabled (ZAFOD) called on the Permanent Secretary of the Ministry for Community Development, Mother and Child Health Care to designate a fully competent focal person. 42 The government department made a clear statement in February

It is important to note that the UN CRPD Committee is facing some delays in evaluating the state reports. Since many countries have ratified the Convention right after it was open for ratification, a big number of reports were submitted around the same time.

The list of organisations who participated in the empirical research are: Zambia Federation of the Disabled (ZAFOD), Zambia Agency for Persons with Disabilities (ZAPD); Zambia Law & Development Commission (ZLDC); Sight Savers International (SSI); Opportunity Zambia (OZ); Zambia National Library and Cultural Centre for the Blind (ZNLCCB); Zambia National Federation of the Blind (ZANFOB); Mental Health Users Network of Zambia (MHUNZA); Zambia Association of Parents of Children with Disabilities (ZAPCD); Zambian National Association of the Deaf (ZNAD); a free-lance disability rights consultant.

ZAFOD is the umbrella organisation of DPOs representing 12 disability organisations.

2012 indicating that they are in the process of re-appointing focal points in every Ministry who will be in charge of disability issues. 43

Due to the lack of any state action to designate a CRPD compliant article 33(2) framework, ZAFOD initiated the establishment of the Independent Monitoring Unit (the IMU) to advance and monitor the implementation process of the CRPD. The purpose of the IMU is to assist in the 'domestication' of the CRPD into Zambian legislation. It is important to emphasise that despite the guidance of the Convention, the IMU was not formally acknowledged by government decision since its creation as an article 33(2) CRPD body. This is probably a direct consequence of the fact that the establishment was purely based on the advocacy work of civil society. It raises some concerns whether the state will recognise recommendations submitted by the IMU in the future.

The IMU is an 18 months project, thus there is no guarantee for its sustainability. Operation of the framework started in January 2011 after capacity building workshops had been carried out for staff members of the participating DPOs. Developing countries experience serious burdens when implementing international human rights treaties. The fact that the IMU project was founded by two major international donor organisations - the European Commission and Power International - draws attention to the obstacle that systematic monitoring activities, including data collection, requires sufficient resources from the state. ⁴⁴ The question is to what extent a state party should use sources of international co-operation to implement the Convention if there are no internal sources available in line with article 4 of the CRPD?

According to the first progress report of the IMU, the project has the specific objective to encourage civil society to independently promote and monitor domestication of the CRPD in Zambia. 45 The composition of the IMU is pluralistic including government departments and agencies, ⁴⁶ international human rights organisations, ⁴⁷ the National Human Rights Institution, ⁴⁸ and a number of umbrella DPOs. ⁴⁹

- More information on the work of the Ministry for Community Development, Mother and Child Health Care is available at http://www.mcdss.gov.zm/cultural.php (accessed 15 October 2012).
- The European Commission financed the project with €89,993 and Power International contributed €9,999.
- Zambia Federation of Disability Organisations (ZAFOD), Independent Monitoring Unit of the implementation of the domestication of the UN CRPD (IMU) *Periodic report* to the government by the IMU (December 2011).
- Ministry of Community Development, Mother and Child Health Care; Zambia Agency for Persons with Disabilities (ZAPD); relevant domestic government ministries (eg Health, Education Justice); Zambia Law Development Commission (ZLDC).
- Action on Disability and Development (ADD); Opportunity Zambia (OZ); International Labour Organisation (ILO); Power 4 Good/ POWER International.
- Human Rights Commission, Zambia.
 ZAFOD; Sight Savers International (SSI); Zambia National Federation of the Blind (ZANFOB).

The disability movement in Zambia under the leadership of the ZAFOD interprets article 33 of the CRPD as a 'way to form a framework for the government and civil society to [adequately] implement ... the Convention'. 50 ZAFOD emphasised the necessity to collaborate with a broad range of stakeholders, including non-governmental organisations outside of the disability movement. However, they believe that the leading role should be played by DPOs who have first-hand experience.⁵¹ It was actually a common misunderstanding within the disability movement, that a platform including different stakeholders would fulfil the requirement of pluralism under the Paris Principle and therefore could serve as an independent body. The IMU is far from being independent in the current structure as its membership consists of governmental bodies.

The Zambia Agency for Persons with Disabilities (ZAPD) is also part of the IMU among other ministerial departments. The Agency carries out a number of activities such as promoting and administering services for all persons with disabilities, keeping statistical records, advising the Ministries on the economic situation of persons with disabilities and coordinating rehabilitation with government bodies. Several interviewees clarified that the role of ZAPD in the framework is to be the link between government and civil society by facilitating an exchange of information. As one interviewee pointed out, the Agency could act as the watchdog and transfer the message from stakeholders to the Ministries. In many countries there is a communicational gap between government and civil society, which eliminates any constructive dialogue or collaboration. It is an interesting initiative in Zambia to resolve this problem.

How independent is the Zambian article 33(2) framework? 3.4

The Human Rights Commission, Zambia (HRC Zambia) is the National Human Rights Institution (NHRI) in the country. It is accredited by the International Coordinating Committee (ICC) as fully compliant with the Paris Principles. The HRC Zambia was established under article 125 of the Constitution of Zambia and mandated by the Human Rights Commission Act⁵² to inter alia investigate and remedy human rights violations, conduct human rights education, monitor the conditions under which persons are detained in prisons and elsewhere, and to monitor government's fulfilment of international and regional human rights treaties and human rights obligations under national law. In order to achieve compliance with the CRPD, the HRC Zambia shall play a role as an independent element in the framework established under article 33(2) of the CRPD to promote, protect and monitor the implementation process. Surprisingly, the institution does

The IMU periodic report (n 46 above). More information on the work of IMU is available at http://www.slideshare.net/ MilikaSakala/imu-report-to-government (accessed 25 January 2013).

not actively participate in the work of the IMU even though it is formally listed among the members.

The Zambian solution to implement article 33 is practically lacking the active contribution of the independent element, and therefore cannot be considered fully compliant with the CRPD. Drafters of the Convention logically incorporated the concept of independence into the framework to guarantee effectiveness and checks and balances of the mechanism. The NHRIs traditionally have experience in human rights monitoring but also play the role of the 'watchdog' to check that government decisions are in line with international human rights standards. Independence is essential to be able to effectively monitor human rights.

While looking for the reasons of the lack of collaboration between disability organisations and the HRC Zambia, the problem of miscommunication immediately became clear. The Commission claimed not to be invited to IMU meetings, however ZAFOD expressed their wish to collaborate with the HRC and thus guarantee sustainability and effectiveness for the monitoring framework.

In fact, the HRC Zambia has not yet been active in monitoring the rights of persons with disabilities, despite their aspirations articulated in the draft National Plan of Action for the period 2010-2020.⁵³ According to this working plan they are willing to carry out advocacy for the enactment of effective legislation for the protection of persons with disabilities and advocate for their involvement in the labour market. They acknowledge the importance to collaborate with the organisations of persons with disabilities and plan to establish a better working relationship with civil society on the occasion of the forthcoming Universal Periodic Review (UPR) and the UN CRPD Committee hearing. All of this shows that the working relationship between the NHRI and the disability movement is yet to be developed to be able to carry out the tasks under article 33 together.

3.5 Current focus of the Independent Monitoring Unit

A number of laws and policies are currently under revision in Zambia. In 2011, the newly elected government promised in its electoral campaign to 'change and benefit within 90 days'. Several interviewees reported that the government is really serious about law making, and keen on consulting with civil society to ensure a dynamic law-making process. It is a really important time for human rights advocates in Zambia to participate and incorporate provisions of the CRPD into disability related pieces of legislations being reviewed by parliament.

Human Rights Commission Zambia, Annual Report 2009 http://www.hrc.org.zm/ media/annual_report_2009.pdf (accessed 4 July 2013).

Presumably it varies significantly depending on the issue in question to what extent civil society wants to be involved in the policy-making process. If there is a debate on the situation of children with albinism in primary education, disability organisations may wish to turn the decision maker's attention to the needs of children with disabilities in schools facing multiple discrimination but do not necessarily participate in the whole process. In contrast, if the government is revising mental health legislation, disability organisations most likely seek to participate from the very beginning to push the discussion in a CRPD compliant direction. Therefore the adequate level of participation could be defined briefly as the highest possible presence that satisfies disability organisations.

3.5.1 The Persons with Disabilities Act

As one of the interviewees pointed out, the main priority for the IMU was the review of the Persons with Disabilities Act⁵⁴ to ensure the new law is compliant with the CRPD. The Bill was enacted in September 2012.⁵⁵ The IMU submitted comments during the review process, which were included in the draft text. Representatives of DPOs were satisfied that their voice was being heard. As one of them pointed out:

It takes a longer while for government to actually implement an international human rights treaty, but the IMU and civil society could provide them with sufficient guidance on how to do it right.⁵⁶

The priority areas the IMU focused on in its submission were education, employment, accessibility, mental health and legal capacity. Although the previous Act from 1996 contains a few solid provisions regarding antidiscrimination, education and accessibility, in general it refers to the old medical model by looking at persons with disabilities in a pitiful way, seeking only medical care and focusing exclusively on rehabilitation and the prevention of disability. DPOs working in the IMU agree that different pieces of legislation shall be CRPD compliant, and the new Disability Act must cover all civil and political rights and social, economic and cultural rights guaranteed in the Convention. Paragraph (b) of the Objectives of the new Persons with Disabilities Act includes a provision to 'promote the participation of persons with disabilities with equal opportunities in the civil, political, economic, social and cultural spheres'. ⁵⁷ Nevertheless Part V of the Act deals with specific areas in details, such as education, employment and social protection, health care, rehabilitation, accessibility and political and public life. 58

³³ of 1996.

http://www.parliament.gov.za.zm/index.php?option=com_docman&task=cat_view&gid=171&Itemid=113&limit=5&limitstart=0&order=date&dir=ASC (accessed 22 January 2013).

Interview with an advocate, 11 July 2012.

The Persons with Disabilities Bill, 2012.

The Bill (n 57 above) part V.

The constitutional review process

At the time of writing, Zambia is in the process of negotiating a new Constitution under the lead of a Technical Committee of Experts, appointed by the government. The Technical Committee started drafting the new Constitution on 1 December 2011. The review is a response to demands for a more democratic political system in the country. The state intends to promote transparency, accountability and the participation of people in governance by developing viable institutions.⁵⁹ According to Ndulo, the draft Constitution of Zambia retains dictatorial presidential powers as contained in the 1996 Constitution instead of moving towards a more democratic state. He argues that the draft even expands dictatorial powers by allowing the president to unilaterally divide and create provinces or districts or by appointing all the important posts without consultation.60

The constitutional review process, at least formally aims to be consultative and to reach a broad range of social groups.⁶¹ The government shows its willingness to involve public opinion in a meaningful way and promises that contributions will be taken into account in a systematic manner. This openness during the drafting procedure may create a favourable atmosphere for the disability movement to effectively advocate in a number of issues relating to the CRPD. Given the important momentum when the government put the concept of participation and democratisation on their political agenda, a highly marginalised group may find effective ways to advocate for a real change. Presumably the democratisation process in general facilitates the empowerment of civil society by stipulating the creation of a strong grass-root movement. ZAFOD and the Human Rights Commission have both submitted comments to the Technical Committee in regard to the new Constitution.⁶² ZAFOD was lobbying for including the provision of the equal recognition before law of persons with disabilities in line with article 12 of the CRPD.

3.5.3 Other legislation under review

There are two other acts under review in Zambia at the time of writing.

MB Ndulo 'Review of the Draft Constitution for the Republic of Zambia' Zambian Watchdog 20 August 2012.

Ndulo (n 59 above) 19.

http://zambianconstitution.org/ (accessed 4 July 2013).
Submission of the HRC Zambia is available here: http://www.hrc.org.zm/media/hrc_submission_to_technical_committee_on_drafting_zambian_constitution.pdf (accessed 4 July 2013); submission of disability organisations is available here: http://zm.sightsavers.org/in_depth/advocacy/14215_Submissions%20by%20a%20consortium%20of%20persons%20with%20disabilities%20organisations%20on%20the%20draft %20constitution.doc (accessed 4 July 2013).

One is the Town and Country Planning $\mathrm{Act},^{63}$ which is expected to include accessibility provisions in line with the CRPD. 64 The Human Rights Commission reported in 2010 that chapter 283 of the Act is lacking adequate regulation on accessible environments. 65 Thus, they suggested the government revise the instruments of area planning. The report also emphasises the importance of involving persons with disabilities from the very first stage in drafting the development plan and in prioritising which currently available financial resources can be spent on improving accessibility.

In addition, there is a review of the out-dated Mental Health Disorders Act 1951,66 which fails to promote the dignity and autonomy of persons with psychosocial disabilities.⁶⁷ The Mental Health Users Network of Zambia (MHUNZA) and ZAFOD have been actively involved in drafting the new Mental Health Act since July 2012 by collecting data, generating evidence and developing mental health policies in collaboration with international experts on mental health law. The main capacity builder in the region, Opportunities Zambia (OZ) emphasised that decision makers should meet with advocates to avoid drafting legislation influenced by the medical approach to disability.⁶⁸ It is important to educate government officials on the principles and obligations of the CRPD.

Criteria for effective participation through the example of the IMU

The following section discusses the experiences of the Zambian disability movement on how to achieve effective participation when implementing and monitoring the CRPD. Representatives of the IMU member organisations gave a clear idea about what they believe the key elements of effective involvement are. Some of the answers certainly overlap each other. It is important to note that the opinions presented here do not necessarily reflect the views of the disability sector as such.

- Town and Country Planning Act (Cap 283). For further information on the Town and Country Planning Act: http://faolex.fao.org/cgi-bin/faolex.exe?rec_id=038789&database=faolex&search_type=link&table=result&lang=eng&format_name=@ERALL (accessed 17 January 2013). The HRC Zambia 'State of Human Rights Report in Zambia: Human Rights & the
- Environment' UNDP, 2010.
- The Mental Health Disorders Act represents the old medical model and allowed detention of anyone who was suspected to be a person with a psychosocial disability. The law further went on to address people with psychosocial disabilities as idiots,
- imbeciles or morons.

 Mental Health and Poverty Project, Policy Brief Developing Effective Mental Health Laws in Africa http://www.who.int/mental_health/policy/development/MHPB7.pdf (accessed 18 January 2013).
- More information on the Mental Health Act review process is available at http:// www.opportunityzambia.org/?p=394#more-394 (accessed 27 January 2013).

Generally speaking, the range of critical success factors seems to be broad and sweeps beyond the common argument that the state party is lacking money to invest in disability rights. Rather, it includes elements such as the on-going democratisation process or the willingness of government to build up a collegiate relation and use the expertise of civil society.

Transparent early stage participation 3.6.1

It was agreed amongst the interviewees in Zambia that civil society needs to be included from the very beginning in any policy-making process to ensure their voice is being heard. In the view of Opportunity Zambia, transparency is an absolute prerequisite for facilitating engagement and effective involvement. The Zambia National Association of the Deaf highlighted the necessity of capacity building and empowerment of the disability movement. This can happen through professional training sessions to teach the disability organisations writing submissions and planning advocacy work. There is already interest expressed by the Zambia National Library and Cultural Centre for the Blind to attend more training on contributing to law reform processes.

3.6.2 Broad collaboration

A great challenge for an advocacy platform is to ensure the participation of a broad range of people coming from the grass-roots level. In Zambia, ZAFOD has already established close working relations with a number of DPOs and intends to find consensus before sending joint submissions to the government. International human rights NGOs, service providers, family organisations and researchers are important allies of the disability movement, however no considerable collaboration has happened with organisations outside of the IMU so far in regard to CRPD monitoring.

3.6.3 Awareness-raising at the grass-roots level

The IMU often works in smaller working groups to provide a better atmosphere for discussions. Interviewees found 'it is a good way to make in-depth recommendations and improve effectiveness'. Members of the IMU went to villages to raise awareness on the CRPD by bringing hard copies of the Convention in large print, Braille and easy-to-read versions. They wanted to educate members of the local disability communities on the provisions of the Convention and asked for input on the submissions the IMU was planning to prepare. This is certainly an important initiative to reach the local people and ensure their opinions are considered when promoting the rights of persons with disabilities at a higher level.

3.6.4 Continuous evaluation

Several interviewees emphasised that the work of the monitoring body also has to be monitored on a regular basis. The designated IMU should report back on any on-going issues to their local members in order to prevent arbitrary decision making practices in the platform.

3.6.5 Direct influence by providing evidence-based information

A simple but straightforward definition was given by Sight Savers Zambia on how to measure the impact of civil society participation: 'We can talk about effectiveness when our opinions are included in the final text of the law or policy document'. This is a great example to see the difference between active and effective involvement as mentioned above in the methodological section. Most interviewees expressed their disappointment when their involvement was tokenistic by being invited to meetings and not considered as partners in the policy-making process. They recognised when their involvement was only active not effective. Therefore disability organisations try to make sure that their contribution gets in the final version of the new Acts. However, the definition of Sight Savers symbolises the far end, when all opinions are considered. This definition does not solve the problem of measuring effectiveness if civil society contributions were only partly considered by the governing bodies. No other interviewees came up with a more precise definition.

Collecting representative data across the country and providing evidence-based information seems to be the area that requires most financial resources within monitoring activities. In this regard, challenges were reported due to the limited resources in disseminating results of research carried out by disability organisations.

4 Strengths of the work of the IMU

First and foremost, the greatest strength of the IMU lies in the commitment of members of the Zambian disability movement. They allocate their time and limited resources to review pieces of legislations, even if they have to do it on a voluntary basis. Their monitoring activities currently aim to incorporate the CRPD provisions into domestic law.

Although the intensity of the members' contribution within the IMU varies significantly, all of the interviewees were aware of the current national legislative changes, such as the review of the Constitution or the Persons with Disabilities Act. They also contributed to the submissions prepared by the IMU in one way or another. Representatives of DPOs seemed to be familiar with the provisions and national level implications of the Convention and used a very CRPD compliant language. Being able

to apply appropriate concepts of the CRPD, such as accessibility. reasonable accommodation, or supported decision making certainly facilitates a stronger position of civil society during negotiations with the government bodies.

A number of the IMU member organisations emphasised the importance of engaging in strategic advocacy work by planning and lobbying in a structured manner. Pro-activity and initiating meetings with the previously identified stakeholders is another asset, which promotes sustainability of participation. As mentioned above, the IMU raises awareness on the CRPD and involves the voice of the community through maintaining connections with the grass-roots level. This facilitates better representation. There is no available data on the frequency of such meetings, but the initiative can be certainly considered a great example and may be followed by other countries.

Another important achievement of the established IMU is that it could help to bring together the fragmented disability movement for a common purpose, namely to address disability rights to the government effectively. A representative of a big organisation emphasised that it is a success of the IMU that the government now recognises the state obligations under CRPD and shows willingness to implement the Convention in different legislations and policies.

5 Challenges and recommendations

In the following section, there is a brief overview of some of the challenges the IMU is currently facing and a number of recommendations will be made on the necessary changes to improve the sustainability of the platform.

5.1 Lack of government support

Since the funding of the IMU comes to an end in January 2013 the project will probably face some serious challenges in the near future. The informational webpage of the IMU has already been de-activated due to budget matters. After the evaluation of the progress report, the platform still expects 25 per cent of the EU fund to come to the IMU. In the meantime they have received some funding from the Open Society Initiative of South Africa (OSISA) to cover activities for the next two years focusing on mental health issues and the Persons with Disabilities Act, which has now been enacted. ⁶⁹ The sustainability of the Monitoring Unit

More information on the Open Society Initiative in Southern Africa is available athttp://www.osisa.org/ (accessed 22 January 2013).

is still uncertain and a guaranteed fund would be necessary to enable them to strategically plan future activities.

Despite the fact that article 33(2) of the CRPD imposes a duty on the state to maintain, strengthen, designate or establish a framework that promotes, protects and monitors the implementation of the Convention, the Zambian government has not acknowledged the IMU as the monitoring body. Moreover, the state has not provided any funding for the IMU since it was established by civil society. This raises serious concerns on the effective operations of the IMU in the future and clearly questions its financial viability.

5.2 Unbalanced participation

The fact that ZAFOD as the umbrella organisation of DPOs in Zambia, takes the leading and coordinating role in the work of the IMU is understandable, although slightly concerning how much ZAFOD dominates the whole framework. Although ZAFOD represents 12 organisations, it does not represent every person with disabilities in the country. The IMU and ZAFOD are not distinguished in the notion of some IMU member organisations. Some of them consider the IMU as a business of ZAFOD rather than a common project. It may affect their willingness to share the tasks occurring in the monitoring process. The reason for the dominance of ZAFOD could be that they provide the secretariat for the IMU and organise the capacity building training for other DPOs. It might have a positive impact on the work of IMU if participants had a clearer understanding of the mutual contribution they are supposed to make.

Those members representing government entities did not feel actively involved in the work of the IMU. For instance, the Zambia Law Development Commission, which is tasked with 'review[ing] and consider[ing] proposals for law reform referred to the Commission by the Minister or the members of the public' has not interacted with the IMU on a regular basis. ⁷⁰ The Commission was unable to review the Disability Act, due to the short deadline provided and certain procedural burdens. However, they refer to their limited mandate and capacity to act only upon a government request; the legislation which established the Law Development Commission does not include such a limitation.

The Mental Health Users Network in Zambia has made a remark that the Anti-Gender-Based Violence Act 2011 reviewed by ZLDC still includes a discriminatory section regarding persons with mental health disabilities. According to the law, persons with mental health disabilities could only apply to a court for a protection order in case they are assisted

by a third party, and not on their own behalf. Disability advocates expressed disappointment that a non-CRPD compliant Act could be passed without any consultation between them and the Law Development Commission. Considering the current focuses of the IMU, the Law Development Commission could be a key strategic partner in reviewing draft legislations.

5.3 Representation

It is very challenging to ensure that the voice of the whole disability movement is being represented in submissions of the IMU. As many of the interviewees emphasised, one of the key elements of effective participation is to find a common direction that all relevant civilian actors agree on. It facilitates better lobbying by having broader co-operation. In contrast, Gemmill and Bamidele-Izu argue that it may be a mistake to seek 'consensus' as it could result in prolonged discussions and watered-down conclusions. 72 In Zambia some of the umbrella DPOs, do not have a nation-wide membership, however, they claim to be a national organisation and legitimate enough to represent a large number of people. This is the reason why the Norwegian Disability Consortium seeks to provide smaller grant schemes available for capacity building of fragmented parts of the disability movement in Zambia. 73

Lack of an independent element **5.4**

As mentioned earlier, it is essential to involve the HRC Zambia in the work of the IMU, as it would ensure independence and compliance with the Paris Principles. In Zambia, the disability movement has taken the leading role in establishing the monitoring mechanism, but at the same time missed out on the opportunity to facilitate an active collaboration with the independent Human Rights Commission. In the drafters' vision, the three core elements of the article 33 framework (government, NHRI and civil society) are conscious about the need for collaboration when sharing tasks among each other around the CRPD implementation. A lack of trust or bad experiences during previous collaboration between the NHRI and NGOs could be the reason for such isolation. Considering that the HRC Zambia has not done extensive work on disability matters before the CRPD entered into force, it is a learning process for the Commission as well. Presumably, the working method of the NHRI was neither accessible nor transparent towards civil society in the past. This can be seen as the reason why civil society does not consider closer collaboration with the

Gemmil & Bamidele-Izu (n 25 above) 78.

The Anti-Gender-Based Violence Act 2011 Part III 10. (4)?.

More information on the Norwegian Disability Consortium is available at http:// www.opportunityzambia.org/wp-content/uploads/2009/12/Criteria-OZ-Small-Grant s-Final-28082009.pdf (accessed 22 January 2013).

NHRI. It is certainly necessary to tackle isolation and establish the basis of a more inclusive and balanced relationship between the entities involved in the article 33(2) framework.

6 Conclusion

There is a very strong, well-organised disability movement in Zambia actively involved in implementing the CRPD through a grass-roots initiative, the IMU. The government has neither formally designated the IMU as an article 33(2) monitoring framework, nor provided funding for its operation. Therefore, the Zambian solution cannot be considered as a promising practise for article 33 implementation. Yet, the disability movement raises awareness of the Convention, actively participate in lawreview processes and strategically plan their advocacy work. In their view, the leading role in advocacy should be played by persons with disabilities from the very first stage.

According to article 33 of the CRPD, an independent element, preferably, the Paris Principle compliant National Human Rights Institution shall be involved in the framework to promote, protect and monitor the implementation of the CRPD. In Zambia, despite of the fact that the Human Rights Commission is currently not participating in the monitoring activities, civil society seems to be satisfied with the functioning of the framework and finds its own involvement active and effective. It may be time-consuming but it is definitely necessary to establish good relations between the Human Rights Commission and the disability movement based on mutual trust and acknowledgement. This would stipulate important structural changes and engagement when implementing the Convention.

Since the current focus of the IMU is around law-review processes, some other tasks relating to protection or monitoring CRPD implementation under article 33(2) may be neglected. They work closely with the government who shows willingness to provide a supportive atmosphere for civilian participation and consider seriously the submissions and professional advices of the DPOs. Facilitating the strong involvement of the disability movement in monitoring the CRPD could enrich the democratisation process in Zambia.

After creating a CRPD compliant legal base in national legislation, at a next stage, the IMU aims to monitor the implementation of those acts and the CRPD countrywide. Even if the IMU is facing financial challenges, members of the disability organisations make an enormous effort to be able to keep on the monitoring activity and make a real change in line with the UN CRPD.