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ADVANCING HUMAN RIGHTS IN OUR REGION

# Human Rights and Disability



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Asia Pacific Forum of National Human Rights Institutions  
GPO Box 5218  
Sydney NSW 1042  
Australia

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*Left:* Afghanis, including many with disabilities, gather to celebrate the International Day of Persons with Disabilities in Kabul, Afghanistan. UN Photo/Fardin Waezi.

*Centre:* Worker with a disability in Dong Nai, Vietnam. Photo by ILO in Asia and the Pacific/A. Nguyen, reproduced under a CC BY-NC-ND 2.0 license.

*Bottom:* A participant take pictures at a special event at the United Nations, New York on the International Day of Persons with Disabilities. UN Photo/Amanda Voisard.

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## Foreword

We both, separately and together, warmly welcome this publication. We wholeheartedly endorse its central theme which has to do with national human rights institutions working in partnership with civil society to bring about meaningful change to advance the rights of persons with disabilities in every corner of the world.

The paradigm shift in the Convention on the Rights of Persons with Disabilities away from charity and welfare towards human rights needs champions – people and institutions that understand the nature of the changes at the level of ideas and who are able to translate these ideas into practicable blueprints for legal and policy reform.

It is these reforms that transform lives. National human rights institutions have evolved considerably since the early 1990s. In many corners of the world they let in the fresh air of international law to inform the domestic process of change. In this way, they both honour international human rights law and add value to local democratic processes. Just as important, they interact extremely effectively with international mechanisms, including the UN Committee on the Rights of Persons with Disabilities and the UN Special Rapporteur on the Rights of Persons with Disabilities.

This fruitful interaction not only assists international mechanisms to appreciate the complexity of change and to arrive at a better informed and more nuanced understating of the circumstances of the relevant State party, it also helps to move the process of domestic change forward. NHRIs are now active contributors to the international monitoring system and they are also avid consumers of the jurisprudence of the CRPD Committee and other treaty monitoring bodies.

The UN system is increasingly receptive to the active engagement of NHRIs, as demonstrated by the landmark General Assembly Resolution 70/163 of December 2015. This is as it should be. Indeed, the CRPD Committee adopted Guidelines on its interaction with NHRIs in August 2016 (see Part II of this Manual). These Guidelines have been crafted to get the very best out of the interaction between NHRIs and the treaty monitoring body. Indeed, the Guidelines serve as a model for other treaty monitoring bodies to follow.

The level of NHRI engagement is already impressive. With this Manual, it should increase and grow in effectiveness. The real winners are people with disabilities, who are sometimes invisible and voiceless in their own communities. Eleanor Roosevelt said that human rights begin in small places. This Manual will play its part in helping us reach those small places.

We welcome the publication of this Manual and commend it as source of insights into effective engagement of NHRIs to the mutual advantage of civil society, international treaty monitoring mechanisms and persons with disabilities in their communities.



**Kieren Fitzpatrick**  
**Director**  
**Asia Pacific Forum of**  
**National Human Rights Institutions**



**Maria Soledad Cisternas Reyes**  
**Former Chair**  
**UN Committee on the**  
**Rights of Persons with Disabilities**

# Acknowledgements

## About the Authors

**Neil Crowther** is an independent expert on equality and human rights with a particular interest in working to secure the rights of persons with disabilities: [www.neilcrowtherconsulting.com](http://www.neilcrowtherconsulting.com).

**Professor Gerard Quinn** is a professor of law at the National University of Ireland, Galway. He serves as Director of the Centre for Disability Law and Policy which was established at the University in 2008. He served two terms with the Irish Human Rights Commission and was the ICC representative during the closing stages of the drafting of the Convention on the Rights of Persons with Disabilities.

**Abigail Rekas** is Ph.D. candidate in Law at the Centre for Disability Law & Policy, National University of Ireland Galway, focusing on access to culture and disability. She holds a JD from Northeastern University School of Law, is a member of the Bar of the Commonwealth of Massachusetts and is a former Marie Curie Early Stage Research Fellow.

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## Dedication

This manual is dedicated to the memory of Caroline (Cabs) Gooding (1959 – 2014), a true pioneer of NHRI work on disability.

## List of abbreviations

<b>APF</b>	Asia Pacific Forum of National Human Rights Institutions
<b>CAT</b>	Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
<b>CEDAW</b>	Convention on the Elimination of All Forms of Discrimination against Women
<b>CRC</b>	Convention on the Rights of the Child
<b>CRPD Committee</b>	UN Committee on the Rights of Persons with Disabilities
<b>DPO(s)</b>	disabled persons' organisation(s)
<b>EU</b>	European Union
<b>ENNHRI</b>	European Network of National Human Rights Institutions
<b>GANHRI</b>	Global Alliance for National Human Rights Institutions
<b>ICC</b>	International Coordinating Committee of National Institutions for the Promotion and Protection of Human Rights
<b>ICCPR</b>	International Covenant on Civil and Political Rights
<b>ICESCR</b>	International Covenant on Economic Social and Cultural Rights
<b>NGO(s)</b>	non-governmental organisation(s)
<b>NHRI(s)</b>	national human rights institution(s)
<b>OECD</b>	Organisation for Economic Cooperation and Development
<b>OHCHR</b>	Office of the High Commissioner for Human Rights
<b>UN</b>	United Nations
<b>UN CRPD</b>	UN Convention on the Rights of Persons with Disabilities
<b>UPR</b>	Universal Periodic Review
<b>WHO</b>	World Health Organization



# Introduction for users

**2. Reaffirms the importance of the development of effective, independent and pluralistic national human rights institutions for the promotion and protection of human rights ...**

**17. Invites the human rights treaty bodies ... to provide for ways to ensure the effective and enhanced participation by national human rights institutions compliant with the Paris principles in all relevant stages of their work.**

**UN General Assembly Resolution 70/163 of 15 December 2016  
National institutions for the promotion and protection of human rights**



This Manual is designed to provide practical guidance for national human rights institutions (NHRIs) that are actively working to advance the human rights of persons with disabilities, as well as those NHRIs that are seeking to strengthen their efforts in this area.

Because of their unique role and position, NHRIs can be key agents to bring about positive change in their countries for persons with disabilities.<sup>1</sup> Through their work, NHRIs help ‘translate’ the majestic generalities of international law into a practical agenda for reform at home, where it matters most.

This Manual provides practical guidance and recommendations about how the role and functions of NHRIs can be directed to provide better protection for persons with disabilities, to promote greater awareness and respect for their rights, and to monitor the progress made and obstacles encountered in advancing their rights

## THE ROLE OF NHRIs

There are a number of roles that NHRIs can and should play to promote and protect the rights of persons with disabilities, irrespective of whether the relevant State has ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).<sup>2</sup> Needless to say, the widespread ratification of the UN CRPD gives added urgency to this task.

The Convention, which was adopted by the UN General Assembly on 16 December 2006, has already had a massive impact in transforming the lives of persons with disabilities around the world. While persons with disabilities and their representative organisations have been the prime movers, NHRIs have been integral to this process of change made possible by the UN CRPD. Indeed, the Convention requires civil society and NHRIs to play separate but complementary roles. This has created a new politics of disability.

There are many innovations in the UN CRPD. However, a key area of innovation discussed in this Manual is the specific role it sets out for NHRIs in the process of reform and change (article 33(2)). That NHRIs have a role to advance all human rights is beyond doubt, but to have that role articulated in a

<sup>1</sup> See R. Goodman, *Human Rights, State Compliance, and Social Change: Assessing National Human Rights Institutions*, 2012; see also G. De Beco and R. Murray, *Commentary on the Paris Principles on National Human Rights Institutions*, 2014; see also Danish Centre for Human Rights, B. Lindsnaes, L. Lindholt and K. Yigen (eds), *National Human Rights Institutions. Articles and Working Papers: Input into the Discussions on the Establishment and Development of the Functions of National Human Rights Institutions*, 2000, available at [www.nhri.net/pdf/nhribook.pdf](http://www.nhri.net/pdf/nhribook.pdf).

<sup>2</sup> General Assembly resolution 61/106, 24 January 2007. The full text of the Convention is available at [www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html).

major treaty is almost as unique as it is welcome.<sup>3</sup> Those who drafted the Convention – which included representatives from NHRIs – realised that elegant pronouncements within the UN system are unlikely, on their own, to drive change at the domestic level.<sup>4</sup> Something else was needed to ensure a dynamic linkage between the rights set out in the UN CRPD and the domestic process of change.

Accordingly, the Convention describes a rich triangular relationship between civil society, governments and NHRIs. First of all, this requires that persons with disabilities and their representative organisations are directly involved in the policy development process and in decisions that affect them (articles 4(3) and 33(3)). This is in keeping with the Convention's deeper commitment to the full and equal personhood and voice of all persons with disabilities. Second, there is no point in strengthening the collective voice of persons with disabilities unless governments become more sensitised to their rights. That is why the UN CRPD calls for “joined up” government efforts on disability issues, with an obligation to take on board the views of civil society (article 33(1)).<sup>5</sup>

Of course, any process of change needs a reality check. That is why a major driver in the ‘new politics of disability’ that the Convention envisages is a ‘framework’ for monitoring, promoting and protecting the rights of persons with disabilities, specifically including independent NHRIs in this work (article 33(2)).<sup>6</sup> NHRIs play a significant part not just in monitoring – and thus providing a reality check on the process of change – but in promoting the goals and principles of the UN CRPD and intervening to protect and advance the rights and interests of persons with disabilities. All three pillars in this process of change are important. However, the relationship between civil society and NHRIs is particularly important since they are both, in their own ways, important and mutually reinforcing agents of change.

This Manual seeks to describe the constructive role that NHRIs can play in this reform process. It also shares a number of examples of good practice to encourage and equip NHRIs for this work.

## THE VALUE OF NHRIs IN THE INTERNATIONAL HUMAN RIGHTS SYSTEM

NHRIs have an important role to play in the international human rights system, both generally and in relation to disability. They can and do contribute to the various treaty monitoring bodies when reviewing the record of their own countries. They can and do participate in the Universal Periodic Review (UPR). They can and do participate in norm-setting activities, most recently in the processes of the Open Ended Working Group to consider proposals for drafting a new thematic treaty on the rights of older persons. And, of course, they interact with the special procedures of the UN Human Rights Council, including the Special Rapporteur on the rights of persons with disabilities. Further, as Professor Andrew Byrnes recounts, NHRIs played a prominent role in drafting the UN CRPD.<sup>7</sup> They also collaborate regionally to assist one another and to contribute to regional human rights mechanisms, including those related to disability. In short, NHRIs are active participants in helping to inform, shape and reshape international human rights mechanisms and the understanding of international human rights norms.

This two-way focus – contributing at the international level and in domestic processes of change – has been welcomed and endorsed by the UN treaty monitoring bodies, including the Committee on the Rights of Persons with Disabilities (the CRPD Committee) and the UN General Assembly.

3 See also the Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment; available at [www.ohchr.org/EN/ProfessionalInterest/Pages/OPCAT.aspx](http://www.ohchr.org/EN/ProfessionalInterest/Pages/OPCAT.aspx).

4 G. Quinn, ‘Resisting the ‘Temptation of Elegance’: Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?’, in O. Mjöll Arnardóttir and G. Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, 2009.

5 Ibid.

6 Ibid.

7 A. Byrnes, ‘The Role of National Human Rights Institutions’, in M. Sabatello and M. Schulze (eds) *Human Rights and Disability Advocacy*, 2014, pp. 223-238.



Participants of the Fifth Session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities to review good practices and challenges in the implementation of the Convention. UN Photo/Evan Schneider

The CRPD Committee met with NHRIs and other national monitoring mechanisms designated under article 33(2) on 25 September 2014. The goal was to explore ways in which NHRIs can contribute to monitoring both at the international and domestic level. The ‘outcome document’ from the meeting proposed several steps to deepen the mutual engagement of both, including drafting Guidelines on the participation of NHRIs in all stages of the Committee’s work. These Guidelines follow logically from the precedent of the 2014 Guidelines on the engagement of civil society with the CRPD Committee.<sup>8</sup> In preparing its Guidelines, the Committee pledged to work closely with NHRIs. The Committee published its draft Guidelines in May 2016 and they were adopted in August 2016. Detailed information about the Guidelines is provided in Part II of this Manual.

8 *Guidelines for the Participation of Disabled Person’s Organizations (DPOs) and Civil Society Organizations in the work of the Committee, CRPD/C/11/2, Annex II, April 2014.*

More generally, in an important Resolution on ‘National institutions for the promotion and protection of human rights’, adopted on 17 December 2015,<sup>9</sup> the UN General Assembly specifically welcomed the work of NHRIs in the Conference of States Parties to the Convention on the Rights of Persons with Disabilities and actively encouraged all treaty monitoring bodies – including, specifically, the CRPD Committee<sup>10</sup> – to further enhance the participation of NHRIs.<sup>11</sup> This Resolution reflects growing practice across the UN system and is a welcome encouragement for greater engagement by NHRIs on disability issues and other human rights issues more broadly.

This Manual includes an in-depth look at the concluding observations of the CRPD Committee on article 33(2) in its 2015 sessions (see Part II) involving 33 States. The Committee’s recommendations are unusually strong and clear. Although most States have yet to fully comply with the letter and spirit of article 33(2), it is clear that the Committee has a very positive vision of the role of NHRIs, especially when they work closely with civil society. This ensures there is space for ‘added value’ to be generated by NHRIs in the area of disability and human rights. Part II also features examples of valuable work that has been undertaken by NHRIs, which demonstrates promising practice that can be emulated by others.

In 2016, seven State reports were considered by the CRPD Committee during its session in March/April; six parallel reports (or ‘shadow reports’) were submitted by NHRIs. These parallel reports are generally short, focused and designed to alert Committee members to specific challenges that the NHRIs have noted in their respective countries. This contribution of independent and credible information is of great value to the Committee. NHRIs have also been present at most of the Committee’s open ‘Days of Discussion’ and they have contributed actively to the drafting of general comments and other statements. This is a very substantial track record and one that will only grow in importance in the future.

## INNOVATIONS IN THE CONVENTION

To fully appreciate the added value and potential of NHRIs as agents of change, it is important to understand the relatively recent switch to a human rights framing of disability. Key to understanding this new framing is recognising that the UN CRPD does not create new human rights, much less ‘disability rights’. Instead it endorses and promotes the move away from a ‘welfare’ or ‘charity’ model to one based on fundamental human rights and freedoms in the context of disability.

In the past, people with disabilities were seen as ‘objects’ to be managed or cared for. The result was a mountain of laws and policies – held together by outdated attitudes – that locked persons with disabilities out of the mainstream and otherwise segregated them. Thanks to the human rights framing of disability, persons with disabilities are now seen as full and equal human ‘subjects’ who enjoy all the rights and privileges of other citizens.<sup>12</sup> The UN CRPD, therefore, has huge symbolic importance by endorsing the human rights framing of disability, something that civil society had demanded for the previous two decades or more. This is the focus of Part I of the Manual.

More practically, the Convention tailors general human rights norms and obligations that apply for the benefit of all people to the very specific situations and accumulated disadvantages faced by persons with disabilities. It seeks to reverse the legacy of the past and to create a future of equal opportunities for all. The UN CRPD is, therefore, an integral and complementary part of the existing set of UN human rights treaties.

Situating the UN CRPD within the existing body of international human rights law is very important. However, the Convention also innovates in several important respects. In fact, its many innovations are very relevant for how we think about existing human rights law. For one thing, it expands our idea

9 General Assembly resolution 70/163; available at [www.asiapacificforum.net/resources/ga-resolution-nhris-2015/](http://www.asiapacificforum.net/resources/ga-resolution-nhris-2015/).

10 Ibid, para. 16.

11 Ibid, para. 14.

12 D. MacKay, ‘The United Nations Convention on the Rights of Persons with Disabilities’ in *Syracuse Journal of International Law and Commerce*, Vol. 34, 2007, pp. 323-331.

of what it means to be human and how to empower people to take charge of their own lives through a richer conception of legal capacity (article 12). Many human rights treaties seek to foster equality of opportunities by opening up spaces that had previously been closed to the protected group. The UN CRPD goes much deeper by highlighting the ‘civil death’ of persons with disabilities and their invisibility in the law. Uncloaking this hidden voice is key to enabling people with disabilities to emerge from the control of others and take charge of their own lives. But there is little point in having this voice unless one can have real choices in the world. That is why the right to live independently and to be included in the community are of such importance (article 19). These can be things that are taken for granted by most people. However, they are particularly powerful in the context of human rights and disability as these basic choices have been systematically denied to persons with disabilities in the past.

Change is inherently difficult since many countries find it ‘normal’ to deny voice and legal capacity to persons with disabilities and have problems moving away from long-standing patterns of institutionalisation and segregation. NHRIs, therefore, have a particularly important role to play in promoting and advocating reforms that restore voice and choice to persons with disabilities.

The Convention also innovates by emphasising how an identity like disability interacts with other identities, such as gender and age (articles 6 and 7). This first attempt to articulate ‘intersectionality’ in international law helps highlight the layered nature of human identity – that a person is not just disabled but also a woman or older person – and how multiple and accumulating forms of discrimination and disadvantage can arise through these intersecting identities. This focus on intersectionality is a major advance on existing international law. Many NHRIs already undertake work with a clear understanding of intersectionality, employing broad themes that sweep beyond narrow identities. This innovation in the UN CRPD gives added impetus to that work, which assists persons with disabilities and has positive effects for others, especially older persons.

The Convention also creatively melds civil and political rights with economic, social and cultural rights, allowing the latter to play a much more direct role in realising the autonomy and freedom of persons with disabilities. It is obvious that social and economic programs are needed to roll back the legacy of the past; for example, de-institutionalisation and the creation of more accessible workplaces. It is equally obvious that guarantees to formal rights on their own are not enough. People need access to the material supports that will enable them take advantage of their newly-won freedoms, such as supports that enable them to take up employment or live in the community.

This co-mingling of traditional obligations to avoid negative treatment with obligations to ‘progressively achieve’ socio-economic rights for persons with disabilities is a highly innovative aspect of the UN CRPD. Indeed, it perhaps restores us to the original vision of the Universal Declaration of Human Rights adopted in 1948. This co-mingling was due, in part, to the fact that traditional social programs were seen as part of the problem, in that they were designed simply to ‘cushion’ persons with disabilities who were otherwise excluded from the mainstream. That traditional approach is now turned on its head, with the result that socio-economic rights are seen in the Convention as key enablers that allow persons with disabilities to live their own lives and to participate actively in their communities. Of course, this has not made the traditional tension between obligations of ‘immediate effect’ and obligations of ‘progressive achievement’ go away. But it has given fresh life to economic and social rights as key enablers of real freedom for persons with disabilities.

A related innovation in the Convention is the positive obligation to provide ‘reasonable accommodation’ for persons with disabilities. Rather uniquely, a failure to achieve this obligation amounts to discrimination under the UN CRPD (article 5(3)). Although not intended to bring about systemic change, the ‘reasonable accommodation’ obligation seeks to tailor general obligations to the very specific circumstances of individuals and applies across all the rights in the Convention. How well this obligation functions is of interest not only to persons with disabilities but also to others, such as older people, who could perhaps benefit from a similar innovation.<sup>13</sup>

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13 C. Jolls, ‘Accommodation Mandates’ in *Stanford Law Review*, Vol. 53, 2000, pp. 223-306.

## ORGANISATION OF THIS MANUAL

This Manual is divided into three Parts.

**Part I deals with ideas.** This is foundational since the move to a human rights framing of disability is both recent and not yet widely understood. It is a shift in values that really matters. However, the daily reality for most people with disabilities is still a long way from these ideals. The legacy of the past will not be erased easily and NHRIs have a critically important role to play in both promoting and popularising this shift to a new way of understanding disability. And, from a very practical point of view, it is clarity on these ideas that will assist NHRIs in deciding which strategy to follow, what to prioritise and how to ensure that their work complements the calls for change made by others.

**Part II deals with the law.** It traces how the shift to this new framing of disability at the level of ideas has informed the development of international and regional human rights law. Front and centre is the Convention on the Rights of Persons with Disabilities. A consideration of its main features – the rights protected, the obligations imposed and the mechanisms for change envisaged – and its operation at the international level is necessary to ground the work of NHRIs and give it practical application at the domestic level.

It is also important to understand the impact of the UN CRPD across other long-standing human rights treaties. Many NHRIs will already have a strong track record on, for example, promoting and protecting the rights of women. They will increasingly have to consider the rights of disabled women in their ongoing work.

Likewise, it is important to be aware of the impact of the Convention within regional organisations and on their human rights instruments; for example, the European Union and the Organization of American States. The ripple effect of the UN CRPD is strong and NHRIs will increasingly be required to mainstream their disability work across these diverse instruments.

**Part III deals the process of change** and the key role that NHRIs can and should play. Since the process of change is multi-faceted and principally involves people with disabilities, this calls for a close relationship between NHRIs and civil society to ensure that the voice of people with disabilities is expressed and heard. NHRIs must be internally organised and operate in ways that model respect for the rights of persons with disabilities. They should also ensure that the general responsibilities of NHRIs to ‘promote, protect and monitor’ the human rights of persons with disabilities is done to the greatest effect.

Each country will have its own legacy from the past to untangle. Each will have its own culture and attitudes that either help or hinder the process of change. Each will have its own political system through which change can be achieved. NHRIs are ideally placed to both grasp the importance of international law and to tailor it to their local circumstances. Any respectable theory of change must include NHRIs. Indeed, the evidence presented in this Manual demonstrates that NHRIs can play a hugely important role in driving the process of change.

# Part I

## The concepts: The human rights framing of disability



**Chapter 1: The human rights re-framing of disability**  
**Chapter 2: Key elements of the human rights frame on disability**

## Introduction to Part I

**Disability studies provide the theoretical background for what we call the shift from the medical to the social model of disability. The social model of disability was developed as a critique to the medical model of disability. However, within disability studies, the social model of disability has been almost as strongly criticized as the medical model of disability. Michael Oliver, one of the founding fathers of the social model of disability, has recently called for a halt to this criticism, unless someone can come up with a better alternative.**

**The CRPD offers such an alternative: the human rights model of disability. It is by no means the only alternative to the social model of disability (many models have been developed, among them recently the capability approach model<sup>14</sup>), but the human rights model is an improvement on the social model of disability, and it is a tool to implement the CRPD.**

**Theresa Degener<sup>15</sup>**



Part I of this Manual aims to clarify the nature and implications of the shift to the human rights frame on disability. The move to the human rights frame is revolutionising the way people, governments and NHRIs view disability. Of course, there is nothing revolutionary in human rights. But its application to disability is still novel and indeed revolutionary, especially considering where most countries have come from.

The shift from one way of thinking to another has practical implications in both policy and law. It provides a new prism through which to view reality. Facts that may not seem relevant within an old frame suddenly come to life within a new one. For example, the exclusion of children with disabilities from mainstream schooling might seem 'natural' under an old frame but it should strike us as unfair under a new human rights frame. A new frame can also provide us with the moral and legal tools to judge the facts as we see them. For example, the exclusion of children with disabilities from inclusive education should now register as a practice that cannot be justified. It gives us clear norms with which to judge the facts, which we now see differently. Indeed, this new frame provides us with the normative basis for advocacy to bring about systemic reform; a blueprint for change that goes beyond seeking redress for individual violations.

The move to the human rights frame entails a wholesale change in how we think about disability. Instead of making the person the 'problem', we are required to identify the barriers to the enjoyment of human rights facing persons with disabilities. Traditional approaches rely on outdated notions of disability that focus more on the peculiarities of the person (as medically understood) than on the barriers to their self-realisation in the world. It follows that one of the first and most important implications of the move to the human rights frame has to do with how disability is framed in law, in public policy and in community attitudes.

14 S. Mitra, 'The Capability Approach and Disability' in *Journal of Disability Policy Studies*, Vol. 16, No. 4, 2006, pp. 236-247; available at <http://dps.sagepub.com/content/16/4/236>.

15 T. Degener, 'A Human Rights Model of Disability,' in P. Blanck and E. Flynn (eds.), *The Routledge Handbook of Disability Law and Human Rights* (forthcoming).

The seemingly arid topic of the definition of disability is actually at the heart of the new framing. A new, non-medical approach has symbolic significance because it promotes the understanding that ‘people are not problems’. Instead, people with disabilities have rights and their problems, such as they are, are located elsewhere. It also has practical significance as it keeps legislators, bureaucrats, service providers and others focused on these barriers and, hopefully, finding solutions to them.

Chapter 1 looks at the shift to the human rights frame and the implications for how law and policy understand and define disability. There has, of course, been a succession of ideas that preceded the ‘human rights’ frame; from the ‘medical model’ of disability to the ‘social model’ of disability with its emphasis on equality of opportunities. The ‘social model’ was further developed into to a fuller ‘human rights’ model, which is explained below. Needless to say, NHRIs should be natural champions for this new framing of disability.

Chapter 2 looks at the process of change demanded by the move to the human rights frame. As noted in the introduction to this Manual, the Convention on the Rights of Persons with Disabilities does not create any new rights. Instead it seeks to make the protection and enjoyment of existing human rights available on an *equal* basis to persons with disabilities. This commitment to genuine equality is front and centre in the Convention. Equality demands that people with disabilities are treated with dignity and respect; that their voice is central in all matters affecting them; that their right to live independently and in the community is assured; that all preparatory processes for active citizenship, including education, are open and inclusive; that all access barriers to participating in their communities are systematically removed; that social supports actually support people with disabilities, not entrap them; and that any process of change is accompanied by a shift in community attitudes and understanding, which is both a precondition for change and a factor that helps sustain it.



Students with a disability at a primary school in Nuku'alofa, Tonga. The class is part of a pilot program for inclusive education. Photo by Connor Ashleigh for AusAID, reproduced under a CC BY 2.0 license

# Chapter 1:

## The human rights re-framing of disability

### KEY QUESTIONS

- What is the human rights frame on disability?
- What difference does it make to move to the human rights frame on disability?
- How and why has the conceptualisation and definition of disability changed as a result?



### 1.1. CONCEPTUAL RE-FRAMING: FROM THE 'MEDICAL MODEL' TO THE 'SOCIAL MODEL' TO THE 'HUMAN RIGHTS MODEL'

Disability has historically been regarded as a 'problem' of – and primarily for – the individual. It has commonly been seen as a 'deficit' of some kind; a physical, sensory, intellectual or mental deviation from a norm. Indeed, the term 'able bodied' has been used to mark persons with disabilities apart. This understanding informed the development of the old WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH).<sup>16</sup> The obvious intent – seen through the medical frame – was to correct the deficit ('fix' the person) or, failing that, care for the person. Transported into the public policy arena, this resulted in policy responses that sought to either cure or care, or a mix of the two. In the process, the impairment was used to define the person and the person, in turn, became the 'problem'.

The 'medical model' understanding of disability was not just about 'control' of the person by medical and other professionals.<sup>17</sup> It centred on the idea that the person's impairment was the primary thing that required attention, not the person behind the impairment. As a consequence, respecting and honouring the individual's personhood was overlooked, along with their equal right to pursue their own lives and dreams, with support where needed.

The medical model of disability reflected and reinforced the broader public policy response of 'cure or care'. While the seeming intent of this agenda was to care, it actually served to segregate and isolate persons with disabilities over time. The expectation that underpinned this policy response was that persons with disabilities could not and would not take part in mainstream community life and activities.

In practical terms, this meant that, for example, education was provided through segregated schools. It meant that employment options were geared toward segregated facilities and sheltered workshops, with little or no support for people to enter the open labour market. It meant that the various pathways into the physical (and online) environment were not adjusted to take account of the presence of persons with disabilities. It meant that social supports, when they were forthcoming, cushioned persons with disabilities rather than facilitated their active engagement in mainstream activities. It meant that the controlling voice we all expect to hold in our own lives was surrendered to others, including service providers. In relatively affluent States, it meant that the development of a social care floor that provided a minimum material baseline but did nothing to open up opportunities and enable people with disabilities

<sup>16</sup> Available at [http://apps.who.int/iris/bitstream/10665/41003/1/9241541261\\_eng.pdf](http://apps.who.int/iris/bitstream/10665/41003/1/9241541261_eng.pdf).

<sup>17</sup> See M. Crossley, 'The Disability Kaleidoscope' in *Notre Dame Law Review*, Vol. 74, 1999, pp. 621-716, see also M. Oliver, *Understanding Disability: From Theory to Practice*, 2009.

to take charge of their own lives and to pursue their goals on an equal basis with others. In less affluent States, it meant confining people with disabilities to their family homes or otherwise out of sight.<sup>18</sup>

If confronted to justify the status of persons with disabilities, most people in the past would automatically do so in terms of providing social welfare or social protection. They would not naturally view the situation of persons with disabilities from a broader perspective of social justice or human rights. This made it difficult for civil society organisations to advocate for a human rights frame on disability since they might be criticised for being ungrateful for the social supports provided to persons with disabilities. The resulting inequality, however, contributed to a vicious cycle of inequality and poverty. As persons with disabilities were marked apart – and then kept apart by public policies – their personal skills and capacities became degraded, which only served to reinforce in others the idea that the resulting inequalities were somehow ‘natural’. The resulting ‘spoiled identity’<sup>19</sup> set in train a self-perpetuating cycle of exclusion.

The problematic nature and unacceptable consequences of the ‘medical’ approach to disability was summarised by the Office of the United Nations High Commissioner for Human Rights (OHCHR):

[W]hen disability is perceived in this way, society’s responses are restricted to only one of two paths: individuals can be “fixed” through medicine or rehabilitation (medical approach); or they can be cared for, through charity or welfare programmes (charity approach). According to this old model, the lives of persons with disabilities are handed over to professionals who control such fundamental decisions as where they will go to school, what support they will receive and where they will live.<sup>20</sup>

The process of challenging this framing of disability only took hold in the past 30 years. The shift from the medical model to the ‘social model’ meant, first of all, understanding that a person with a disability is not *defined* by their disability; in other words, their personhood transcends their disability. Disability is something that complicates life but it does not efface it. Second, it means locating the human rights ‘problems’ that people with disabilities experience in the barriers that society has established. In other words, it is society that compounds the problems associated with the impairment and thus creates the disability; the so-called ‘social construction’ of disability.<sup>21</sup> While the impact of impairments or health conditions on the functional capacities of individuals is not denied, ‘disability’ is now best regarded as the product of an interaction between impairments and socially constructed *disabling barriers* that prevent people with impairments from exercising their own autonomy and from participating fully in all spheres of life. This is sometimes referred to as the ‘social model’ of disability or the ‘human rights model’.

Though closely related, the social model of disability does not exactly overlap with the human rights model of disability. One eminent commentator, Theresia Degener, current Vice President of the Committee on the Rights of Persons with Disabilities, draws six interesting distinctions between the two models.<sup>22</sup>

A first point of distinction is that the human rights model moves beyond social observation to provide the moral signposts for reform. Degener says that “while the social model merely explains disability, the human rights model encompasses values for disability policy that acknowledge the dignity of disabled persons”. Further, “the social model does not seek to provide moral principles or values as a foundation of disability policy. The CRPD, however, seeks exactly that.”<sup>23</sup>

18 E. Kamundia ‘Choice, Support and Inclusion: Implementing Article 19 of the Convention on the Rights of Persons with Disabilities in Kenya’ in *African Disability Rights Yearbook*, Vol. 1, 2013, pp. 49-72; available at [www.adry.up.ac.za/index.php/2013-1-articles/elizabeth-kamundia](http://www.adry.up.ac.za/index.php/2013-1-articles/elizabeth-kamundia).

19 For a classic statement on ‘spoiled identity’ – that is, internalising the views others hold on one and thus perpetuating a vicious circle – see E. Goffman, *Stigma: Notes on the Management of Spoiled Identity*, 1963.

20 OHCHR, *Monitoring the Convention on the Rights of Persons with Disabilities Guidance for Human Rights Monitors*, Professional Training Series No. 17, 2010; available at [www.ohchr.org/Documents/Publications/Disabilities\\_training\\_17EN.pdf](http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf).

21 See M. Crossley, ‘The Disability Kaleidoscope’ in *Notre Dame Law Review*, Vol. 74, 1999, p. 653; see also United States National Council on Disability, *Righting the Americans with Disabilities Act*, December 2004; available at [www.ncd.gov/publications/2004/Dec12004](http://www.ncd.gov/publications/2004/Dec12004).

22 T. Degener, ‘A Human Rights Model of Disability,’ in P. Blanck and E. Flynn (eds.), *The Routledge Handbook of Disability Law and Human Rights* (forthcoming).

23 Ibid.

A second point of distinction is the broader scope of the human rights model, which extends beyond traditional anti-discrimination law. Degener notes that “while the social model approach to disability policy supports anti-discrimination policy and civil rights reforms, the human rights model is more comprehensive in that it encompasses both sets of rights; civil and political, as well as economic, social and cultural rights”.<sup>24</sup> This point is particularly relevant when it comes to the Convention on the Rights of Persons with Disabilities because, as the Introduction to this Manual explains, the human rights model enabled the Convention drafters to go beyond the traditional scope of anti-discrimination law to focus on the personhood of persons with disabilities, including their full legal capacity to make decisions. This approach also enabled them to bring together economic, social and cultural rights with civil and political rights.

A third point of distinction involves an honest acknowledgement of the difference – and sometimes the pain – associated with impairment. The social model, on one reading, does not give sufficient attention to the reality of this difference. The human rights model, according to Degener, “acknowledges these life circumstances and demands them to be considered when social justice theories are developed”.<sup>25</sup> In other words, disability is not purely a social construction. It is real and it requires us to face it and respond positively.

A fourth point of distinction is that there is greater scope within the human rights model to acknowledge multiple identities and the importance of identity. The point Degener makes is that traditional human rights law has within it the capacity to move beyond an identity-specific focus – for example, women, race or disability – and that this capacity is underlined by several provisions in the UN CRPD that acknowledge overlapping and intersecting identities, especially in relation to women with disabilities and children with disabilities.

A fifth point of distinction is that while prevention is not encompassed within the social model, it can be part of a human rights approach – albeit under certain limited circumstances. According to Degener, the focus of the social model was not on people with disabilities but on how they were treated by others. However, to her at least, public health preventive strategies can be encompassed within a human rights frame, provided that they do not stray into eugenics or worse.

Finally, the sixth point of distinction is that while the “social model of disability can explain why two thirds of the one billion disabled persons in the world live in poverty, the human rights model offers a roadmap for change”.<sup>26</sup> This highlights a key success of the UN CRPD. It seeks to put in place the necessary social and economic supports that can enable persons with disabilities to take charge of their own lives and assist them out of poverty.

These distinctions are worth bearing in mind. An important lesson that can be derived from Degener’s analysis is that while the human rights model of disability builds on the social model, it also complements it in two important ways: first, by providing a normative basis on which to judge the status of persons with disabilities and, even more importantly, to drive a process of reform and change.

Advocacy movements around the world have been highly successful over the past 30 years in changing the narrative on disability. We have moved decisively away from the medical model, to the social model, and now to the human rights model, with its emphasis on change.<sup>27</sup> This advocacy was sparked by the advent of the civil rights movement in the United States in the 1960s, especially the passing of the 1964 Civil Rights Act. It led to a parallel re-framing of disability issues as civil rights issues in the disability community and a demand for legislation equivalent to the Civil Rights Act. A series of disconnected pieces of legislation were adopted in the 1970s and 1980s before culminating in the Americans with Disabilities Act (ADA) of 1990. The passage of this legislation brought worldwide attention and guided

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24 Ibid.

25 Ibid.

26 Ibid.

27 See, for example, National Council on Disability, *Righting the Americans with Disabilities Act*, December 2004.

global civil society advocacy towards an equality framing on disability. Indeed, this had implications for the constant framing and re-framing of disability at the international level.

However, as recently as the United Nations World Programme of Action on Disability in 1982, the traditional focus of disability policy was on prevention and rehabilitation. The equality agenda, in as much as it featured, was generally tacked on as an extra consideration. This traditional narrative changed dramatically with the UN General Assembly Resolution on the equalisation of opportunities for persons with disabilities (1993) which – as the title suggests – focused almost exclusively on civil rights and equality. A major impetus for this shift at the global level was the pioneering legislation in the United States and elsewhere.

This phenomenon of ‘borrowing’ at the international level from major innovations at the domestic level also affected regional organisations. The Council of Europe, for example, adopted a major set of policy guidelines for its Member States in 1992 that were based almost exclusively on an equality frame.<sup>28</sup> Likewise, the European Union signalled its firm policy adoption of the equality of opportunities model in 1996.<sup>29</sup>

This early shift to the equality model – an essential element of the social model of disability – in the 1990s gave civil society in every corner of the world a common language to discuss disability. This helped strengthen the emerging global disability rights movement and enabled it to connect across nations and regions. It led to a feeling of solidarity and a willingness to cooperate to achieve tangible results. It also meant that, when the time came, civil society organisations were ready, willing and able to make a leading contribution to drafting the Convention on the Rights of Persons with Disabilities.

While it employs an equality frame, the Convention goes broader to encompass a fuller human rights model (in the sense understood by Degener above). This is reflected in article 1 which states that the primary purpose of the Convention is to:

[P]romote, protect and ensure the *full and equal* enjoyment of all human rights and fundamental freedoms by all persons with disabilities.

This combined social model/human rights model has clear implications in how one views disability. The preamble to the Convention calls on States to recognise that:

[D]isability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.<sup>30</sup>

As such, the promotion of the rights of persons with disabilities involves identifying and removing socially constructed barriers that stand in the way of the enjoyment of human rights by persons with disabilities.

What the human rights framing of disability brings to light is the extent to which persons with disabilities were, in the past, treated as ‘objects’ to be minded, cared for and pitied, usually at the convenience of others. While the medical model marked people apart, it was the laws, public policies and a myriad of spending programs that actually kept people apart. It is this legacy that must now be tackled. The human rights model puts those laws, public policies and spending programs front and centre of any agenda for change. It also ensures that persons with disabilities are treated as ‘subjects’ capable of taking charge of their own lives and with an equal right to do so. It means treating people with disabilities *equally* with others.

28 Council of Europe, Committee of Ministers, Recommendation No. R (92)6 on a Coherent Policy for People with Disabilities, 9 April 1992.

29 European Commission, Communication of the Commission on Equality of Opportunity for Persons with Disabilities: A New Community Disability Strategy, COM(96) 406, 30 July 1996.

30 Preambular para. e.

It is interesting to note that the WHO International Classification of Functioning, Disability and Health – which is intended to be of use to States in designing their service systems – now embraces the social model/human rights model of disability by highlighting barriers to participation.<sup>31</sup> So the keeper of the medical model has itself now moved beyond a strictly medical approach to disability.

## 1.2. IMPLICATIONS OF THE HUMAN RIGHTS FRAME

If the focus of the human rights frame on disability is on removing the barriers to recognition as a person, and all that this entails for personal freedom and inclusion, then it is only logical that definitions of disability will have to alter. Most traditional definitions are based on the ‘deficit’ of disability. This has had the result of making the person the ‘problem’. The focus on impairment when defining disability should be avoided as it is not consistent with the human rights re-framing of disability from ‘object’ to ‘subject’.

Changing the traditional approach to disability in law, in public policy and in entitlement programs sends a very powerful message that it is the barriers that count, not the individual circumstances of the person. This entails law reform challenges for most States.

On occasion – and especially with regard to setting eligibility criteria for entitlement programs – States will be confronted with the need to define persons with disabilities with respect to certain impairments or the severity of the impairment. The shift to the human rights framing of disability – grounded as it is in the social model – does not entirely remove the need to make such definitions. After all, States need clarity about the coverage of the Convention and need to be able to distinguish persons with disabilities from others. Accordingly, the UN CRPD provides that:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.<sup>32</sup>

So impairment counts, whether it is physical, mental, intellectual or sensory. The Convention also insists that the impairment be long-term in nature, although it may be intermittent. However, severity does not count. This means, for example, that the right to live independently applies equally to those with severe or multiple disabilities as it does to those with impairments of a lesser degree or order. The nature or source of the impairment does not count. Indeed the preamble to the UN CRPD reminds States of the need:

... to promote and protect the human rights of all persons with disabilities, including those who require more intensive support.

This is something that is too easily forgotten when it comes to, for example, the exclusion of some children from inclusive education or some persons with disabilities, who have high support needs, from community living. Contrary to the ‘natural’ inclinations of some, the severity of impairment is itself not an excuse for exclusion. Of course, it might prove more difficult to achieve, as in the case of community living for those with high support needs. However, a situation such as this is exactly what the concept of ‘progressive achievement’ seeks to address. The existence of a severe impairment is not, by itself, a reason to deny a person with high support needs the right to live in the community with others. Although the severity of the disability may require different approaches to the realisation of that right, it does not in itself negate the right.

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31 Available at [www.who.int/classifications/icf/en/](http://www.who.int/classifications/icf/en/).

32 Article 1.

The human rights framing of disability and, specifically, the rights set out in the Convention are relevant to an extremely broad section of the world's population. As the WHO World Report on Disability (2011) noted:

Persons with disabilities are diverse and heterogeneous, while stereotypical views of disability emphasise wheelchair users and a few other 'classic' groups such as blind people and deaf people. Disability encompasses the child born with a congenital condition such as cerebral palsy or the young soldier who loses his leg to a land mine, or the middle aged woman with severe arthritis, or the older person with dementia, among many others.<sup>33</sup>



Celebrations in Kathmandu marking the International Day of Persons with Disabilities, 3 December 2016.  
Photo by the National Human Rights Commission of Nepal

### 1.3. DEFINITIONS IN ANTI-DISCRIMINATION LAW

The human rights framing of disability is especially important when it comes to anti-discrimination law. If persons with disabilities have been treated in the past as ‘objects’ and not ‘subjects’, and if one consequence of this has been a systematic denial of their rights, then it makes sense that ensuring equality for persons with disabilities must be the primary objective of any legislative tool. That is to say, the law must promote respect for the *equal* and effective enjoyment of all rights by persons with disabilities.

It is obvious that anti-discrimination law is one of the strongest tools available to States to challenge out-dated practices.<sup>34</sup> The most famous example of this is the Americans with Disabilities Act (ADA) of 1990, which is probably one of the most widely copied pieces of civil rights legislation in the world.<sup>35</sup> It is clear that legislation of this type is a necessary first step towards embedding the human rights model of disability. It should, of course, be complemented by a range of programs and initiatives that help deliver broad systemic change.

The advantage of anti-discrimination legislation is that it places power in the hands of the individual to challenge outdated practices. Where such laws are not in place, NHRIs have a clear responsibility to advocate for them. Where they are in place, NHRIs have a clear responsibility to frame the definition of disability to ensure the focus is firmly on the barriers to equality that need to be removed.

Given that such laws are generally directed against the behaviour of others, it might even seem unnecessary to include a definition of disability. After all, what matters most is that the relevant parties are clear about their responsibilities to persons with disabilities and are clear about those behaviours that are prohibited. However, some States have enacted anti-discrimination laws – which generally pre-date the UN CRPD – with impairment-specific definitions of disability. This can have the effect, intended or otherwise, of undermining the human rights model of disability and even restricting a person’s legal standing or entitlement to use the law.

For example, for a person in Britain to bring a complaint of disability discrimination, a court or tribunal must first establish that the person has “a physical or mental impairment which has a substantial and long term adverse effect on a person’s ability to carry out normal day-to-day activities”.<sup>36</sup> This approach still focuses on the impairment and *its* impact, rather than on the aggravating factors found outside the impairment. In addition to containing qualifications not found in the UN CRPD, such as the requirement that an impairment must be “substantial” and have an “adverse effect on normal day to day activities”, it has been argued that this definition, which was originally included in Britain’s Disability Discrimination Act of 1994, is based upon the medical model of disability and therefore out of place in anti-discrimination law. Similarly, Australia’s Disability Discrimination Act 1992 includes a very broad medicalised definition of disability. While the Australian legislation avoids the particular qualifications included in the British legislation, it also appears to resonate with the medical model of disability rather than the social model or the human rights model.<sup>37</sup>

In defence of impairment-based definitions in anti-discrimination legislation, it might be argued that, since the underlying purpose of such laws is to counter discriminatory barriers and behaviours of others, then those third parties should know with reasonable clarity to whom their obligations apply. An interesting paradox arises here, as impairment-based definitions have generally not created any barriers to accessing justice – unlike more social definitions of disability used in, for example, the Americans with

34 INTERIGHTS have produced several reference manuals for lawyers, available at [www.interights.org/lawyers-manuals/index.html](http://www.interights.org/lawyers-manuals/index.html). See also the various handbooks produced by the European Agency for Fundamental Rights, available at <http://fra.europa.eu/en/publications-and-resources>.

35 The full text of the Act is available at [www.ada.gov/2010\\_regs.htm](http://www.ada.gov/2010_regs.htm).

36 Section 1(1); available at [www.legislation.gov.uk/ukpga/1995/50/section/1](http://www.legislation.gov.uk/ukpga/1995/50/section/1).

37 Section 4(1); available at [www.comlaw.gov.au/Details/C2015C00252](http://www.comlaw.gov.au/Details/C2015C00252).

Disabilities Act.<sup>38</sup> In a series of cases known as the Sutton trilogy,<sup>39</sup> the United States Supreme Court arguably failed to understand the social model approach used in the Americans with Disabilities Act and narrowed the categories of those entitled to protection under the Act. Regardless of the merits, many litigants with disabilities found it hard to get their day in court since they failed to meet the definitional threshold demanded by the Supreme Court. This required amending legislation from Congress to “re-right the ADA”<sup>40</sup>

In sum, one important implication of the move to the human rights frame is that impairment-specific definitions of disability should be avoided in anti-discrimination law where the focus is clearly on countering discriminatory barriers and behaviours. If it is necessary, for the sake of legal clarity, to define those groups protected by the law, it should be done in a way that does not undermine the focus of the legislation or create unnecessary barriers in terms of access to justice.

This seemingly academic point is highly relevant to the work of NHRIs. NHRIs should ensure that definitions of disability in domestic anti-discrimination law do not perpetuate old approaches that ‘make the person the problem’. The goal of the legislation should be to squarely address the structural barriers and the behaviour of third parties that unfairly limit the opportunities of persons with disabilities. Anti-discrimination law is symbolic of the re-framing of disability that has taken place in recent decades. If the law is not re-framed with this approach at its heart, then it is hard to see how any associated measures can succeed.

#### 1.4. THE NEED FOR A BROAD LIFE COURSE PERSPECTIVE

A life course perspective is very important in relation to disability.<sup>41</sup> Many more people with disabilities are now ageing. This means they encounter the very same transition points experienced by others; for example, transition from school to employment, parenthood, the advent of sickness or disease, and old age. As a result, policies designed to deal with these ‘normal’ transition points must be extended to embrace persons with disabilities. NHRIs whose work focuses on these ‘normal’ transition points will have to mainstream persons with disabilities.

Impairment is not, for many people, from birth. It can be associated, in particular, with the ageing process. This means that the prevalence of impairment and long-term health conditions is rising in ageing societies. While not all older persons are persons with disabilities, there is sufficient overlap to justify a strong focus on age and disability. This is the subject of the very fine 2012 Toronto Declaration on “bridging knowledge, policy, and practice in aging and disability”.<sup>42</sup> The distinct but overlapping fields of ageing and disability mean that the UN CRPD will be a useful guide in framing of an eventual Convention on the Rights of Older Persons.<sup>43</sup> NHRIs are rightly increasing their focus on the rights of older persons. Accordingly, this work will have to encompass and mainstream persons with disabilities who are ageing.

38 See, for example, P. Miller, ‘Reclaiming the Vision: the ADA and Definition of Disability’ in *Brandeis Law Journal*, Vol. 41, 2003, p. 769.

39 The Sutton trilogy refers to: *Sutton v. United Airlines, Inc.*, 527 U.S. 471 (1999); *Murphy v. United Parcel Service, Inc.*, 527 U.S. 516 (1999); and *Alberston’s, Inc. v. Kirkingburg*, 527 U.S. 555 (1999).

40 See United States National Council on Disability, *Righting the Americans with Disabilities Act*, December 2004; see also ADA Amendments Act of 2008, available at [www.eeoc.gov/laws/statutes/adaaa.cfm](http://www.eeoc.gov/laws/statutes/adaaa.cfm).

41 M. Priestley (ed), *Disability and the Life Course: Global Perspectives 2001*. See also E. Jeppson Grassman and A. Whitaker, *Ageing with Disability: A Lifecourse Perspective*, 2013.

42 J. Bickenbach, C. Bigby, L. Salvador-Carulla, T. Heller, M. Leonardi, B. LeRoy, et al. ‘The Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability’ in *International Journal of Integrated Care*, Vol. 12, 2012; available at [www.ijic.org/index.php/ijic/article/view/1086/192](http://www.ijic.org/index.php/ijic/article/view/1086/192).

43 For a discussion of the usefulness of the Convention on the Rights of Persons with Disabilities in the context of a possible convention on the rights of older persons, see R. Ruebner, T. Do and A. Taylor (eds.), *International and Comparative Law on the Rights of Older People*, 2015.

It is also important to note that “the population with impairments is not static and people move in and out of this group over time”<sup>44</sup> This suggests that a great majority of citizens will, at some point in their lives, experience disability, either directly or indirectly. NHRIs working on disability issues should be sensitive to the ‘floating’ nature of much of the population. Indeed, the increasing focus of NHRIs on ‘intersectionality’ – that is, multiple and overlapping identities – will itself have to be attuned to disability issues.

## 1.5. INTERSECTIONALITY: THE NEED TO FRAME DISABILITY ALONGSIDE OTHER IDENTITIES

Not everyone is affected equally by the various challenges and barriers that can arise in relation to disability. The 2011 World Report on Disability noted that:

... while disability correlates with disadvantage, not all persons with disabilities are equally disadvantaged. Women with disabilities experience the combined disadvantages of gender as well as disability .... People who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings than those who experience physical or sensory impairments.<sup>45</sup>

Overlapping or multiple discrimination on several or combined grounds – for example, age and disability – magnifies the impact on the person. In other words, having multiple identities can bring with it multiple disadvantages that might – separately – be associated with those identities. The UN CRPD takes a major step forward by expressly covering this ‘intersectional’ discrimination.<sup>46</sup> This is important because our identities are never fully contained by one characteristic but include a number of intersecting identities, such as disability, gender, age, race and religion. It is also important because such overlapping identities can compound the discrimination experienced by some groups.<sup>47</sup> The Convention explicitly covers intersectionality with respect to women with disabilities (article 6) and children with disabilities (article 7).

## 1.6. BROADENING PROTECTION TO OTHERS WHO DO NOT HAVE A DISABILITY

Discriminatory behaviour on the ground of disability is not only experienced by persons with disabilities. It is important to emphasise that the prohibition of discrimination “on the basis of disability” (article 5(2) of the UN CRPD) may cover those who are not themselves disabled, as understood under the broad definition in article 1. However, they may experience discrimination because of their relationship to someone who is disabled. This is known as ‘associative discrimination’. It is important because the ripple effects of discrimination can be felt by carers, family members and others with whom persons with disabilities share their lives. For example, associative discrimination can profoundly affect mothers of children with disabilities who may find it difficult, if not impossible, to enter, stay in or re-enter the workforce. Furthermore, the high opportunity costs associated with caring may mean that a carer is penalised later on in life by not having had the opportunity to grow a pension, thereby exposing them to poverty in old age.

Associative discrimination has been held by many courts to be implicitly protected by anti-discrimination law.<sup>48</sup> Furthermore, some anti-discrimination laws protect people who do not have a disability but who

44 United Kingdom Department for Work and Pensions, *Fulfilling Potential: Building a Deeper Understanding of Disability in the UK Today*, 2013, p. 22; available at [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/320509/building-understanding-main-report.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/320509/building-understanding-main-report.pdf).

45 World Health Organization; p. 8; available at [www.refworld.org/docid/50854a322.html](http://www.refworld.org/docid/50854a322.html).

46 See preambular para. (p).

47 The intersection between disability and other grounds of discrimination is addressed in detail in *Equal Rights Review*, Vol. 16, 2016; available at [www.equalrightstrust.org/equal-rights-review-volume-sixteen-2016](http://www.equalrightstrust.org/equal-rights-review-volume-sixteen-2016).

48 See, for example, Case C-303/06 *Coleman v. Attridge Law & Steve Law* (2008) ECJ in which the European Court of Justice determined a mother of a disabled person was protected under the provisions of Directive 2000/78.

are assumed to have a disability. This makes sense if the goal of the legislation is to tackle social and attitudinal barriers in relation to disability.

Likewise, it makes sense to extend the same protection to those who may previously have had a disability but who do not presently have that disability. For example, if knowledge about a person's past health status is widely known then it is foreseeable that some people may react negatively or discriminate against the person on the basis of that person's (previous) disability. A contemporary flashpoint involves so-called 'genetic discrimination', which refers to the discriminatory use of genetic information which may be required in relation to job applications or applications for insurance or financial credit. This information can be used negatively to exclude persons with disabilities – and those who may have a predisposition to acquire a disability in the future – from employment, insurance services and financial credit. The Genetic Information Non-Discrimination Act was enacted by the United States to protect people against these dangers and much thought is being given to enacting similar legislation in other countries.<sup>49</sup>

The UN CRPD's prohibition of discrimination "on the basis of disability" is broad enough to encompass discriminatory behaviour against those who do not presently have a disability but whose genetic predisposition makes them susceptible to the onset of a disability later in life. NHRIs should be particularly attentive to the many ways in which technology can be harnessed positively for persons with disabilities, as well as used negatively to further exclude them.

## 1.7. STATISTICS AND DATA: MAINTAINING A FOCUS ON BARRIERS, NOT PREVALENCE

The move to the human rights model on disability has implications for data collection and analysis. In the past, data was mostly collected to determine the prevalence of disability and particular kinds of disabilities. This was commonly defended as a way to assess numbers and needs in order to plan programs and services to meet those needs. However, the human rights frame requires us to go well beyond this narrow agenda in order to dismantle the barriers facing people with disabilities.

We need, therefore, to collect data that can help build a richly textured picture of the status of persons with disabilities: the barriers they face, the opportunities they have and the level of inclusion they enjoy in their communities. That is why, rather uniquely, the UN CRPD contains an article dealing with statistics and data collection (article 31).

The reality, however, is that most data sets on disability continue to focus on prevalence and do so in an impairment-specific way. They tend not to measure the gap between abstract rights and the current status of persons with disabilities. This requires a focus not on the prevalence of disability but on the civil status of persons with disabilities. Doing this properly requires the development of clear and detailed indicators.<sup>50</sup> OHCHR distinguishes between three different sets of indicators:

- **Process indicators**, which focus on the State commitment to addressing human rights issues
- **Substance indicators**, which focus on the laws, policies and programs that help the State deliver on its human rights commitments
- **Outcome indicators**, with a focus on how individuals actually experience or enjoy their rights.<sup>51</sup>

There are several projects underway in different parts of the world to develop indicator sets in relation to disability and, specifically, the UN CRPD. Working closely with the European Union Academic Network

49 P. Blanck, A. De Paor and G. Quinn (eds.), *Genetic Discrimination: Transatlantic Perspectives on the Case for a European Level Legal Response*, 2014.

50 Secretariat to the Convention on the Rights of Persons with Disabilities, 'United Nations Expert Group Meeting on Disability Data and Statistics, Monitoring and Evaluation: The Way Forward – a Disability Inclusive Agenda towards 2015 and Beyond', 8-12 July 2014; available at [www.un.org/disabilities/documents/egm2014/EGM\\_FINAL\\_08102014.pdf](http://www.un.org/disabilities/documents/egm2014/EGM_FINAL_08102014.pdf).

51 OHCHR, *Human Rights Indicator: A Guide to Measurement and Implementation*, 2012; available at [www.ohchr.org/Documents/Publications/Human\\_rights\\_indicators\\_en.pdf](http://www.ohchr.org/Documents/Publications/Human_rights_indicators_en.pdf).

of Experts on Disability, the **European Union Fundamental Rights Agency** has developed useful indicators on the right to participate in the political life of the nation.<sup>52</sup> It has also produced a set of indicators on the right to live independently and be included in the community.<sup>53</sup> The **Danish Institute on Human Rights** has developed ‘gold indicators’ that measure progress towards meeting the obligations of the Convention across a range of domains.<sup>54</sup> NHRIs should consult these indicator sets and adjust them to their own country environment.

To assist States, the World Health Organization (WHO) has developed a ‘model disability survey’ which “is a general population survey that provides detailed and nuanced information about how people with and without disabilities conduct their lives and the difficulties they encounter, regardless of any underlying health condition or impairment. The [survey] helps Member States identify the barriers that contribute to the problems people encounter, which, in turn, helps guide policy and service development.”<sup>55</sup> The WHO website contains links to national disability surveys.

NHRIs can play a role to help tailor and use these indicator sets in order to collect meaningful data. This topic is of crucial importance. If the wrong things are measured then the policy solutions that follow will answer the wrong questions. The move to the human rights model ensures that the focus must be on the experiences of persons with disabilities and the barriers they face. By making sure that the right questions are asked, the right data is collected and the right kind of policy responses are explored, NHRIs can model and apply the human rights frame in practice.

## 1.8. THE SCOPE FOR SOME IMPAIRMENT-SPECIFIC DEFINITIONS IN BROADER SOCIAL LAW

The human rights model moves the definition of disability away from impairment toward the interaction of impairment with arbitrary barriers. This does not mean that States do not have some discretion when it comes to establishing narrower definitions, especially for the purpose of targeting scarce resources for a definable group or when determining eligibility criteria for certain programs or services. They may also do so if the intention is to improve the status of particularly disadvantaged groups.<sup>56</sup> This legislation is more typical of a social agenda rather than a civil rights or human rights agenda. Both sets of laws are needed, however.

Impairment-specific definitions are acceptable if they do not undermine the broad goals and principles of the UN CRPD. Of course, there may be instances where such impairment-specific definitions are too removed from the key goal of overcoming disadvantage and advancing equality; for example, a law that preserves certain low-paying and low-status jobs for particular impairment groups. In principle, however, such approaches are not necessarily at odds with the human rights frame and the spirit of the Convention. However, NHRIs have a particular responsibility to ensure that such legislation meets these broader objectives.

52 ‘Indicators on the Right to Political Participation of People with Disabilities’; available at <http://fra.europa.eu/en/publications-and-resources/data-and-maps/comparative-data/political-participation>.

53 ‘Rights of Persons with Disabilities (The Right to Independent Living)’; available at <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>.

54 Available at [www.humanrights.dk/activities/our-work-denmark/disability/gold-indicators-crpd](http://www.humanrights.dk/activities/our-work-denmark/disability/gold-indicators-crpd).

55 Available at [www.who.int/disabilities/data/mds/en/](http://www.who.int/disabilities/data/mds/en/).

56 OHCHR, *Monitoring the Convention on the Rights of Persons with Disabilities: Guidance for Human Rights Monitors*, Professional Training Series No. 17, 2010; available at [www.ohchr.org/Documents/Publications/Disabilities\\_training\\_17EN.pdf](http://www.ohchr.org/Documents/Publications/Disabilities_training_17EN.pdf).

# Chapter 2:

## Key elements of the human rights frame on disability

### KEY QUESTIONS

- What are the key principles and concepts that encapsulate the human rights frame on disability?
- How does the human rights frame help drive change?



### 2.1. THE OVERARCHING GOAL OF EQUALITY AND NON-DISCRIMINATION

If we turn the traditional framing of disability away from the person and towards the problems facing that person, the next logical step is to tackle those problems. Persons with disabilities do not claim special rights or even ‘disability rights’. They claim the same human rights that are afforded equally to all. This is why it is said that the UN CRPD does not create any ‘new’ rights. Rather, it seeks practical ways to make existing rights real and meaningful in the lives of people with disabilities. As article 1 states, the Convention seeks the full and *equal* enjoyment of existing rights for and by persons with disabilities.

An overarching commitment to equality therefore underpins the human rights frame on disability. Professor Oddny Arnardottir identifies three different generations of equality thinking in relation to disability:

- Universal sameness (1950s – 1970s)
- Specific difference (1970s – 1990s)
- Multidimensional disadvantage (current trends).<sup>57</sup>

The first approach purports to treat people exactly the same, regardless of their differences. That approach, however, does nothing to advance the access rights of those in wheelchairs who, under this model, have an ‘equal’ right to climb stairs. The second approach takes a much more positive view of the difference of disability and seeks to accommodate them, which is reflected in the ‘reasonable accommodation’ obligation in anti-discrimination law. While it is an improvement, this approach does not tackle the cumulative effects of generations of exclusion. The third approach is much more attuned to accumulated disadvantages and multiple forms (and effects) of discrimination. It also seeks to reverse them. Arnardottir characterises the UN CRPD as belonging to the third approach and concludes that “the CRPD represents the more complex and layered human rights law appropriate to the challenges of the 21st century.”<sup>58</sup>

57 O. Arnardottir, ‘A Future of Multidimensional Disadvantage: Equality?’ in O. Arnardottir and G. Quinn (eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, 2009, pp. 41-66. For a more general and classic statement on how to handle difference within the law, see M. Minow, *Making all the Difference: Inclusion, Exclusion and American Law*, 1991.

58 O. Arnardottir, ‘A Future of Multidimensional Disadvantage: Equality?’ in O. Arnardottir and G. Quinn (eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, 2009, p. 66.

Not surprisingly, the equality and non-discrimination provision informs the whole text of the Convention. Indeed, most of the substantive rights it sets out are said to be secured “on an equal basis with others”. Article 5(1) (on equality and non-discrimination) more specifically recognises that:

... all persons [with disabilities] are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.

Further, article 5(2) requires States to take action to:

... prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.

This does not mean that material differences are to be ignored. On the contrary, these differences are to be acknowledged and positively accommodated. Accordingly, the UN CRPD borrows from advanced anti-discrimination law in different parts of the world to include ‘reasonable accommodation’<sup>59</sup> within the definition of discrimination (article 2):

Discrimination on the basis of disability...includes all forms of discrimination, *including denial of reasonable accommodation*.

[emphasis added]

Reasonable accommodation, in turn, means:

... necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.<sup>60</sup>

The reasonable accommodation obligation was first included in the United States Civil Rights Act (on the basis of religion, as interpreted by the courts)<sup>61</sup> and gradually became one of the defining features of modern disability discrimination law. It was interpreted as an essential feature of early anti-discrimination law in America in relation to disability (Rehabilitation Act, 1973)<sup>62</sup> and then became the cornerstone of the Americans with Disabilities Act (1990).<sup>63</sup> This Act is one of the most admired and copied pieces of disability legislation in the world, with variations enacted in the 1990s by Australia, the United Kingdom, Ireland and Sweden. Even the 2000 European-level Directive on non-discrimination copied its provisions on reasonable accommodation.<sup>64</sup> Most famously of all, that obligation is now codified in the definition of discrimination in UN CRPD.

A fundamental distinction between ‘reasonable accommodation’ and traditional ‘positive action measures’ is that the former are individualised and tailored to the person, while the latter are more general in nature. The obligation to provide reasonable accommodation applies to both public and private bodies and across all the rights and obligations in the UN CRPD; for example, in relation to transport, education, employment and access to justice. Further, the obligation is both immediate and compulsory,

59 For more information on reasonable accommodation, see C. Jolls, ‘Antidiscrimination and Accommodation’, Yale Law School, Faculty Scholarship Series, Paper 1455, 2001; L. Waddington and A. Hendriks, ‘The Expanding Concept of Employment Discrimination in Europe: From Direct and Indirect Discrimination to Reasonable Accommodation Discrimination’ in *International Journal of Comparative Labour Law and Industrial Relations*, Vol. 18, 2002, p. 403; P. Karlan and G. Rutherglen, ‘Disabilities, Discrimination, and Reasonable Accommodation’ in *Duke Law Journal*, Vol. 46, 1996, p. 1.

60 Article 2, Convention on the Rights of Persons with Disabilities.

61 Available at [www.eeoc.gov/laws/statutes/titlevii.cfm](http://www.eeoc.gov/laws/statutes/titlevii.cfm).

62 Available at [www.disability.gov/rehabilitation-act-1973/](http://www.disability.gov/rehabilitation-act-1973/).

63 Available at [www.ada.gov/2010\\_regs.htm](http://www.ada.gov/2010_regs.htm).

64 On the extension of this obligation at a regional level, see L. Waddington, ‘EU Disability Anti-Discrimination Law: the UN CRPD, Reasonable Accommodation and CJEU Case Law’, presentation to the Academy of European Law, December 2014; [www.era-comm.eu/oldoku/Adiskri/07\\_Disability/2014\\_Dec\\_WADDINGTON\\_EN.pdf](http://www.era-comm.eu/oldoku/Adiskri/07_Disability/2014_Dec_WADDINGTON_EN.pdf).

More traditional ‘positive action measures’ are specifically permitted by the Convention:

[S]pecific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.<sup>65</sup>

In summary, the concept of equality and non-discrimination lies at the heart of the human rights model of disability and is best exemplified in article 5 of the UN CRPD. It is central to the enjoyment of each human right since all the rights in the Convention are to be secured *equally*. A nuanced understanding of equality requires individually tailored ‘reasonable accommodations’ for people with disabilities. Space is also permitted for positive action measures and, in fact, many of the substantive articles of the Convention spell out what these measures entail.

It is worth recalling some of the abuses relating to equality, in theory and practice, that have previously taken place. In the past – at least in some minds – the social exclusion of persons with disabilities was rationalised in the name of equality. Following the thinking of Greek philosopher Aristotle, it was said that the society’s core duty was to ‘treat equals equally and unequals unequally’. Therefore, courts and legislatures, it was believed, had to acknowledge material differences and allow those who were significantly different to be treated differently (‘separate but equal’). Though (barely) superficially plausible, the advent of a human rights frame on disability has thoroughly transformed this calculus. We now see such differences as largely socially constructed or, if real, as exaggerations and stereotypes to be challenged. However, situations may still arise where States attempt to rationalise separate treatment for people with disabilities on the basis that it is not a violation of equality and is in fact demanded by a theory of equality. NHRIs should be mindful of this possibility and strongly challenge it when or if it arises.<sup>66</sup>

### CONSTITUTIONAL EQUALITY GUARANTEES FOR PERSONS WITH DISABILITIES

Article 3 of the **Basic Law of the Federal Republic of Germany** states that all persons shall be equal before the law and no person shall be treated unfavourably because of disability.

Section 15 of the 1982 **Canadian Charter of Fundamental Rights and Freedoms** provides: “Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.”

The 1995 **Constitution of Uganda** provides that a person “shall not be discriminated against on the ground of sex, race, colour, ethnic origin, tribe, birth, creed or religion, or social or economic standing, political opinion or disability”.<sup>67</sup>



65 Article 5(4).

66 For a more nuanced understanding, see R. Colker, *When is Separate Unequal: A Disability Perspective*, 2008.

67 Constitution of the Republic of Uganda, s. 21(2).

## LAWS TO PROHIBIT DISCRIMINATION AND PROMOTE EQUALITY OF OPPORTUNITY

### **Equality Act 2010 (Great Britain)**

The Equality Act 2010 consolidated and largely harmonised all of Britain's anti-discrimination laws, including the previous Disability Discrimination Acts. It covers discrimination on the grounds of disability, gender, race, sexual orientation, religion or belief, age, marriage and civil partnership, and gender reassignment.

The Act extends to all areas of employment (with the exception of the armed forces in relation to persons with disabilities), education, access to goods, facilities and services, including the discharge of public functions, and membership of associations.

With respect to disability, the Act prohibits:

- **Direct discrimination**, including discrimination against people who do not have disabilities on grounds of their association with a person with a disability or because they are perceived to have a disability
- **Discrimination arising from disability**, in situations where the reason for the unfavourable treatment is not the disability itself, but something that arises as a consequence of the disability
- **Indirect discrimination**
- **Failure to make reasonable adjustments**, including in relation to policies, procedures and practices, auxiliary aids and services and physical features
- **The use by employers of pre-employment health questionnaires.**

In relation to goods, facilities and services and education, the duty to make reasonable adjustments is owed to *disabled persons* rather than only individual people. It is therefore an 'anticipatory duty'; that is, duty bearers are expected to take steps to make adjustments, such as step-free access or information in alternative formats, in anticipation of persons with disabilities wishing to make use of their services or attend their educational institution.

The Act also places a positive duty on public bodies to have 'due regard' to the need to eliminate discrimination, advance equality of opportunity and foster good relations (promote understanding and tackle prejudice).<sup>68</sup>



## 2.2. VOICE AND CHOICE: RE-CENTRING PERSONS WITH DISABILITIES IN THEIR OWN LIVES AND IN ALL COLLECTIVE PROCESSES OF CHANGE

If equality is the guiding principle of the UN CRPD, then it must be attached to substantive rights. These rights are considered in detail in Part II of this Manual. There are many ways of characterising these rights. For ease of explanation, they are characterised here in terms of restoring voice and choice to people with disabilities; ending segregation and planning for social inclusion; removing access barriers; re-framing social rights and provision to ensure they serve the autonomy of the individual; and changing public attitudes to sustain change.

68 Available at [www.legislation.gov.uk/ukpga/2010/15/contents](http://www.legislation.gov.uk/ukpga/2010/15/contents).

One way that the human rights model of disability advances the social model is to place a spotlight on fundamental considerations like personhood. It is commonly said that persons with disabilities were, in the past – and to a large extent, today – treated as ‘objects’ and not as ‘subjects’ possessing equal rights. A profound effect of this has been the extent to which the very personhood of persons with disabilities was denied: their right to take charge of their own lives, to remain in charge of their own lives and to have their own wishes and preferences respected by others. This ‘civil death’ – for example, through the transfer of the rights of personhood to a third party, such as a guardian – is not something that is unique to persons with disabilities. People who were enslaved and indeed many married women throughout history have suffered ‘civil death’.<sup>69</sup> Restoring personhood to persons with disabilities, especially those with mental or intellectual disabilities, has become a litmus test of the move to the human rights model of disability. The UN CRPD, like all human rights treaties, allows for States to make ‘reservations’ providing those reservations do not frustrate the object and purpose of the treaty. Ending ‘civil death’ (guardianship regimes) and restoring civil life (through supported decision-making regimes) is seen by most as being so important as to form one of the essential objects and purposes of the Convention.

Another result of this ‘civil death’ is that many persons with disabilities have been denied their right to live the way they want to live, where they want to live and with whom they want to live. Of course, none of us has a human right to live in a salubrious neighbourhood. Resource constraints dictate otherwise. Yet, even given these ‘natural’ constraints, most people choose their own homes and living conditions. This is important not merely because our home both protects and projects our identity, it is important because our homes connect us to the community. The denial of the right to live independently and be included in the community violates the autonomy rights of persons with disabilities and strips them of the possibility of growing with others in the community.

It is widely understood that the right to legal capacity – that is, to make decisions for oneself – and the right to live independently and be included in the community highlight the paradigm shift in the Convention. In contrast to the medical model of disability, these principles support an unmasking of the person behind the disability, a refusal to allow the person to be defined by the disability, a restoration of power to the person over their own lives and, at its most basic, a right to choose where to live and with whom, according to one’s own preferences.

That is why, for example, the UN CRPD places so much emphasis on the right to recognition before the law (article 12) and the right to live independently and be included in the community (article 19). The former right restores decision-making power and autonomy to persons with disabilities. It affords them the right to make decisions that suit their own wishes and preferences – a right not to be infantilised throughout their lives. Crucially, the exercise of this right depends on access to a range of supports, most of which occur naturally in the community and which most people take for granted. The latter right restores decision-making power over where to live and with whom. Furthermore, it envisages people with disabilities living in the community, with choices and services equal to others.

The concept of ‘voice’ has a collective dimension as well as an individual one. From one perspective, the big ‘problem’ in the field of disability is the cumulative impact of ‘bad’ legislation or practice. However, from a process-based perspective, the ‘big’ problem is the almost complete absence of people with disabilities and their representative organisations in the process of change. The concept of voice applies not only in relation to decision making on personal matters, it also has a group or collective component. Making sure that the collective voice of persons with disabilities are represented and heard is no guarantee that they will be followed. However, it does mean that their perspective cannot be ignored as was largely the case in the past.

69 W. Blackstone, *Commentaries on the Laws of England, Book the First: The Rights of Persons*; available at [http://avalon.law.yale.edu/subject\\_menus/blackstone.asp](http://avalon.law.yale.edu/subject_menus/blackstone.asp).

This idea of collective voice has moral significance because it means that policies cannot be developed over the heads of people who will be affected by those policies. It has political significance because it enriches the policy process that would otherwise be impoverished without the input of those who are experts by experience. And it now has legal significance because the UN CRPD requires States to include and actively involve persons with disabilities in policy development and in other major decisions that affect them (article 4.3).

As Part II describes, these rights (voice and choice) are complex and not without their share of controversy. They blend two different but compatible philosophies: one that accentuates individual autonomy and another that accentuates social inclusion and support. More than any other, these rights symbolise the shift toward the realising human rights for all, as envisaged by Convention. They seek to reverse decades, if not centuries, of denying people with disabilities the right to count as a person and to determine their own lives and future and to fulfil themselves in the community.

## 2.3. SOCIAL INCLUSION: CREATING PATHWAYS INTO THE LIFE-WORLD

Most people fulfil themselves and develop their own unique identity through interacting with others. Most people integrate and socialise in the workplace, in school, in sports, in culture and in leisure. Most people have free access to the justice system and to the broader political system. However, many persons with disabilities are either excluded from, or experience barriers within, all dimensions of community life. Since they are not expected to be there, they are effectively excluded as no allowance is made for their presence.

This segregation is a consequence of the cumulative effects of prejudice, hostility, discrimination and inaccessibility. The resulting invisibility of persons with disabilities and their social disconnectedness consolidates and reinforces the cycle of exclusion. Accordingly, social inclusion is one of the key foundations of the human rights frame on disability.

The UN CRPD is resolute in its commitment to the rights of persons with disabilities to “full and effective participation and inclusion in society” (article 3(c)). This principle is reflected in most of the headline articles of the Convention dealing with, for example, inclusive education (article 24) and the open labour market (article 27). Fundamentally, this means that persons with disabilities have a right to “be everywhere in the world”,<sup>70</sup> living, learning, working and socialising with and alongside persons without disabilities.

The UN CRPD, therefore, also promotes a decisive shift away from all forms of involuntary and ‘congregated’ arrangements, such as institutional living, sheltered workplaces, special segregated schools, day centres and other arrangements that separate persons with disabilities from the wider community. However, doing so requires action by States and other actors to create the conditions necessary for effective participation and full inclusion of people with disabilities, including taking steps to ‘open up’ society and its institutions and dedicating public resources to remove barriers and support participation. For example, in relation to employment and work, this might include introducing and enforcing anti-discrimination law, conducting awareness-raising programs to tackle negative employer stereotypes regarding the capabilities of persons with disabilities and investing public resources in the supports that persons with disabilities and employers may require. In the field of education, it may require making adjustments to the curriculum and to teaching methods.

70 Vienna Declaration and Programme of Action, World Conference on Human Rights, 25 June 1993; available at [www.ohchr.org/EN/ProfessionalInterest/Pages/Vienna.aspx](http://www.ohchr.org/EN/ProfessionalInterest/Pages/Vienna.aspx).



The Office of the Ombudsman in Samoa conducted interviews with people with disabilities across the island nation for its 2015 State of Human Rights Report. Photo by the Office of the Ombudsman Samoa

## 2.4. ACCESSIBILITY: BREAKING DOWN BARRIERS INTO THE LIFE-WORLD

Giving people with disabilities power over their own lives and calling for an end to segregation will not deliver the desired results unless and until we dismantle the many barriers facing people with disabilities and build an inclusive environment. Inaccessibility is largely a legacy of ignoring the difference of disability and treating it negatively. Of course, accessibility was not a priority in the past since there was no expectation that persons with disabilities would take part in community life. The shift to the human rights model, therefore, makes accessibility an issue in a way that it wasn't before. Importantly for our lives in the 21st century, the concept of access applies as much to the electronic environment as it does to the built environment. Article 9 of the UN CRPD is devoted entirely to the issue of accessibility.

The rationales for accessibility are made clear in General Comment No. 2 of the Committee on the Rights of Persons with Disabilities:

Accessibility is a precondition for persons with disabilities to live independently and participate fully and equally in society. Without access to the physical environment, to transportation, to information and communication, including information and communications technologies and systems, and to other facilities and services open or provided to the public, persons with disabilities would not have equal opportunities for participation in their respective societies.<sup>71</sup>

Reversing this legacy of exclusion is difficult. As the 2011 World Report on Disability noted:

Built environments, transport systems and information are often inaccessible (to persons with disabilities). Lack of access to transport is frequently a reason for a person with disabilities being discouraged from seeking work or prevented from accessing healthcare. Even in countries with laws on accessibility, compliance in public buildings is often very low. The communication needs of persons with disabilities are often unmet. Information is frequently unavailable in accessible formats and some people with disabilities are unable to access basic information and communications technology such as telephones and television.<sup>72</sup>

The concept of universal design is central to the creation of infrastructure that is accessible to persons with disabilities. Article 2 of the UN CRPD provides the following definition:

“Universal design” means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

The concept of accessibility relates to persons with disabilities as a whole, while the concept of ‘reasonable accommodation’, while complimentary, considers the individualised needs of particular persons. The obligation of ‘reasonable accommodation’ on its own will not solve the major inaccessibility issues; something more programmatic is also needed.

**The Danish Institute for Human Rights has promoted accessibility in a number of ways. Its publication – *Come on In: On Accessibility to Buildings* – is aimed at all those who work with accessibility to buildings, including people who formulate building policies and people who train those who will work in the building professions, as well as developers, voluntary organisations and disability organisations fighting for the right to inclusion in society.<sup>73</sup> In the area of transportation, the Danish Institute for Human Rights has contacted all bus companies in Denmark and requested specific information on access to buses for people in wheelchairs and users of electric scooters, in order to clarify whether the current level of access meets the obligations in the UN CRPD and in European Union law. This has led to a change in practice and an initiative to further develop access to buses in Denmark.**



71 See the Introduction to General Comment No. 2; available at [www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx).

72 Page 263; available at [www.who.int/disabilities/world\\_report/2011/en/](http://www.who.int/disabilities/world_report/2011/en/).

73 Danish Institute for Human Rights, *Come On In*, 2013; available at [www.humanrights.dk/files/media/dokumenter/handicap\\_konventionen/comeonin.pdf](http://www.humanrights.dk/files/media/dokumenter/handicap_konventionen/comeonin.pdf).

## 2.5. SOCIAL SUPPORT: CALIBRATING ECONOMIC AND SOCIAL RIGHTS TO UNDERPIN THE AUTONOMY

Social support has seldom provided the right kinds of support to persons with disabilities in the past. Indeed, our social protection/welfare systems have tended to ‘cushion’ persons with disabilities – and even then not very effectively – from the mainstream. These systems were not premised on the notion that persons with disabilities would want to live an active and productive life.

The ‘social support’ approach to disability dominated our recent past. Most people viewed this as normal and ‘the right thing to do’. Reframing public opinion to place the focus on the rights of people with disabilities and to promote their inclusion in all aspects of community life is challenging for many people. However, it is vitally important and NHRIs have a huge role to play in helping shift community attitudes.

The need to reframe the social support paradigm is doubly important because of the close link between disability and poverty. We know that persons with disabilities are more likely to be poor and that poorer people are more likely to become disabled. The UN CRPD acknowledges that “the majority of persons with disabilities live in conditions of poverty” and notes the “critical need to address the negative impact of poverty on persons with disabilities”.<sup>74</sup> Indeed, some 80 per cent of persons with disabilities live in developing countries.<sup>75</sup>

Disability increases the risk of poverty. This is because persons with disabilities face significant disadvantage in securing an adequate income through paid employment (an income penalty). It is also because persons with disabilities face extra costs related to their impairments or health condition and to overcoming the barriers they face when seeking to participate fully in society (a cost of living penalty). The extra costs faced by persons with disabilities are often not taken into account in general measures to alleviate poverty.

The main route out of poverty – paid employment – is largely closed to persons with disabilities. People with disabilities are more likely to be unemployed than non-disabled people. In OECD countries, the employment rate of people with disabilities (44%) hovers around half that for people without disabilities (75%).<sup>76</sup> People with intellectual disabilities and mental health problems experience the greatest disadvantage.<sup>77</sup> Internationally, the average employment rate of women with disabilities is less than half that of men with disabilities.<sup>78</sup>

However, the way social rights were delivered in the past almost assumed the non-presence of persons with disabilities in the workplace. They were, instead, ‘compensated’ for their absence. Further, to remain entitled for these payments, many people with disabilities had to impoverish themselves by divesting themselves of any assets they were fortunate enough to inherit or acquire. The overall effect was that by the time the UN CRPD was being drafted, economic and social rights were seen by many as part of the problem rather than part of the solution.

The shift to the human rights frame, therefore, has significant implications for the design and delivery of social rights programs and entitlements. On close analysis, it is clear that the drafters of the UN CRPD were prepared for this challenge. That is why many of the rights contained in the substantive provisions of the Convention blend a fundamental right – for example, freedom of expression – with socio-economic rights, supports and obligations to help secure that right in practice for people with disabilities. This can make life a bit difficult for advocates, lawyers and NHRIs alike since the rights and obligations in the Convention do not come neatly packaged into those that are ‘immediately achievable’

74 Preambular paragraph (t).

75 WHO, *World Report on Disability*, 2011; available at [www.who.int/disabilities/world\\_report/2011/en/](http://www.who.int/disabilities/world_report/2011/en/).

76 Ibid.

77 Ibid.

78 WHO, *World Health Survey 2002–2004*; available at [www.who.int/healthinfo/survey/en](http://www.who.int/healthinfo/survey/en).

and those that require 'progressive achievement'. However, that is the price to pay for the very creative blending of both sets of rights that seek to ensure that socio-economic supports do, in fact, provide people with disabilities with the supports they require.

Nearly all of the rights contained in the UN CRPD have this unique blend of obligations that are of 'immediate effect' and those that require 'progressive achievement'. The overarching presence of the non-discrimination principle (article 5) does not change the normal dynamics between these two sets of obligations. That is to say, the non-discrimination idea does not work to convert what would otherwise be an obligation of 'progressive achievement' into an obligation of 'immediate effect'. This can be a tricky area for many including NHRIs. It requires NHRIs to identify the various elements of a particular right that are amenable to 'progressive achievement', how they work to underpin the overall goal of that relevant right, and what meaningful milestones and measures of progress can be developed.

## 2.6. BREAKING THE CYCLE OF EXCLUSION: CHANGING PUBLIC ATTITUDES

It is obvious that the social attitudes and prejudices that typify traditional laws and policies on disability go very deep. However, it is questionable whether changing bad laws in isolation is enough to sustain change. Hearts and minds also need to change if the human rights frame on disability is to sink deep roots and fully replace the old charity model. In turn, segregationist laws and policies also promote and reinforce the idea that exclusion is 'natural'. Something is needed to break this cycle, since outdated laws that are repealed are likely to be reproduced in a different form if the underlying attitudes remain.

That is why article 8 on awareness raising was included in the UN CRPD. It requires States to take steps to raise awareness about the rights of persons with disabilities, to combat negative or harmful stereotypes and to promote an understanding of the capabilities and contributions of persons with disabilities. If a human rights agenda is successful, it should lead to an increased presence of persons with disabilities across all parts of community life and endeavour. Greater visibility of persons with disabilities should also help shift public attitudes and counter negative stereotypes. This would be a natural by-product of inclusion strategies. However, the Convention goes further to demand more positive and intentional action on the part of the State to promote respect for the rights of persons with disabilities; for example, by encouraging positive images about disability in the media.

The importance of nurturing public opinion cannot be overstated. Without it, progress for persons with disabilities can be easily seen as them receiving 'special treatment'. Similarly, setbacks for persons with disabilities will not be viewed as setbacks but simply as the 'natural' result of constrained public resources and the need to make economic growth and wealth creation the priority. This resulting – and seemingly indefinite – postponement of realising human rights commitments affects many people and groups but has devastating effects for persons with disabilities who are, in effect, told to wait a generation or two until the local economy improves. And without nurturing public opinion, third parties – for example, parent groups of children without disabilities – might resist inclusion in schools since they might see it as a potential 'drag' on the quality of education for their children rather than the equal enjoyment of a right by a child with a disability. That might blinker them from seeing educational inclusion as a positive for non-disabled children in terms of learning and practicing diversity, tolerance and citizenship.

NHRIs have a particularly important role to play in how they communicate to the public about disability. The work they do, the priorities they choose and the way they do their work all have expressive value. NHRIs have to be particularly attentive to the way they talk about their work on disability and explain the shift to the human rights framing of disability. They also have a vital role to play in countering negative narratives around disability. Every gain is incremental and is always vulnerable to being undone.

## Further reading for Part I



### On the status of persons with disabilities

There are now numerous large studies on the status of persons with disabilities around the world.

- *World Report on Disability*, World Health Organisation & World Bank, 2011.
- *Situation of Persons with Disabilities: Implementation of the UN Convention in 15 countries and in 9 Austrian federal provinces based on 40 social indicators*, ESSL Social Index Pilot Study, 2010.



### On disability social action movements

There are many books on the rise of disability social action movements around the world.

- H. Vanhala, *Making Rights a Reality: Disability Rights Activists and Legal Mobilization* (Cambridge University Press, 2014)
- D.Z. Fleisher and F. Zames, *The Disability Rights Movement: from Charity to Confrontation* (Temple University Press, 2001).

### Disability policy book series (by publisher)

Many major publishing houses now have dedicated book series in disability.

- NYU Disability Studies (not strictly law; 29 books so far):  
<http://nyupress.org/advanced-search/?subjectId=17>
- Syracuse University, Critical Perspectives on Disability (5 volumes so far):  
[www.syracuseuniversitypress.syr.edu/subject/disability.html](http://www.syracuseuniversitypress.syr.edu/subject/disability.html)
- Manchester University Press, Disability History Series (new series):  
[www.manchesteruniversitypress.co.uk/articles/new-series-disability-history/](http://www.manchesteruniversitypress.co.uk/articles/new-series-disability-history/)
- Baylor University Press, book series on Religion, Theology and Disability (5 volumes so far):  
[www.baylorpress.com/en/Series/16/Studies%20in%20Religion,%20Theology,%20and%20Disability](http://www.baylorpress.com/en/Series/16/Studies%20in%20Religion,%20Theology,%20and%20Disability)
- Routledge, Advances in Disability Studies series (10 books so far):  
[www.routledge.com/series/RADS](http://www.routledge.com/series/RADS)

### On various perspectives/models on disability

This is only a highly selective sampling of major works: books and articles. Most of them deal with the framing of disability and the contest between different models.

The Leeds University (UK) Centre on Disability Studies hosts an exceptionally useful online archive of articles and material: <http://disability-studies.leeds.ac.uk/library/>

- E. Kittay and L. Carlson (eds.), *Cognitive Disability and its Challenge to Moral Philosophy*, (Wiley Blackwell, 2010)
- P. Beresford, M. Nettle and R. Perring, *Towards a Social Model of Madness and Distress: Exploring what service users say* (Joseph Rowntree Foundation, 2010)

- K. Kristiansen, S. Vehmas and T. Shakespere, *Arguing about Disability: Philosophical perspectives* (Routledge 2010)
- K. Johnson and M. Wolfe, *People with Intellectual Disabilities – Toward a good life* (Bristol Policy Press, 2010)
- K. Brownlie and A. Cureton (eds.), *Disability and Disadvantage* (Oxford, 2009)
- C. Barnes and G. Mercer (eds.), *Disability* (Polity Press, Key Concepts, 2008)
- S. Mitra, 'The Capability Approach and Disability', Vol 16, No 4, *Journal of Disability Policy Studies* (2006)
- R. McRuer, *Crip Theory: Cultural Signs of Queerness and Disability* (NYU Press, 2006)
- T. Shakespeare, *Disability Rights and Wrongs Revisited* (Routledge, 2006)
- S. Riddell and N. Watson, *Disability, Culture and Identity* (Pearson, 2003)
- T. Titchkosky, *Disability, Self and Society* (University of Toronto Press, 2003)
- R. Traustadottir and K. Johnson (eds.), *Women with Intellectual Disabilities: Finding a place in the world* (Jessica Kingsley, 2000)
- T. Shakespeare, 'The Social Model of Disability: an Outdated Ideology', Vol 2 *Research in Social Science & Disability* (2002)
- M. Corker and T. Shakespeare (eds.), *Disability/Postmodernity: Embodying disability theory* (Continuum Press, 2002)
- P. Longmore and L. Umansky, *The New Disability History* (NYU Press, 2001)
- C. Barnes, G. Mercer and T. Shakespeare, *Exploring Disability: A Sociological Introduction* (Polity Press, 1999)
- C. Thomas, *Female Forms: Experiencing and Understanding Disability* (Open University Press 1999)
- T. Shakespeare (ed.) *The Disability Reader: Social Science Perspectives* (Continuum, 1999)
- J. Swain, V. Finkelstein, S. French and M. Oliver, *Disabling Barriers: Enabling Environments* (Sage, 1994)
- J. Morris, *Pride against Prejudice: Transforming attitudes towards disability* (The Woman's Press, 1991)
- Mark Priestly (in consultation with Vic Finkelstein and Ken Davis), *The Union of the Physically Impaired Against Segregation and the Disability Alliance Discuss Fundamental Principles of Disability* (reflecting a discussion in 1975). Though dated, this is a classic.

## YouTube and other video resources

There is now a large selection of videos on YouTube and other sites explaining the new thinking in disability from persons with disabilities themselves.

- C. Casey (2011) 'Looking Past Limits', TED: Ideas Worth Spreading, December 2011  
Available at [www.ted.com/talks/caroline\\_casey\\_looking\\_past\\_limits.html](http://www.ted.com/talks/caroline_casey_looking_past_limits.html)
- Channel 4 (2012) 'Meet the Superhumans', YouTube  
Available at [www.youtube.com/watch?v=tuAPPeRg3Nw](http://www.youtube.com/watch?v=tuAPPeRg3Nw)
- Baggs, A. (2007), 'In My Language', YouTube  
Available at [www.youtube.com/watch?v=JnylM1hI2jc](http://www.youtube.com/watch?v=JnylM1hI2jc)

## Journals in the broad disability policy/law field

These journals are not in the field of law but some cover public policy issued and all are illuminating on understanding the current status of persons with disabilities. Many of these databases (below) assume a paid subscription.

### Disability studies

- Journal of Disability Policy Studies:  
<http://dps.sagepub.com/>
- Disability and Society:  
[www.tandfonline.com/toc/cdso20/current](http://www.tandfonline.com/toc/cdso20/current)
- Disability Studies Quarterly:  
<http://dsq-sds.org/>
- International Journal of Disability, Development, and Education:  
[www.tandfonline.com/action/journalInformation?show%20=aimsScope&journalCode=cijd20#.Vyx5nBUrJsa](http://www.tandfonline.com/action/journalInformation?show%20=aimsScope&journalCode=cijd20#.Vyx5nBUrJsa)
- Journal of Literary & Cultural Disability Studies:  
<http://online.liverpooluniversitypress.co.uk/loi/jlcds>
- Journal of Disability and Religion:  
[www.tandfonline.com/loi/wrdh20?open=13&repitition=0](http://www.tandfonline.com/loi/wrdh20?open=13&repitition=0)
- Research in Social Science and Disability:  
[www.emeraldinsight.com/series/rssd](http://www.emeraldinsight.com/series/rssd)

### Disability area studies/regional disability

- African Yearbook on Disability Rights:  
[www.osisa.org/books/law/regional/african-disability-rights-yearbook](http://www.osisa.org/books/law/regional/african-disability-rights-yearbook)
- ALTER – European Journal of Disability Research / Revue Européenne de Recherche sur le Handicap:  
[www.journals.elsevier.com/alter-european-journal-of-disability-research-journal-europeen-de-recherche-sur-le-handicap/](http://www.journals.elsevier.com/alter-european-journal-of-disability-research-journal-europeen-de-recherche-sur-le-handicap/)
- European Yearbook of Disability Law:  
[www.nuigalway.ie/cdlp/yearbook.html](http://www.nuigalway.ie/cdlp/yearbook.html)
- Scandinavian Journal of Disability Research:  
[www.tandfonline.com/toc/sjdr20/current](http://www.tandfonline.com/toc/sjdr20/current)
- International Disability Rights Monitor, Series of Regional Reports on Disability Rights, (Americas, 2004, Asia, 2005, Europe, 2007, etc).

### Intellectual disability

- Advances in Mental Health and Intellectual Disabilities:  
[www.emeraldinsight.com/loi/amhid](http://www.emeraldinsight.com/loi/amhid)
- British Journal of Learning Disabilities:  
[http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1468-3156](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3156)
- Focus on Autism and Other Developmental Disabilities  
<http://foa.sagepub.com/>

- Journal of Applied Research in Intellectual Disabilities:  
[http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1468-3148/issues](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-3148/issues)
- Journal of Intellectual Disabilities:  
<http://jid.sagepub.com/>
- Journal of Learning Disabilities:  
<http://ldx.sagepub.com/>
- Journal of Policy and Practice in Intellectual Disabilities:  
[http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1741-1130](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1741-1130)
- Learning Disability Quarterly:  
<http://ldq.sagepub.com/>

### **Medical/rehabilitation**

- Disability & Health Journal:  
[www.disabilityandhealthjnl.com/home](http://www.disabilityandhealthjnl.com/home)
- Disability and Rehabilitation:  
[www.tandfonline.com/toc/idre20/current](http://www.tandfonline.com/toc/idre20/current)
- International journal of disability, community & rehabilitation (IJDCR):  
[www.ijdcr.ca/](http://www.ijdcr.ca/)
- Sexuality and Disability:  
<http://link.springer.com/journal/11195>

### **Accessibility**

- Technology and Disability:  
[www.iospress.nl/journal/technology-and-disability/](http://www.iospress.nl/journal/technology-and-disability/)

## Part II The law: International human rights law and disability



**Section I: Convention on the Rights of Persons with Disabilities**

**Section II: Other international and regional human rights instruments and disability**

## Introduction to Part II

**What, then, does the Convention do? In essence, it elaborates in considerable detail the rights of persons with disabilities under international law and sets out a code of implementation for governments.**

**It is a practically focused convention because it was so closely informed by the experiences of persons with disabilities worldwide, as represented by their organizations in the negotiations.**

**They clearly articulated the challenges, difficulties, and requirements of persons with disabilities in their interaction with society at large, and it is those areas – and they are myriad – on which the Convention focuses.**

**It will be the benchmark for future standards and action.**

**Ambassador Don MacKay  
Former Chairperson of the UN Ad Hoc Committee<sup>79</sup>**



Part II of this Manual provides an overview of the structure and content of the Convention on the Rights of Persons with Disabilities. It also explores other relevant international and regional human rights standards – both general and thematic – which continue to apply to disability, notwithstanding the adoption of the Convention. In general terms, these ‘extra-Convention’ standards are being interpreted and applied in line with the content and spirit of the Convention. As such, they also play a part in advancing the human rights of persons with disabilities.

Section I examines the Convention in detail, while Section II covers other general and thematic human rights instruments that apply to disability. Both are relevant to the work of NHRIs on the ground.

<sup>79</sup> D. Mackay, ‘The United Nations Convention on the Rights of Persons with Disabilities’ in *Syracuse Journal of International Law and Commerce*, Vol. 34, 2006, p. 327.

# Section I Convention on the Rights of Persons with Disabilities



**Chapter 3:** Overview of the purpose, content and structure of the Convention

**Chapter 4:** International monitoring: The tasks and functioning of the UN Committee on the Rights of Persons with Disabilities

# Chapter 3:

## Overview of the purpose, content and structure of the Convention

### KEY QUESTIONS

- What are the guiding principles of the UN CRPD?
- What rights are protected and what obligations are imposed?
- What institutional machinery is required to drive change at the domestic level?
- What is the nature of international supervision?



### 3.1. PURPOSE OF THE UN CRPD: SECURING EQUAL RESPECT FOR HUMAN RIGHTS

The Convention on the Rights of Persons with Disabilities was adopted by the UN General Assembly on 13 December 2006. It came into force on 3 May 2008 upon ratification by 20 States. At the time of writing, 161 States and one ‘regional integration organisation’ – the European Union – have ratified the Convention.<sup>80</sup>

Article 1 of the UN CRPD states that its purpose is:

... to promote, protect and ensure the *full and equal* enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

[emphasis added]

As article 1 makes plain, the concept of equality is central to the Convention. As mentioned in Part I of this Manual, this concept of equality goes beyond ‘equality as sameness’ and even beyond ‘equality recognising difference’. It embraces cumulative disadvantage and seeks to meld civil and political rights with economic, social and cultural rights to reverse these disadvantages.

The 2007 UN Enable *Handbook for Parliamentarians* explains:

The Convention is a complement to existing international human rights treaties. It does not recognize any new human rights of persons with disabilities, but rather clarifies the obligations and legal duties of States to respect and ensure the equal enjoyment of all human rights by all persons with disabilities. The Convention identifies areas where adaptations have to be made so that persons with disabilities can exercise their rights and areas where the protection of their rights must be reinforced because those rights have been routinely violated. It also establishes universal minimum standards that should apply to everyone and that provide the basis for a coherent framework for action.<sup>81</sup>

80 For up-to-date information on signatures and ratifications of the Convention and its Optional Protocol, see [www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/latest-developments.html](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/latest-developments.html).

81 OHCHR and Inter-Parliamentary Union, *From Exclusion to Equality. Realising the Rights of Persons with Disabilities: Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*, 2007, p. 5; available at [www.un.org/disabilities/documents/toolaction/ipuhb.pdf](http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf).

Given that the purpose of the Convention is to achieve equal enjoyment of all existing rights, it made sense for those who drafted it to identify the obstacles to the enjoyment of specific rights and to include specific obligations to deal with those obstacles, article by article. The general obligations of States to reform laws, policies and practices (article 4) is, therefore, accompanied by specific obligations in each substantive article, depending on the subject area.

### 3.2. GUIDING PRINCIPLES OF THE UN CRPD

The rights and obligations in the UN CRPD are underpinned by a set of indivisible and interdependent principles in article 3. They are grounded in existing international human rights law and were framed in light of historical problems relating to disability. Since these principles give life to the spirit of the Convention, it is useful to refer to them when in doubt about the meaning of specific articles.

As set out under article 3, these principles are rather undifferentiated. One way of thinking about them – and there are different ways – is to reflect on the principles in light of the shift from the ‘medical model’ of disability to the ‘social model’ and now to the ‘human rights model’.

**Dignity** (article 3(a)): This underscores inherent and equal worth of each human being, regardless of disability. It reinforces the point that persons with disabilities must be seen as full ‘subjects’ and not as ‘objects’ to be cared for or managed by others.<sup>82</sup>

**Autonomy** (article 3(a)): This underscores the right of each person to chart their own life course and make their own autonomous decisions. It reinforces the point that the person is an end in themselves and is capable of choosing their own ends in a wide variety of dimensions to their personal lives.<sup>83</sup>

**Equality of opportunity and non-discrimination** (article 3(e)): This underscores the point that not only do persons with disabilities have their own personhood and autonomy, all rights must be afforded to them on an equal basis as others. Again, the concept of equality can be seen as central to the entire Convention.<sup>84</sup>

**Respect for difference** (article 3(d)): This underscores the point that the material ‘difference’ of disability, such as it is, is to be viewed positively and not negatively. Accordingly, any temptation to use the material ‘difference’ of intellectual disability, for example, to justify the segregation of persons with disabilities must be resisted.

**Respect for intersecting identities** (article 3(g), (h)). This underscores the importance of recognising equality between men and women and respect for the rights of the child. It highlights the malleable nature of human identity, where a wide range of personal characteristics, including gender and age, can overlap. This understanding gives us another window through which to ‘see’ – and seek to reverse – accumulated disadvantages that may have accrued through multiple discrimination in the past.<sup>85</sup>

**Full and effective participation and inclusion in society** (article 3(c)): This point serves to underscore the reality, for everyone, that it is through social interaction that we become fully human and grow over time. Having this possibility adds to the quality of our lives. It follows, therefore, that a comprehensive public policy commitment to social – as well as economic and public – inclusion is necessary in order to “achieve full and equal enjoyment of all human rights” (article 1).<sup>86</sup>

82 See, generally, M. Rosen, *Dignity, Its History and Meaning*, 2012; and C. McCrudden, *Understanding Human Dignity*, 2013.

83 For a useful introduction to the concept of autonomy, see G. Dworkin, *The Theory and Practice of Autonomy*, 1988. A useful think tank on the application of autonomy in the context of disability can be found at Essex University: see <http://autonomy.essex.ac.uk>.

84 The previously noted essay by Prof. Arnardottir is probably the best explication of the fit between equality theory (and its many layers). See ‘A Future of Multidimensional Disadvantage: Equality?’ in O. Arnardottir and G. Quinn (eds.), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, 2009, pp. 41-66.

85 For a more detailed discussion on intersectionality, see *Equal Rights Review*, Vol. 16, 2016; available at [www.equalrightstrust.org/news/equal-rights-review-vol-16-here-focus-intersectionality](http://www.equalrightstrust.org/news/equal-rights-review-vol-16-here-focus-intersectionality).

86 See generally, A. Rimmerman, *Social Inclusion of people with Disabilities: National and International Perspectives*, 2013.

These principles, taken together, provide the lens through which the following substantive articles of the UN CRPD should be viewed and interpreted. The Convention begins with dignity, autonomy, equality, intersecting identities, respect for difference, social inclusion and full participation. It is grounded in a deep understanding of and commitment to personhood.

### 3.3. GENERAL OBLIGATIONS IMPOSED ON STATES PARTIES

In addition to the rights-specific obligations contained in its substantive provisions, the UN CRPD includes a provision (article 4) that sets out the general obligations of States parties with respect to implementation. Most of them are eminently logical and designed to embed a positive dynamic of change at the country level.

#### **Do no wrong**

States parties are obliged to refrain from engaging in any act or practice that is inconsistent with the Convention and to ensure that public authorities and institutions act in conformity with the Convention (article 4(1)(d)).

NHRIs can play a vital role to identify cases where laws, policies and practices violate the Convention. They can play an equally useful role to strengthen the advocacy of civil society for positive change and to champion law reform.

#### **Reform old laws and adopt new ones**

States parties are obliged to adopt appropriate legislative, administrative and other measures to implement the Convention and to modify or abolish existing laws, regulations, customs or practices that constitute discrimination against persons with disabilities (article 4(1)(a), (b)).

To achieve this, a comprehensive review process will nearly always be required. NHRIs can play a very useful role to propose the outlines for reform or to make sure that reform proposals are framed in such a way as to ensure compliance with the UN CRPD. In some States, NHRIs may be mandated or invited to lead this process and to advise government on the necessary steps to achieve or work towards compliance with the Convention; for example, through the development of a National Action Plan.<sup>87</sup>

#### **Proactively tackle discrimination**

State parties must take all appropriate measures to eliminate discrimination on the basis of disability by any person, organisation or private enterprise (article 4(1)(e)).

This suggests, at a minimum, that States put in place comprehensive legislation to prohibit discrimination against persons with disabilities, including the failure to provide 'reasonable accommodation'. It also indicates, through the use of the word 'eliminate', an expectation that States will take proactive steps to identify and tackle systemic or institutionalised discrimination faced by persons with disabilities. This would include discrimination that results from long-standing negative social attitudes, from the cultures and customary practices of institutions, or from policies, procedures and practices.

NHRIs can assist their States to develop, implement and enforce anti-discrimination legislation. They can deliver education programs for duty bearers and rights holders and, where relevant, they can assist individuals who have encountered discrimination. NHRIs should ensure that the definition of disability in anti-discrimination legislation removes the focus from the medical condition of the person and fixes it on the barriers and behaviours that must be removed or regulated.

<sup>87</sup> European Union Agency for Fundamental Rights, *Implementing the UN CRPD: An Overview of Legal Reforms in EU Member States* (May 2015), available at <http://fra.europa.eu/en/publication/2015/implementing-un-crpd-overview-legal-reforms-eu-member-states>.

It is also important to note that the obligation requires States to regulate the actions of both public and private bodies. Most citizens spend a considerable amount of their lives interacting with private entities so it is crucial that these be brought within the scope of national anti-discrimination law.

### **Take the collective voice of persons with disabilities seriously in the setting of policies**

States parties are obliged to ensure that persons with disabilities, including children with disabilities, and their representative organisations are consulted and actively involved in the development and implementation of laws and policies to implement the Convention, and in other decision-making processes about issues that affect them (article 4(3)).

This approach is crucial to the process of change. It is not enough to simply change laws – the process by which these laws were made in the first place needs to change in order that the change itself becomes sustainable. This means that the voice of persons with disabilities must become central to the way policy is developed and decisions are taken. This will require a fundamental shift in the way that governments and NHRIs engage with and involve persons with disabilities and their organisations; a ‘new politics of disability’.

In addition to involving persons with disabilities in the work they do, NHRIs should promote and monitor their effective involvement by all arms of the State. Some may also support persons with disabilities and their representative organisations to be more effective in their engagement with government. This could involve, for example, providing training on human rights or through acting as a convener between persons with disabilities and State agencies.

### **Mainstream disability in existing laws and policies**

States parties are required to take into account the protection and promotion of the human rights of persons with disabilities in all policies and programs (article 4(1)(c)). This obliges governments to take concrete steps to ensure that the rights of persons with disabilities are mainstreamed into policy making and program development, including both domestic and foreign policy. Progress towards this goal can be measured using an impact assessment – which NHRIs can assist States to design and implement – and include the scrutiny of proposals, draft laws and programs and through the involvement of persons with disabilities in the design, development and implementation of policy and programs. NHRIs should follow same principles and mainstream disability into their ongoing work; for example, on gender.

### **Progressively realise those elements of the rights in the UN CRPD that are economic, social and cultural in nature**

States parties are obliged to take measures to achieve progressively the full realisation of the economic, social and cultural rights included in the Convention, to the maximum of their available resources and, where needed, within the framework of international cooperation (article 4(2)).

Not everything can happen straight away, especially in the context of disability, where whole systems have evolved over time and need to be transformed. However, States have an obligation to do as much as they can to give effect to the socio-economic rights contained in the Convention. They must take deliberate, concrete and targeted steps towards the realisation of economic, social and cultural rights “to the maximum extent of their available resources”.

Transformation of existing systems is key to achieving the aims of the UN CRPD. To do this, States need to evaluate their existing systems and have a plan for change with dedicated resources and a clear timeline. Tracking the pace and implementation of change is critically important. NHRIs have a key role to play here, as governments will often claim that the cost is prohibitive or that now is not the right time. Scarce resources are always a reality for governments. However, NHRIs can and should insist that their government prepares a plan for change. For example, they can encourage and support government to consult with civil society, set clear targets and milestones and adopt an open review process to measure change.

Without such a plan, structural changes, which are especially necessary in the context of disability, will never be made.

### **Support research into universal design and accessibility**

States parties are required to undertake and promote research and development in relation to universally designed goods, services, equipment and facilities, to promote their availability and use and to promote universal design in the development of standards and guidelines. They are required to do the same with respect to new technologies, including information and communication technologies, mobility aids, devices and assistive technologies (article 4(1)(f)).

Accessibility does not happen without research and development. Therefore, these obligations may be met in numerous ways, which are not specified in the Convention. For example, governments might promote research and development into accessibility, universal design and new technologies through financial or other incentives to businesses, through schemes to support and recognise innovation, or by directly commissioning research and development. Many NHRIs will lack internal expertise regarding the often highly technical issues in relation to accessibility and universal design. However, NHRIs should seek to gauge the degree to which the government is genuinely meeting its responsibilities in this area; for example, by establishing how much money the State is investing in relevant research and development or by assessing its promotional strategies and activities. National, and indeed, regional, research funding bodies should also be scrutinised by NHRIs.

### **Close the information gap**

States parties must provide accessible information regarding mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities (article 4(1)(h)).

Knowledge is empowerment. Proof of effectiveness should relate to levels of awareness and understanding among persons with disabilities. NHRIs should encourage States to evaluate and tailor their information strategies and approaches to meet the diverse needs of people with disabilities. NHRIs should also seek to lead by example and ensure that all information they produce is available in accessible formats and distributed through accessible channels, including the institution's website.

### **Sensitise professionals and those who work in services to the rights of persons with disabilities**

States parties are required to promote training for professionals and staff working with persons with disabilities regarding the rights in the Convention in order to improve access to and provision of services that will help realise those rights in practice (article 4(1)(i)).

People run institutions and people develop the systems by which those institutions operate. If systems change, the culture and outlook of services and staff should also change. In fact, human development is as much a key to change as is accessibility. This may mean, for example, retraining people who have worked as staff in institutional settings to support persons with disabilities to live independently in the community, or working with teachers to develop strategies that promote the effective inclusion of children with disabilities in the classroom. It is unlikely that NHRIs will have all the necessary expertise or capacity to design or deliver such training. However, NHRIs should seek to ensure that such programs are provided. They may also provide advice regarding course content and materials on the rights of persons with disabilities. NHRI input with respect to traditional staffing arrangements – for example, in mental health facilities – can also be extremely important in bringing attitudes and practice in line with the principles of the UN CRPD.

### Ensure the full territorial coverage of the Convention

The UN CRPD makes clear that “the provisions of the present Convention shall extend to all parts of federal States without any limitations or exceptions”.<sup>88</sup> Big challenges and questions remain regarding how States parties take adequate steps to ensure that federal, regional and local authorities – that may enjoy considerable legal autonomy – comply with the UN CRPD. In States with federal structures, action may be necessary to develop mechanisms for coordination between the NHRI and the various regional or local monitoring bodies on matters to do with promoting, protecting and monitoring implementation of the Convention. One thing is clear, however: a federal structure of governance does not mean that a State can evade accountability for the performance of sub-national entities.

### Listen to the voice of persons with disabilities

In keeping with the core purpose of the Convention to achieve equal rights, arguably the most important of the general obligations is the State obligation to involve persons with disabilities in analysing their own situation and proposing blueprints for change. This applies as much to the work of NHRIs as it does to government. In fact, this point is made explicit in article 33(3). Even if the obligation to listen to and respect the collective voice of people with disabilities was not set out in article 33(3), it would be required as a direct implication of the logic of article 4(3).

## 3.4. SUBSTANTIVE RIGHTS IN THE UN CRPD (ARTICLES 5-30)

This section does not seek to provide a full account or analysis of all the rights protected by the Convention. Instead, it groups them together in light of the underlying principles set out in article 3.

### Dignity rights

A number of articles in the UN CRPD are principally concerned with the respectful treatment of persons with disabilities, including:

- **Right to life** (article 10)
- **Right to respect physical and mental integrity** (article 17)
- **Freedom from torture, cruel, inhuman or degrading treatment** (article 15), with particular emphasis on the rights of persons with disabilities not to be subject to non-consensual medical or scientific experimentation
- **Freedom from exploitation, violence and abuse** (article 16), requiring action to prevent, monitor and prosecute instances of violence, including gender-based violence, against persons with disabilities and to provide support to persons with disabilities who have been the subject of violence
- **Situations of risk and humanitarian emergencies** (article 11), placing emphasis on the need for States parties to ensure measures are taken regarding the safety of persons with disabilities in relation to “situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters”
- **Right to health** (article 25), including equal access to sexual and reproductive health programs and in relation to life and health insurance
- **Right to an adequate standard of living and to social protection** (article 28), including assistance with respect to disability-related expenses.

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88 Article 4(5).

## Autonomy and liberty rights

A number of articles, individually and collectively, reinforce the right of persons with disabilities to be the author of their own lives, with choices equal to others, including:

- **Equal recognition before the law and legal capacity** (article 12), which requires States parties to prohibit the deprivation of legal capacity on the grounds of disability and to transition from ‘substitute’ to ‘supported decision-making’ in law and practice
- **Living independently and to be included in the community** (article 19), which requires States parties to ensure that persons with disabilities enjoy choices equal to others with respect to where and with whom they live and to not be obliged to live in a particular living arrangement
- **Liberty and security of the person** (article 14), which requires States parties to prohibit the deprivation of liberty on grounds of disability (see Chapter 2 for more information)
- **Freedom of movement and nationality** (article 18)
- **Freedom of expression and opinion** (article 21), which requires action by States parties to support persons with disabilities to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice and to urge private entities and media outlets to provide information and services in accessible formats
- **Respect for privacy** (article 22), with particular emphasis on protecting the privacy of personal, health and rehabilitation information of persons with disabilities
- **Respect for home and the family** (article 23), including the rights of persons with disabilities to get married, to retain their fertility, to have and bring up children and the equal right of children with disabilities to a family life.

## Equality and non-discrimination

**Equality before and under the law** (article 5) demands the prohibition of discrimination on the basis of disability with respect to all the rights in the UN CRPD. It covers both public and private sectors and includes denial of ‘reasonable accommodation’. Article 5 provides a framework to investigate the extent to which all of the rights are realised for persons with disabilities “on an equal basis with others”.

## Participation rights

The following articles concern the right of persons with disabilities to full inclusion and effective participation in community life:

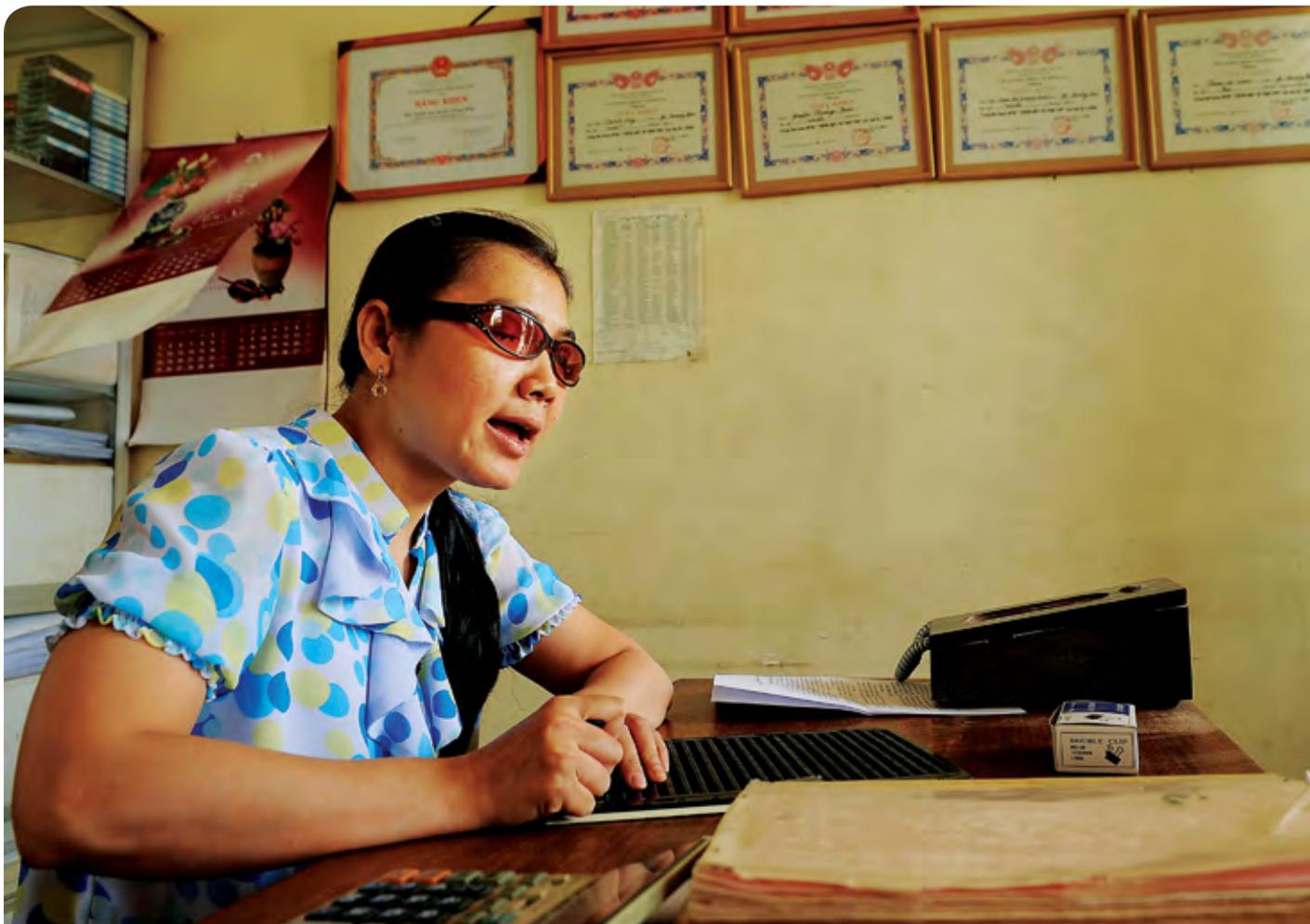
- **Participation in political and public life** (article 29) includes the right to vote and to be elected, as well as the right to accommodations and support in relation to exercising the right to vote and wider participation in political and public life
- **Participation in cultural life, leisure and sport** (article 30), includes access to cultural events, television and the media, and ensuring that laws regarding intellectual property rights do not create barriers of access to cultural materials by persons with disabilities and promote access to mainstream sport, leisure and recreation.
- **Education** (article 24), which promotes the inclusion of children and adults with disabilities in the general education system and a shift away from segregated schools
- **Work and employment** (article 27) which promotes access to the open labour market for persons with disabilities and a shift away from ‘sheltered’ employment

- **Access to justice** (article 13), including through “the provision of procedural and age-appropriate accommodations in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages”.

### Intersecting identities

**Women with disabilities** (article 6): The preamble to the UN CRPD highlights that “women and girls with disabilities are often at greater risk, both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation” and emphasises “the need to incorporate a gender perspective in all efforts to promote the full enjoyment of human rights and fundamental freedoms by persons with disabilities”. Article 6 explicitly requires States parties to take measures to protect, promote and ensure the rights of women and girls with disabilities.

**Children with disabilities** (article 7): Article 7 creates a bridge between the UN CRPD and the Convention on the Rights of the Child, reinforcing the principle that “the best interests of the child shall be a primary consideration” in decisions that concern them and stating clearly that “children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children”.



Woman working in Dong Nai, Vietnam. Photo by ILO/A. Nguyen, reproduced under a CC BY-NC-ND 2.0 licence

## Cross-cutting or transversal provisions

The UN CRPD provides assistance in understanding and interpreting other articles, including in relation to:

- **Definitions** (article 2) that explain what is meant by key terms in the Convention, including discrimination, reasonable accommodation and universal design
- **General or guiding principles** (article 3), which are discussed in detail above
- **Accessibility** (article 9), in relation to the built environment, transportation, goods and services, information and communication
- **Awareness raising** (article 8), which requires States parties to take action to combat prejudice and stereotypes faced by persons with disabilities, including through public awareness campaigns, education in schools and encouraging a positive portrayal of persons with disabilities by the media. The Convention places particular emphasis on promoting awareness of the capabilities and contributions of persons with disabilities.

The Convention also includes a number of articles that are highly particular to persons with disabilities. While they have a relationship to existing rights under other international human rights treaties, they do not have exact equivalents:

- **Personal mobility** (article 20) promotes independence for persons with disabilities through the provision of training, assistance, aids and equipment
- **Habilitation and rehabilitation** (article 26) enables, respectively, persons with disabilities from birth and those who have acquired a disability to attain and maintain independence, especially in terms of health, employment, education and social services.

It is important to note that the UN CRPD does not seek to separate out rights (and substantive provisions) according to whether they are primarily civil and political in character or economic, social and cultural in character. It is probably best to assume that each right (and the associated obligations) blends both sets of rights and obligations. As such, it probably makes more sense to characterise them according to their function (e.g. promoting dignity) rather than using traditional framings of rights and obligations. This co-mingling can be complicating but probably no more so than was originally intended by the Universal Declaration of Human Rights.

## 3.5. ARTICLE 33: THE ROLE OF GOVERNMENT, NHRIs AND CIVIL SOCIETY TO IMPLEMENT THE UN CRPD

As highlighted in Part I of this Manual, the Convention contemplates a deep process of change and reform in States parties. It involves more than simply requiring governments to comply with the treaty. Unique among human rights treaties, the UN CRPD requires, and sets out in clear terms, an institutional architecture for change that States parties must establish. Indeed, and as an engine of change, the very success of the Convention will depend on how successfully this domestic architecture is able to work.<sup>89</sup> The three core elements of this architecture for change are described below.

<sup>89</sup> See G. Quinn 'Resisting the Temptation of Elegance: Can the Convention on the Rights of Persons with Disabilities Socialise States to Right Behaviour?', in O. Arnardottir and G. Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives*, 2009; pp. 215-255.

## Smart and joined-up government

### A clear focal point within government (article 33(1))

A lack of coherent focus on persons with disabilities within governments in the past has led to wide gaps in policies across a range of issues. As a result, people with disabilities have fallen through these gaps, with terrible personal consequences. Joined-up government is important for everyone, but it is especially important for persons with disabilities. They have been particularly ill-served by processes of governance and service delivery that do not recognise the dangers that arise from policy 'grey areas' or discontinuing services.

The Convention does not set out what form a government focal point (or focal points) should take or the specific functions that should be performed by the focal point. In some cases, new arrangements may have to be established. In other cases, existing arrangements may be capable of assuming this role.

The note to the 2014 Conference of States Parties, prepared by the Secretariat for the Convention on the Rights of Persons with Disabilities, suggested some key elements that should be considered when establishing a government focal point:<sup>90</sup>

- **Mainstreaming:** A lead focal point in government should ideally be complimented by focal points across government departments/ministries to encourage mainstreaming and to coordinate the implementation of policies and programs. In other words, more than one focal point may be necessary. One very successful example is the coordination of civil rights divisions within key United States government departments (e.g. the Department of Education) with the 'lead' civil rights division located in the Department of Justice.
- **Reflect the principles underlying the Convention:** The choice of location for the lead focal point should reflect the principles that underlie the Convention, "with preference given to ministries responsible for human rights, social affairs and justice (and designation to the ministries of health or of welfare and labour avoided)". In other words, it is both the symbolism and the power of the relevant department that should be the guiding principle in locating the lead focal point. It is the power to generate sustained change that matters most.
- **Senior level support:** The focal point should be either located in, or enjoy support from, the most senior levels of government, such as the Office of the President or Prime Minister, and be accountable to a senior minister.
- **The power to lead and coordinate:** Related to the previous point, it is critical that the focal point has the authority to lead and coordinate government-wide initiatives and that it has the expertise to promote, guide, inform and advise across government.
- **Oversight of the Convention:** The focal point should take the lead role on monitoring, reporting, awareness raising, liaison with the monitoring framework and interacting with civil society, including organisations of persons with disabilities, regarding implementation of the UN CRPD.

Importantly, and consistent with the theme of 'voice', the focal point (or focal points) should actively consult with persons with disabilities. It is not advisable, however, that the focal point directly include persons with disabilities and their representative organisations. That would cross the line into executive territory. But, at a minimum, the focal point should only act after close consultation with civil society, which can be done by setting up a consultative forum or platform.

90 'National Implementation and Monitoring: Matters relating to the Implementation of the Convention'; available at [www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf](http://www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf).

### A coordination mechanism across government

Even when there is a strong and effective focal point on disability policy within government, there is no guarantee that the implementation of policy will be coherent within and across all government responsibilities. Setting policies without ensuring their full implementation is sure to create cynicism about the sincerity of government's commitment to change. That is why an extra step is often needed: establishing or designating a coordinating mechanism within government to "facilitate related action in different sectors and at different levels" (article 33(1)).

Policy and implementation needs to be more than theoretically coherent. It must be delivered in a way that minimises gaps. Article 33(1) does not explicitly demand the existence of a coordination mechanism, nor does it specify an ideal form or describe the functions it should assume. However, the Note by the Secretariat for the Convention on the Rights of Persons with Disabilities to the 2014 Conference of States Parties states that:

Several States have coordination mechanisms on disability issues in place, in some cases predating the ratification of the Convention. Although arrangements differ, coordinating committees often include representatives from various ministries and organizations of persons with disabilities as well as other civil society organizations, the private sector and trade unions. Their mandates often focus on policy development, the promotion of dialogue in the disability field, awareness-raising and similar functions. Coordination committees often have a secretariat, in several cases housed within ministries of social welfare.<sup>91</sup>

### PROMISING PRACTICE

While not focused solely on the rights of persons with disabilities, the **Scottish National Action Plan for Human Rights (SNAP)** was produced by a drafting group from across the public and voluntary sectors and overseen by an Advisory Council whose members reflected the diversity of Scottish civic life. SNAP will coordinate action by a wide range of public bodies and voluntary organisations towards achieving its vision of "of a Scotland in which everyone is able to live with human dignity".<sup>92</sup>



### A framework outside government to monitor

We have seen that the general obligations contained in article 4 are there to drive and inform a process of change. However, any credible theory of change requires a 'reality check', one that is capable of highlighting deficiencies or gaps and otherwise assisting in the process of embedding the principles of the Convention across the work of government. Article 33(2) establishes this framework.

Governments need tools to inform them how well they are doing on disability issues, what kinds of obstacles exist and how they might be addressed. In addition, government action often needs to be complemented by the actions of other actors. That is why article 33(2) requires States to:

....maintain, strengthen, designate or establish at the national level a framework that includes one or more independent mechanisms, to promote, protect and monitor implementation of the Convention.

The Convention specifies that when designating or establishing the "independent mechanism(s)" to be included in the framework, States parties are to "take into account" the principles relating the status and functioning of national institutions. This is usually read as meaning the Paris Principles.<sup>93</sup> Constructive ambiguity in the text meant that the Paris Principles are not mentioned explicitly.

91 Ibid.

92 More information is available at [www.scottishhumanrights.com/scotlands-national-action-plan/](http://www.scottishhumanrights.com/scotlands-national-action-plan/).

93 General Assembly resolution 48/134; available at [www.asiapacificforum.net/resources/understanding-paris-principles/](http://www.asiapacificforum.net/resources/understanding-paris-principles/).

However, a reading of the *travaux préparatoires* reveals that it was indeed the Paris Principles that were intended<sup>94</sup> and it is now standard practice for the CRPD Committee to demand that the relevant ‘independent mechanism’ complies with the Paris Principles. In effect, the term “take into account” is usually interpreted as meaning that the States parties must adhere to the Paris Principles. The framework – which can be very broad and inclusive – must contain at least one, if not more, ‘independent mechanisms’.

The Note by the Secretariat for the Convention on the Rights of Persons with Disabilities to the 2014 Conference of States Parties<sup>95</sup> suggests that three key requirements need to be given effect in the monitoring framework:

- The framework must include one or more independent mechanisms that take into account the Paris Principles. This does not mean that only entities complying with the Paris Principles should be part of the framework; rather, it means that at least one mechanism that is established and functions on the basis of the Paris Principles must be included;
- The framework must be capable of adequately promoting, protecting and monitoring the implementation of the Convention. This means that the framework needs to be given an adequate mandate and the institutional capacity required to effectively perform its functions;
- Civil society, and persons with disabilities and their representative organizations in particular, need to be involved and fully participate in the monitoring process.

Frameworks are generally composed of bodies outside of government. They can – and probably should – include subject-specific bodies like national disability policy advisory authorities. The independent mechanism(s) should be genuinely independent. They need not each individually possess all the functions needed to perform the tasks required by article 33(2) to promote, protect and monitor. However, between them – and especially between all the entities in the framework – these tasks have to be performed.

An analysis of the 33 sets of concluding observations of the CRPD Committee<sup>96</sup> on article 33(2) from 2014–2015 reveals a number of interesting trends.

First, with respect to the majority of State reports examined, the CRPD Committee recommended the formal establishment of a framework and the designation of one or more independent mechanisms. This recommendation was made to: the Cook Islands, Croatia, Czech Republic, Dominican Republic, Mongolia, Turkmenistan, Ecuador Sweden, Australia, Austria, Paraguay, Argentina, China, Hong Kong, Peru, Spain, Brazil, the European Union, Ukraine, Mauritius and Gabon.

The recommendation made to Gabon (para. 62) was typical of that made to other States: “The Committee recommends that the State party designate an independent framework aligned to the Paris Principles, with an allocated budget and ensure the participation of persons with disabilities as required by Article 33(3)”.<sup>97</sup> In one instance the Committee recommended rolling back the intrusion of an executive body into the operation of the framework (the European Union).<sup>98</sup>

94 The *travaux préparatoires* are available at [www.un.org/development/desa/disabilities/resources/ad-hoc-committee-on-a-comprehensive-and-integral-international-convention-on-the-protection-and-promotion-of-the-rights-and-dignity-of-persons-with-disabilities.html](http://www.un.org/development/desa/disabilities/resources/ad-hoc-committee-on-a-comprehensive-and-integral-international-convention-on-the-protection-and-promotion-of-the-rights-and-dignity-of-persons-with-disabilities.html).

95 See [www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf](http://www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf).

96 The concluding observations of the CRPD Committee are available at [www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx).

97 CRPD/C/GAB/CO/1.

98 CRPD/C/EU/CO/1.

Second, in some cases, the Committee actually specified the body it thought should form part of the framework or the independent mechanism in the framework. For example, with respect to the Czech Republic, the Committee concluded (para. 61) that “the office of Ombudsman should be entrusted with the mandate as the independent national monitoring mechanism”.<sup>99</sup> Similarly, and with respect to Mexico, the Committee (para. 62) urged “the State party to ensure that the National Human Rights Commission and the 32 state human rights commissions, as the independent monitoring mechanism for the Convention”.<sup>100</sup> Likewise, with respect to Kenya, the Committee concluded (para. 60) that the State party “establish a national mechanism to monitor the implementation of the convention, with the participation of the Kenya National Commission on Human Rights as an institution in compliance with the Paris Principles”.<sup>101</sup> The Committee repeatedly referred to the Paris Principles in most of its concluding observations.

Third, in at least two sets of concluding observations, the Committee stressed the importance of a formal process of designating the framework (Croatia and El Salvador). With respect to El Salvador, the Committee recommended (para. 70) “that the State party officially designate mechanisms to monitor the implementation of the Convention involving both civil society and in institutions fulfilling the Paris Principles regarding independent human rights institutions”.<sup>102</sup>

Fourth, the Committee repeatedly stressed the importance of civil society involvement in the monitoring framework, as well as in the work of the independent mechanisms (NHRIs). This arose, in particular, with respect to Croatia, Dominican Republic, Mongolia, Denmark and China. For example, and with respect to Croatia, the Committee recommended that the State party (para. 53) “provide DPOs and other civil society organisations with adequate resources for full and effective participation in the national implementation and monitoring process.”<sup>103</sup> With respect to the Dominican Republic, the Committee recommended that the State party (para 63) “involve organisations of persons with disabilities ... in the mechanism established under Article 33 paragraph 2 of the Convention”.<sup>104</sup> And with respect to China, the Committee “strongly” recommended (para. 50) that the State party revise its laws to allow, “non-governmental organisations other than the China Disabled Persons’ Federation to represent the interests of disabled people in the State party and to be involved in the monitoring process. It further recommends the establishment of an independent monitoring mechanism in line with Article 33(2) and in accordance with the Paris Principles.”<sup>105</sup>

Fifth, in the concluding observations made to Germany, Mongolia, Republic of Korea, Austria and Qatar, the Committee stressed the importance of NHRIs having sufficient material and human resources to perform their tasks. For example, with respect to Germany, (para. 62) the Committee recommended the State party to “strengthen the capacities of the independent monitoring mechanism ... [by ensuring the] availability of resources for more comprehensive and effective monitoring at the Lander and municipal levels”.<sup>106</sup> With respect to Mongolia, the Committee recommended (para. 52) that the State party provide the independent mechanism “with adequate human, technical and financial resources”.<sup>107</sup>

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99 CRPD/C/CZE/CO/1.

100 CRPD/C/MEX/CO/1.

101 CRPD/C/KEN/CO/1.

102 CRPD/C/SLV/CO/1.

103 CRPD/C/HRV/CO/1.

104 CRPD/C/DOM/CO/1.

105 CRPD/C/CHN/CO/1.

106 CRPD/C/DEU/CO/1.

107 CRPD/C/MNG/CO/1.

The Committee also stressed the importance of guarantees of independence in the functioning of the independent mechanisms. For example, with respect to Belgium (para. 49), the Committee recommended that “the State party complete the process to ensure the Centre’s compliance with the Paris Principles”.<sup>108</sup> Likewise, and with respect to Ecuador (para. 55), the Committee “reminds the State party that the national monitoring mechanism must be independent ... In this context the Committee urges the State party to adopt the necessary legal measures to clearly establish the independent mechanism under the Convention in lines with the Paris Principles.”<sup>109</sup>

The Committee has also been attentive to the complexities of federal arrangements. For example, and with respect to Germany (para. 62), the Committee recommended that the State party “reinforce the necessary resources ... including the legal status of Lander Commissioners for matters relating to disabled persons”.<sup>110</sup> With respect to Denmark, the Committee recommended (para. 67) that the State should “should also take the necessary measures for the establishment of an independent monitoring mechanism in the Faroe Islands. The Committee also recommends that the Government of the Faroe Islands establish a human rights institution for the promotion and protection of human rights, in accordance with the Paris Principles.”<sup>111</sup>

These are remarkably robust recommendations. They indicate a clear and deep vision of article 33(3). As is obvious from the Committee’s concerns about the legislative designation of independent mechanisms, along with their funding, resourcing and structural guarantees of independence, States still have some way to go. The recommendations also highlight a clear recognition of the ‘added value’ that NHRIs offer, especially when the voice of persons with disabilities is embedded in their work.

**The Irish Human Rights and Equality Commission recently completed a study looking at what sort of monitoring ‘framework’ is best suited to different domestic circumstances, following ratification of the UN CRPD. *Establishing a Monitoring Framework in Ireland for the United Nations Convention on the Rights of Persons with Disabilities*, published in May 2016, summarises how different countries constitute their frameworks and how civil society is generally engaged with these frameworks. The report also considers the Irish context and identifies options for the Irish framework’, including designating the Commission as a ‘single-body independent mechanism and framework’. While the decision is ultimately one for the government, the report provides a useful contribution to the discussion.<sup>112</sup>**



## Civil society at the heart of change

Article 4(3) demands that the collective voice of persons with disabilities should be an integral part of the policy process and in making decisions that directly affect them. Because of article 4(3) – and even if article 33(3) did not mention civil society – it is beyond doubt that the tasks set out in article 33(1) (‘joined-up government’) and article 33(2) (‘framework to monitor’) cannot be performed without the active consultation and involvement of persons with disabilities and their representative organisations. This specifically includes the work of independent mechanisms like NHRIs.

108 CRPD/C/BEL/CO/1.

109 CRPD/C/EQU/CO/1.

110 CRPD/C/DEU/CO/1.

111 CRPD/C/DNK/CO/1.

112 The report is available at [www.ihrec.ie/documents/establishing-monitoring-framework-ireland-united-nations-convention-rights-persons-disabilities/](http://www.ihrec.ie/documents/establishing-monitoring-framework-ireland-united-nations-convention-rights-persons-disabilities/).

While, ideally, civil society should be consulted by the focal point within government, they can and should be part of the coordination mechanism within government. They must certainly be part of the framework for monitoring set out in article 33(2).

Persons with disabilities should also be involved in the work of NHRIs. They may be directly involved; for example, where persons with disabilities are appointed as Commissioners or staff within NHRIs or where they sit on advisory groups or committees. Involvement may also be *via* representative organisations. Here it is important to draw a distinction between organisations ‘for’ persons with disabilities, such as some charitable organisations and service providers that are led and staffed overwhelmingly by persons who do not have a disability, and organisations ‘of’ persons with disabilities, which are led overwhelmingly by persons with disabilities. It is also important that organisations of persons with disabilities represent the plurality of persons with disabilities including, in particular, the experiences and perspectives of people with psychosocial disabilities, intellectual disabilities, women and children with disabilities, older persons with disabilities and persons with disabilities from minority ethnic or indigenous groups. Representativity – and judgments about representivity – are inherently difficult and will no doubt prove challenging.

The Note by the Secretariat for the Convention on the Rights of Persons with Disabilities to the 2014 Conference of States Parties recommends that:

The potential to have national human rights institutions serve as independent mechanisms and organizations of persons with disabilities as participating entities of the monitoring framework should be explored.

A number of States have taken this approach and examples of their work are provided in Part III of this Manual.

### 3.6. TOOLS FOR EFFECTIVE POLICY-MAKING: DATA COLLECTION (ARTICLE 31)

Article 31 requires States parties to collect appropriate information, including statistical and research data, to enable them to develop and implement policies to give effect to the UN CRPD. In doing so, they must comply with established safeguards regarding confidentiality, privacy and data collection, as well as with ethical principles in the collection and use of statistics.

The Convention also emphasises the importance of disaggregating data in order to identify the necessary steps required to implement the Convention. This clearly indicates the need for data that identifies the barriers faced by persons with disabilities in exercising their rights, rather than on the prevalence of disability or specific impairments.

The UN CRPD also requires that this data is disseminated and accessible to persons with disabilities. A very recent promising practice involves the Office of the Ombudsman of Samoa and the preparation of its annual Human Rights Report. In 2016, the report will focus on disability.<sup>113</sup> It is currently conducting a survey to which the public are invited to contribute. Furthermore, it is collecting narrative stories or case studies of the lived experience of persons with disabilities. This is the first time this has been done in Samoa and the outcomes will be used to inform policy making.

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113 Reports of the Ombudsman of Samoa are available at [www.ombudsman.gov.ws](http://www.ombudsman.gov.ws).

### PROMISING PRACTICE

In 2013, the **United Kingdom's Government Office for Disability Issues** published *Fulfilling Potential: Building a deeper understanding of disability in the UK today*, which sought to:

- Provide an analysis of the current evidence on disability in the United Kingdom to inform the development of the next stage of work on the government's disability strategy 'Fulfilling Potential – the development of actions, outcomes and indicators'
- Inform public understanding and prompt debate about disability and the issues faced by persons with disabilities
- Raise awareness, drive a change in attitudes and support an increase in commitment to improving the lives of persons with disabilities in the United Kingdom.



The evidence base is structured in two parts. The first part provides analysis of the number of persons with disability in the United Kingdom, as well as looking at the way disability develops over the life course and at the fluctuating nature of disability. The second part focuses on the lives of persons with disabilities by looking at trends in outcomes and barriers to taking part in different areas of life. The evidence is structured around the themes of early intervention; choice and control; and inclusive communities. The document also summarises the analytical evidence on disability.<sup>114</sup>

## 3.7. INTERNATIONAL COOPERATION AND INCLUSIVE DEVELOPMENT (ARTICLE 32)

It was inevitable that international cooperation would figure prominently in the Convention (article 32). Some States have made tremendous progress on disability issues and the lessons of this progress should be shared to enable other States to take stock. In addition, development aid programs should, at a minimum, not cut across or undermine the objectives of the Convention. Given that the ultimate aim of the UN CRPD is change and sustaining a process of change, it makes sense to ensure that development aid programs do not support old or segregationist systems. In fact, these programs should be reviewed and recalibrated to contribute directly to the process of change. However, where there are deficiencies in development aid programs, contracting States cannot cite this article as a defence for their own failure to meet their treaty obligations (article 32(2)).

There are four sets of overlapping obligations in article 32. First, there is an obligation to ensure that international cooperation and international (and bilateral) development assistance programs are accessible to persons with disabilities (article 32(1)(a)). Second, States parties have an obligation to facilitate capacity building, including the sharing of information, experience and training programs. These capacity-building measures should include capacity building between NHRIs. Third, States parties have an obligation to facilitate cooperation in research and access to scientific and technical knowledge. This can and should include research done by NHRIs. Fourth, States parties have an obligation to provide, as appropriate, technical and economic assistance, including sharing accessible and assistive technologies.

114 Available at [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/320509/building-understanding-main-report.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/320509/building-understanding-main-report.pdf).

The **European Network of National Human Rights Institutions (ENNHRI)** is one of four regional networks of NHRIs within the Global Alliance of National Human Rights Institutions. ENNHRI has a Convention on the Rights of Persons with Disabilities Working Group that acts as a point of contact among NHRIs at the European level, and between the NHRIs and the European Union and other international institutions. The working group also develops good practice and shares knowledge.<sup>115</sup>



### 3.8. CONFERENCE OF STATES PARTIES TO THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (ARTICLE 40)

The UN CRPD is innovative because it moves beyond a sole focus on violations. It recognises that an open exchange of experiences and ideas is required to generate and sustain long-term change. Accordingly, the Convention envisions a standing conference of States parties (article 40). This provides a potentially powerful platform for States to learn from one another in a multilateral forum.

States that have ratified the Convention meet annually at the UN headquarters in New York. There have been eight meetings so far, with agendas spanning a broad range of topics, such as the inclusion of persons with disabilities in the post-2015 sustainable development goals and, most recently, implementation and monitoring of the UN CRPD at the national level.<sup>116</sup>

NHRIs can attend the Conference of States Parties and have acquired significant *ad hoc* recognition, including the right to make statements. They have also successfully hosted a number of side events. At the 2014 Conference of States Parties, the International Coordinating Committee (ICC) of National Institutions for the Promotion and Protection of Human Rights (now known as the Global Alliance of National Human Rights Institutions) called for the participation rights of NHRIs in the Conference to be strengthened:

The ICC is appreciative of the work of the Conference Bureau and the Secretariat in facilitating the independent involvement of NHRIs in the work of the COSP and the recognition afforded to NHRIs.

The ICC notes, however, that this strong relationship has yet to be formally recognized in the Rules of Procedure. The ICC therefore encourages the Bureau to consider amending the Rule so as to grant formal participation rights to 'A status' accredited NHRIs, the ICC and regional coordinating committees speaking on behalf of their accredited members.

This is in line with the UNGA resolution that urges strengthened coordination between NHRIs and UN mechanisms (A/RES/68/171).<sup>117</sup>

Support for the Conference of States Parties is provided by the Secretariat for the Convention on the Rights of Persons with Disabilities.<sup>118</sup>

115 For more information, see [www.ennhri.org/The-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD](http://www.ennhri.org/The-Committee-on-the-Rights-of-Persons-with-Disabilities-CRPD).

116 For more information on the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, see [www.un.org/development/desa/disabilities/conference-of-states-parties-to-the-convention-on-the-rights-of-persons-with-disabilities-2.html](http://www.un.org/development/desa/disabilities/conference-of-states-parties-to-the-convention-on-the-rights-of-persons-with-disabilities-2.html).

117 ICC Statement to the Seventh Conference of State Parties of the Convention on the Rights of Persons with Disabilities, 10 June 2014, UN Headquarters, New York.

118 More information on the Secretariat is available at [www.un.org/development/desa/disabilities/about-us.html](http://www.un.org/development/desa/disabilities/about-us.html).

# Chapter 4: International monitoring: The tasks and functioning of the Committee on the Rights of Persons with Disabilities

## KEY QUESTION

- What is the composition and role of the Committee on the Rights of Persons with Disabilities?



## 4.1. COMPOSITION, APPOINTMENT AND OPERATION

The Committee on the Rights of Persons with Disabilities is the body of independent experts that monitors implementation of the Convention by States parties (article 34).<sup>119</sup> Its members are elected by States parties at the annual Conference of States Parties.

The Committee discharges its role by:

- Examining periodic reports by States parties on their implementation of the Convention
- Issuing State-specific recommendations through concluding observations on State examinations
- Clarifying aspects of the Convention and developing jurisprudence through the development of general comments, guidance and recommendations
- Undertaking capacity building activities with States parties
- Assessing individual communications under the Optional Protocol to the Convention
- Conducting inquiries under the Optional Protocol to the Convention.

The process of electing members to the Committee is set out in article 34 of the UN CRPD. Members serve four-years terms for a maximum of two terms. They undertake this role in their personal capacity, not as representatives of their State.

Article 38 focuses on the relationship between the Committee and other bodies which include, in the main, UN bodies. It does not explicitly mention NHRIs. Nevertheless, the Committee has the inherent jurisdiction to grant audience to NHRIs. Indeed, this is explicitly reflected in Rule 51 of its Rules of Procedure, adopted in 2014:

Representatives of national human rights institutions may be invited by the Committee to make oral or written statements and provide information or documentation in areas relevant to the Committee's activities under the Convention to meetings of the Committee.<sup>120</sup>

119 More information on the Committee is available at [www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx).

120 CRPD/C/1, adopted 5 June 2014.

## 4.2. EXAMINING PERIODIC STATE REPORTS ON IMPLEMENTATION OF THE UN CRPD

Each State party to the Convention must submit to the Committee an initial comprehensive report on measures taken to implement the Convention within two years of the Convention entering into force for that State, followed by subsequent reports every four years or when requested to do so by the Committee (article 35). The Committee has published reporting guidelines concerning both initial and periodic reports on its website.<sup>121</sup> The proceedings of the Committee are webcast.<sup>122</sup>

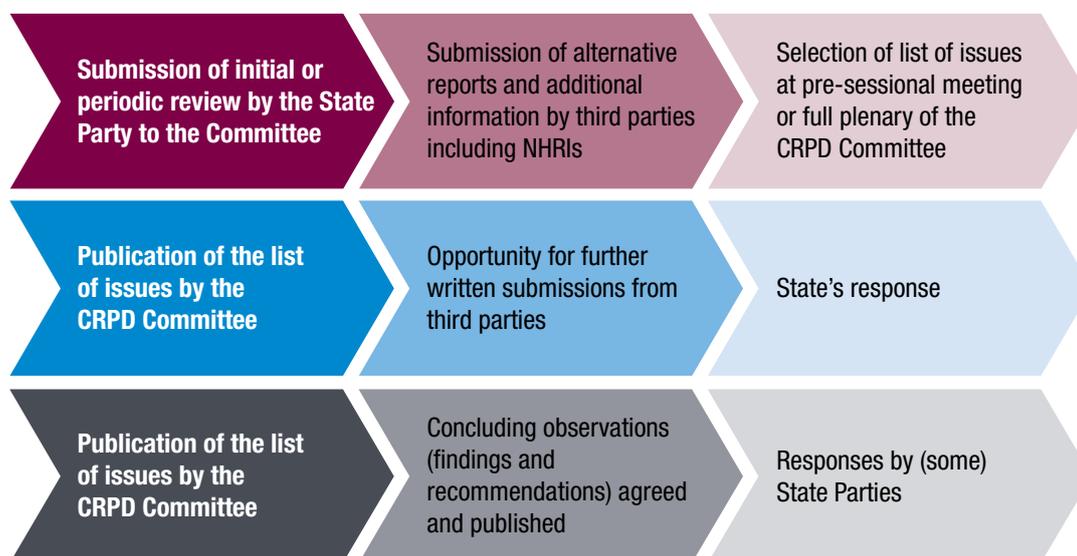
The Committee has said that it:

... welcomes National Human Rights Institutions to provide country-specific information on issues relevant to the implementation of the Convention in the months prior to the adoption of the List of Issues or prior to the examination of the State party's report.<sup>123</sup>

The Committee has suggested that NHRIs can contribute to the State examination process by:

- Providing written information that is concise, specific, reliable and as objective as possible
- Highlighting priority concerns and suggesting possible country-specific recommendations to facilitate the work of the Committee
- Submitting “alternative reports” which follow the same form of presentation as reports submitted by countries.<sup>124</sup>

NHRIs who have engaged with other treaty monitoring bodies will be familiar with the stages of the State examination process. The diagram below sets out these stages. NHRIs can engage and contribute at each stage of the process, including commenting on draft State reports prior to submission and during the examination itself. Examples of NHRIs that have done so are included in Part III of this Manual.



121 CRPD/C/2/3.

122 See [www.treatybodywebcast.org](http://www.treatybodywebcast.org).

123 See 'Information for National Human Rights Institutions and Civil Society Organisations', available at [www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx).

124 Ibid.

For example, in the 15th session of the Committee (March-April 2016), seven State reports were considered and NHRIs submitted parallel reports in relation to six of these (Chile, Portugal, Serbia, Slovakia, Thailand and Uganda).<sup>125</sup>

With respect to Chile, the excellent 15-page ‘complementary report’ of the **National Institute of Human Rights of Chile** focused on accessibility, legal capacity, torture, freedom of expression, inclusive education, health, work and employment.<sup>126</sup> There was also a particularly interesting analysis on sterilisations and forced treatment.

With respect to Portugal, the **Ombudsman of Portugal** also submitted a 15-page report. It focused on a wide range of topics including equality, violence against women and girls with disabilities, accessibility, inclusive education and participation. Its main concerns focused on the lack of inclusion, specifically in employment, the lack of accessibility, the lack of support for carers, domestic violence against persons with disabilities and the low levels of political participation by persons with disabilities.<sup>127</sup>

With respect to Serbia, the **Serbian Protector of Citizens** (Ombudsman) submitted a seven-page ‘selected list of issues’. It covered accessibility, the right to live independently and be included in the community, personal mobility and work and employment. The section dealing with the right to live independently was particularly telling. The lack of progress on deinstitutionalisation is well documented and the Ombudsman put forward many practical recommendations that could be extremely useful to the Committee (e.g. a recommendation calling for “development of action plans defining the short-term and long-term steps that need to be taken, with clearly indicated deadlines and resources, and a clear evaluation plan providing for an assessment and prompt reacting when necessary”).<sup>128</sup>

With respect to Slovakia, the **Slovak Centre for Human Rights** submitted a 14-page set of observations on the State report. It touched on issues such as legal capacity, the appointment of a dedicated Commissioner on human rights and disability, accessibility, education, employment and designation of a focal point under article 33. It also, usefully, contained a set of recommendations, including welcoming law reform to narrow down the institution of guardianship.<sup>129</sup>

With respect to Thailand, the **National Human Rights Commission of Thailand** submitted a 20-page report on implementation of the Convention. Its submission also contained many practical recommendations for the Committee to ponder. The report focused on the lack of emphasis on implementing existing laws, on participation, and on awareness raising. Particularly impressive was its close attention to health and rehabilitation and several practical recommendations to tackle existing barriers.<sup>130</sup>

With respect to Uganda, the **Uganda Human Rights Commission** prepared an 11-page submission that addressed issues relating to accessibility, discrimination, education, health, political participation, employment and incorporation of the Convention into Ugandan law. Each heading was followed by succinct and practical recommendations for consideration by the Committee. One recommendation concerned making the denial of ‘reasonable accommodation’ a form of discrimination under Ugandan law. A particularly impressive section considered disability in the Ugandan prison system and the phenomenon of indefinite duration of incarceration on the ground of disability. Another extremely useful section examined mental health law and policy in Uganda, highlighting the need to move toward a community-based recovery model.

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125 [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=1050&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=1050&Lang=en).

126 Ibid; see under ‘Chile’.

127 Ibid; see under ‘Portugal’.

128 Ibid; see under ‘Serbia’.

129 Ibid; see under ‘Slovakia’.

130 Ibid; see under ‘Thailand’.

With respect to Germany, the submission made by the **German Institute for Human Rights** was especially useful.<sup>131</sup> The format of the report was singularly helpful. On any given right or issue, the report summarised the positions of the State, civil society and the Institute (as the body officially designated as the independent mechanism in the national monitoring framework). This approach had a direct influence on the list of issues prepared by the Committee and addressed to the State party, as well as on the concluding observations of the Committee with respect to Germany.

The parallel report submitted by the **Australian Human Rights Commission** with respect to the examination of the Australian State party report was also very powerful.<sup>132</sup> This 14-page report acknowledged a large degree of progress but also focused on areas where progress was slower; for example, in regulating and policing violence against people with disabilities in institutional settings (combining analysis of several articles in the Convention), access to justice, involuntary and non-therapeutic sterilisation and employment. This also had a measurable impact on the concluding observations of the Committee with respect to Australia.

This brief survey shows that NHRI are engaging very effectively with the Committee as part of the State reporting process. Most of the submissions contextualised the information provided in State reports and highlighted ongoing deficiencies. Many put forward very practical recommendations to push the reform process forward. The reports were also economical in length, making them of great use to the Committee in understanding the national context and those areas where challenges remain.

### 4.3. GENERAL COMMENTS, OPINIONS, STATEMENTS AND GUIDELINES

Rule 47 of the CRPD Committee's Rules of Procedure allow it to adopt 'general comments'. These are important for NHRIs as they clarify the Committee's position on complex questions of policy and practice regarding implementation of the UN CRPD. They will also likely inform the way the Committee appraises the performance of States during its examinations.

The Committee also produces statements to engage with and seek to influence topical developments, to reinforce its position or to encourage action. These statements can be useful for NHRIs acting at the international level or within their own States.

The Committee has also issued guidelines regarding its working methods and on how different actors, including civil society and NHRIs, can engage with its work.

At the time of writing, the Committee has published four general comments. General Comment No. 1 (2014) concerns article 12 on equal recognition before the law; General Comment No. 2 (2014) concerns article 9 on accessibility; General Comment No. 3 (2016) concerns article 6 on women and girls with disabilities; and General Comment 4 (2016) concerns article 24 on the right to inclusive education.<sup>133</sup>

The Committee is also planning a general comment on article 19 (living independently and being included in the community).

Two NHRIs made submissions in relation to the general comment on education. The **Danish Institute for Human Rights** described its 'gold standard' indicators on education and highlighted the importance of enforcing rights through complaints. In its submission, the **Equal Opportunities Commission of Hong Kong** focused on assessment, (in)sufficient training for teachers and other supports.<sup>134</sup>

131 13th Session of the CRPD Committee; available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=982&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=982&Lang=en).

132 10th Session of the CRPD Committee; available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=883&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=883&Lang=en).

133 The four general comments are available at [www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx).

134 These and other submissions are available at [www.ohchr.org/EN/HRBodies/CRPD/Pages/DGDontherighttoeducationforpersonswithdisabilities.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGDontherighttoeducationforpersonswithdisabilities.aspx).

With respect to the proposed general comment on community living, the Committee received written submissions from the **Belgian Interfederal Centre for Equal Opportunities**, the **New Zealand Human Rights Commission** and the **European Union Fundamental Rights Agency** (not strictly an NHRI but a close analogue for the EU).<sup>135</sup> The seven-page submission from Belgium focused on a culture of institutionalisation and the lack of an overall policy and funding for community living. It concluded with a number of succinct and useful “points for attention for the general comment”. The five-page submission made by the **New Zealand Human Rights Commission** connected article 19 (community living) with article 12 (supported decision-making). This is especially innovative and should have an impact when the Committee finalises its general comment. The three-page submission of the **EU Fundamental Rights Agency** drew attention to its impressive set of indicators on article 19 and its ongoing work on the practical steps that need to be undertaken to move from institutions to community living. The annex usefully directs readers to the rich literature the Agency has produced on the topic.

This snapshot reveals a strong degree of engagement by NHRIs in the work of the Committee to prepare its general comments.

The Committee has also published the following statements and guidelines, which are available on its website:

- Guidelines on Article 14 of the UN Convention on the Rights of Persons with Disabilities: the right to liberty and security of persons with disabilities (2015)
- Statement of the Committee on the Rights of Persons with Disabilities on including the rights of persons with disabilities in the post-2015 agenda on disability and development
- Joint Statement of the Chairpersons of the UN Human Rights Treaty Bodies to the UN Summit, High Level Plenary Meeting of the General Assembly 20-22 September 2010 on the relationship between implementation of economic and social rights and the Millennium Development Goals
- Statement on Sustainable Development Goals-Addressed to the Eighth session of the Open Working Group on Sustainable Development Goals-January 2014
- Statement on disability inclusion in the Third World Conference on Disaster Risk Reduction and Beyond
- Statement on Article 14 of the Convention on the Rights of Persons with Disabilities: the right to liberty and security of the person.

The Committee has also made statements regarding the inclusion of persons with disabilities in response to specific situations of risk and humanitarian disaster, including the earthquake in Qinghai, China, the earthquake and tsunami in Chile, and the situation in Haiti.<sup>136</sup>

#### 4.4. 2014 GUIDELINES ON THE PARTICIPATION OF CIVIL SOCIETY IN THE WORK OF THE COMMITTEE

In 2014, the Committee published *Guidelines on the Participation of Disabled Persons Organizations (DPOs) and Civil Society Organizations in the work of the Committee*.<sup>137</sup> It is a clear and highly practical set of recommendations covering their participation in the State reporting process, thematic briefings, the elaboration of draft general comments, days of general debate, interventions in communications, inquiries, capacity building and the protection of persons against victimisation.

135 These and other submissions are available at [www.ohchr.org/EN/HRBodies/CRPD/Pages/CallIDGDtoliveindependently.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/CallIDGDtoliveindependently.aspx).

136 Available at [www.ohchr.org/EN/NewsEvents/Pages/newssearch.aspx?NTID=STM&MID=Committ\\_Disabilities](http://www.ohchr.org/EN/NewsEvents/Pages/newssearch.aspx?NTID=STM&MID=Committ_Disabilities).

137 CRPD/C/11/2, Annex II.

The Committee plans to produce similar guidance for NHRIs and other ‘independent mechanisms’. It held a special meeting with representatives of such bodies on 25 September 2014 to explore the issues involved. The key outcomes of that meeting were that:

- The Committee will develop guidelines on the participation of NHRIs and National Monitoring Mechanisms (NMMs) at all stages of the Committee’s work
- The Committee will continue contributing to the establishment and strengthening of NHRIs and NMMs through the Committee’s concluding observations
- The Committee encouraged NHRIs to avail themselves of the Committee’s support with capacity building
- The Committee indicated that it will explore the possibility of working closely with NHRIs and NMMs in developing core indicators for the monitoring of the Convention
- The Committee will also explore other ways of supporting the monitoring activities of NHRIs and NMMs, including by the establishment of a database to exchange information on good practices in monitoring the implementation of the Convention
- The Committee emphasised the importance of the participation of organisations of persons with disabilities in national monitoring activities and identified this as a matter requiring further attention.<sup>138</sup>

#### 4.5. 2016 GUIDELINES ON THE PARTICIPATION OF NHRIs IN THE WORK OF THE COMMITTEE

The Committee published its draft Guidelines on NHRIs in May 2016.<sup>139</sup> They were adopted in August 2016: *Guidelines on Independent Monitoring Frameworks and their Participation in the work of the Committee*. They build on similar guidelines adopted by other treaty monitoring bodies and seek to contribute to the broader process across the UN system to create more opportunities for contribution by NHRIs.

The Guidelines include an introduction and three substantive chapters. The introduction emphasises the need for both substantive and functional independence of NHRIs. It also encourages States parties to equip NHRIs with an additional and adequate budget and human resources to enable them carry out their article 33 functions (paras. 13-14). This strongly reinforces key elements of the Paris Principles. The first chapter considers the scope of articles 33(2) and 33(3), the second chapter examines the participation of ‘independent monitoring frameworks’ in the proceedings of the Committee and the third chapter focuses on monitoring of the Convention by NHRIs at the national level.

The text makes it plain that the Guidelines will apply to the relationship between the Committee and NHRIs regardless of whether an NHRI has been formally designated as part of the article 33(2) framework. They would therefore cover the activities of NHRIs who, for one reason or another, are not a member of the relevant ‘framework’ but which nevertheless do important work on disability issues (para. 7).

A few things stand out in the Guidelines. First, some ambiguity remains concerning whether the ‘framework’ itself has to be independent – the text explicitly refers to an ‘independent monitoring framework’ throughout – or whether it is the ‘independent mechanism’ within the framework that must be independent. On the one hand, the text contemplates membership of the framework of entities that are part of, or close to, the executive and therefore demands that any potential conflicts of interest be managed or regulated (para. 20). On the other hand, the Committee has specifically ruled against the European Commission being a part of the relevant article 33.2 ‘framework’.

138 CRPD/C/12/2, Annex V.

139 See [www.ohchr.org/EN/HRBodies/CRPD/Pages/DraftGuidelinesestablishmentindependentmonitoring.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DraftGuidelinesestablishmentindependentmonitoring.aspx).

Some clarity is therefore needed as to whether the entirety of the framework should be independent, whether membership by executive bodies is permissible provided it is controlled, and when membership by executive bodies, like the European Commission, is precluded altogether. Probably the best interpretation is that while the designated independent mechanism must comply with the Paris Principles, the other entities in the framework have to exhibit some functional independence from the executive in order to be effective.

Second, the Committee envisages a robust role for NHRIs to engage in the work of the Committee itself. It encourages NHRIs to submit their own shadow reports to State party reviews, to contribute to framing the list of issues for the review, and to follow up on implementation of the recommendations the Committee makes in its concluding observations to their respective States. NHRIs are encouraged to contribute to the development of the Committee's general comments on the UN CRPD. There is also useful language in the Guidelines on the engagement of NHRIs in the Committee's communications procedure and its inquiry procedure. All of this is extremely welcome.

Third, the Guidelines endorse OHCHR's general approach to the development of monitoring indicators, which assess substance (the law), process (implementation) and outcomes (how people actually experience the enjoyment of their rights).<sup>140</sup> In addition, the Guidelines deal with the issue of reprisals against human rights defenders, including the role NHRIs can play in highlighting and combating reprisals at the national level. They also address reprisals against NHRIs and their staff. This is extremely welcome as the political environment in which NHRIs work is not always receptive, even though disability is often seen as a 'neutral' political issue.

Overall, the Guidelines formalise emerging practice and provide a new platform to intensify the engagement of NHRIs with the Committee.



Participants attending an event to mark the International Day of Persons with Disabilities. UN Photo/Amanda Voisard

140 OHCHR, *Human Rights Indicators: A Guide to Measurement and Implementation*, 2012.

## 4.6. PROVIDING STATE-SPECIFIC RECOMMENDATIONS THROUGH CONCLUDING OBSERVATIONS

The concluding observations made by the CRPD Committee to States parties contain a wealth of guidance. Each set of concluding observations must be read on their own. Cumulatively, they help to inform the overall approach and evolving jurisprudence of the Committee.<sup>141</sup> This can be summarised in the following points.

First, with respect to States' approaches to implementation of the UN CRPD, the Committee has concluded that States should:

- Establish clear and coherent national action plans to implement the rights of persons with disabilities
- Fully include persons with disabilities in the implementation of the Convention
- Improve statistics and data collection concerning implementation of the rights of persons with disabilities, including ensuring data is disaggregated
- Attend to the requirements of article 33, including designating a focal point within government; identifying, reforming or establishing a Paris Principles-compliant body to assume the role of 'independent mechanism'; and ensuring the full involvement of persons with disabilities in implementation and monitoring.<sup>142</sup>

Second, regarding 'dignity rights', the Committee has concluded that States should:

- Ensure that policy and protocols relating to situations of risk and humanitarian emergency address persons with disabilities.
- End forced psychiatric treatments, including drugs and electroconvulsive treatment, and procedures, such as the use of caged net beds, which amount to cruel, inhuman or degrading treatment
- Outlaw and end the practice of forced sterilisation
- Recognise and implement strategies and actions to address violence against women with disabilities.

Third, with respect to 'autonomy rights', the Committee has concluded that States should:

- Reform law and practice which denies legal capacity on grounds of disability – in particular intellectual and psychosocial disabilities – and replace substituted decision-making regimes, such as plenary guardianship, with 'supported decision-making'
- Reform law and practice which deprives people of their liberty on grounds of disability without adequate safeguards
- Give official recognition to local sign language
- Remove legal obstacles preventing persons with disabilities from entering into marriage, including denial of legal capacity.

Fourth, with respect to promoting equality and ending discrimination, the Committee has concluded that States should:

1. Recognise discrimination on grounds of disability in law and ensure the scope of the legislation addresses all discrimination, including denial of reasonable accommodation, across all sectors and areas of life

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141 See <http://juris.ohchr.org/en/search/results?Bodies=4&sortOrder=Date>.

142 See, for example, CRPD/C/GAB/CO/1, paras. 70-71.

2. With the involvement of persons with disabilities, States should develop and implement a program of awareness raising to reinforce positive images of persons with disabilities.

Fifth, with respect to 'participation rights', the Committee has urged States to:

- Increase enrolment in school of children with disabilities, ensuring reasonable accommodations are available and promote inclusive education over special education
- Ensure equal access to health services and address inequalities in health outcomes, including life expectancy, between persons with and without disabilities
- Address gaps in social protection
- Act to address the significant levels of unemployment among persons with disabilities
- Ensure all persons with disabilities enjoy the right to vote and to repeal laws or regulations which deny persons with psycho-social or intellectual disabilities the right to vote because they have been placed under legal guardianship.

While the process of clarifying jurisprudence through concluding observations is ongoing, the patterns set out above are well entrenched. NHRIs have a key role to play in publicising the concluding recommendations the Committee has made to their State and advocating for their implementation at the national level.

## 4.7. THE COMMITTEE'S ROLE WITH RESPECT TO NATIONAL CAPACITY BUILDING

Article 37 of the Convention establishes a reciprocal relationship between States parties and the CRPD Committee. While article 37(1) places obligations on States to cooperate with the Committee and to assist its members to fulfil their mandate, article 37(2) says that the Committee shall consider ways and means to enhance national capacities for the implementation of the Convention, including through international cooperation.

In its own way, the Committee can act as a 'focal point' within the UN system, connecting UN assets to the challenge of developing national capacities. This serves to underscore the constructive nature of the dialogue between States parties and the Committee. Following the Committee's special meeting with NHRIs on 25 September 2014, the Committee issued a statement encouraging NHRIs to:

... avail themselves of the Committee's role as a capacity-building agent under article 37, paragraph 2, of the Convention.<sup>143</sup>

### NATIONAL CAPACITY BUILDING IN ACTION

The **Spanish Committee of Representatives of Persons with Disabilities (CERMI)** sought the support of the Committee regarding its work to influence proposed reforms to the Spanish criminal code that would otherwise have had the result of facilitating deprivation of liberty of persons with disabilities. CERMI arranged meetings between an expert from the Committee and Spanish parliamentarians who were, at that time, scrutinising the draft legislation. In addition, CERMI organised two meetings with media representatives to raise awareness of the potential impact of the proposed reforms.



143 See CRPD/C/12/2, Annex V.

## 4.8. INDIVIDUAL AND GROUP COMMUNICATIONS UNDER THE OPTIONAL PROTOCOL

The individual (or group) communications procedure under the Optional Protocol to the Convention on the Rights of Persons with Disabilities permits individuals and/or groups of individuals in a State that has ratified the Optional Protocol to complain to the Committee that a State has breached one of its obligations under the Convention. The complaint is known as a 'communication'.<sup>144</sup>

Strict admissibility criteria apply to such communications. A communication is deemed inadmissible if:

- It is anonymous
- It is an abuse of or incompatible with the provisions of the Convention
- The same complaint has already been examined by the Committee
- The same complaint has been or is being examined under another international investigations procedure
- All available domestic remedies have not yet been exhausted
- It is ill-founded or not sufficiently substantiated
- The facts occurred and terminated prior to entry into force of the Protocol for the State in question.<sup>145</sup>

If the communication is deemed admissible, the Committee will examine the complaint, establish its views and recommendations on the communication and send them to the State in question. Those views and recommendations appear in the Committee's public report to the UN General Assembly. It is typically a paper-based exercise, with neither the complainant nor the State party required to appear before the Committee. However, there is nothing to preclude a hearing before the Committee.

NHRIs have a crucial role to play in helping to ensure the individual communications procedure is used appropriately and effectively; for example, by producing information and advice on the admissibility criteria for the general public and by assisting individuals or groups to prepare complaints and compile evidence.

The Committee has also indicated that it would welcome the support of NHRIs in considering communications and in developing its jurisprudence, though it has yet to issue formal Guidelines on this matter.

A statistical survey on individual complaints is available on the OHCHR website.<sup>146</sup>

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144 See 'Fact Sheet on the Procedure for Submitting Communications to the Committee on the Rights of Persons with Disabilities under the Optional Protocol to the Convention', CRPD/C/5/2/Rev.1, 2012.

145 Ibid.

146 Accessed at: [www.ohchr.org/Documents/HRBodies/CRPD/StatisticalSurvey.xls](http://www.ohchr.org/Documents/HRBodies/CRPD/StatisticalSurvey.xls).

## SUMMARIES OF CRPD COMMITTEE VIEWS ON COMMUNICATIONS LODGED UNDER THE OPTIONAL PROTOCOL

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International Disability Alliance



### ***C v Brazil* (no. 10/2013)**

On 2 October 2014, the Committee adopted its views in this case against Brazil concerning a woman who had been demoted after taking more than three months of medical leave in accordance with her employer's policy, following a series of injuries which led to chronic illness and the permanent impairment of her knee. While the Committee found the complaint inadmissible for non-exhaustion of domestic remedies, it nevertheless explored whether the complaint fell within the scope of the Convention and concluded that the difference between illness and disability is a difference of degree and not a difference of kind, and that a health impairment which is initially conceived of as illness can develop into an impairment in the context of disability because of its duration or its chronic development. The Committee highlighted that a human rights-based model of disability requires taking into account the diversity of persons with disabilities, as well as the interaction between individuals with impairments and attitudinal and environmental barriers.

### ***X v Argentina* (no. 8/2012)**

On 11 April 2014, the Committee adopted its views in this case against Argentina concerning a prisoner with disabilities who was receiving medical treatment on a daily basis as an outpatient. He complained of the conditions of detention, including lack of accessibility, and of the transfer between the prison and the hospital which he alleged put his life and health at risk. Based on his right to access adequate medical care and rehabilitation, he made repeated requests to be held in home arrest – all of which were denied. The Committee rejected his claims on the merits under articles 10, 25 and 26 of the Convention, finding it inconclusive that his life and health were put at risk by the transfer from prison to the hospital and that there was insufficient evidence to refute that his medical needs were being met. The Committee upheld the petitioner's complaints with respect to the lack of accessibility within the prison and the lack of accommodations made to guarantee his mobility, finding violations of articles 9(1), 9(2) and 14(2) of the Convention, as well as a violation of article 17 for the precarious conditions of detention to which he was subjected on account of the lack of accessibility and failure to provide reasonable accommodation within the prison.

### ***Liliane Gröninger v Germany* (no. 2/2010)**

On 4 April 2014, the Committee adopted its views in this case against Germany concerning the right to work of a young disabled man in which the Committee found that the State failed to promote the right to work by failing to facilitate inclusion into the labour market. The German Social law provides for the granting of a subsidy for persons with disabilities to integrate in the labour force, which is only applicable to persons with disabilities whose full working capacity may be restored within 36 months. The legal conditions for the granting of the integration subsidy is that an employer should make a binding employment offer to the individual and apply for the integration subsidy, after which the Employment Agency should evaluate the situation and take a decision on the duration and amount of the integration subsidy to be allocated (the subsidy would amount to a maximum of 70% of the wages, for a maximum period of 60 months). The complaint alleged that the granting of the subsidy is discriminatory as it only applies to those whose full working capacity may be restored and it does not create rights for disabled persons, as the right to claim such a subsidy belongs exclusively to the employer.



In this case, the young man had been registered with the Employment Agency since 2002 yet it was alleged he had no access to general technical, continuous and vocational guidance and training programs, or to placement services, and that where he had been able to access vocational training through private means, the Employment Agency refused to pay for his participation. Further, it was raised that the Employment Agency did not provide any support or assistance when looking for a job: where he had applied for positions and was interviewed, upon contacting the Employment Agency, potential employers turned down his application.

The Committee found that the existing model for the provision of integration subsidies did not effectively promote the employment of persons with disabilities. It found in particular that there are difficulties faced by potential employers when trying to access the integration subsidy for the employment of a person with disabilities and that the administrative complexities put applicants in disadvantageous position. This may in turn result in indirect discrimination. The Committee therefore concluded that the integration subsidies scheme, as applied in this case, was not in accordance with the State party's obligations under article 27(1)(h), read together with article 3(a), (b), (c) and (e), article 4(1)(a) and article 5(1) of the Convention.

#### ***Zsolt Bujdosó and five others v Hungary (no. 4/2011)***

On 9 September 2013, the Committee adopted its views in this case which concerned six persons with intellectual disabilities whose names had been removed from the electoral register upon being placed under guardianship, in accordance with the Constitution. As a result, they had been denied the right to vote in parliamentary and municipal elections in 2010, in violation of articles 29 and 12 of the Convention. While the State party claimed that this automatic denial of the right to vote of persons under guardianship had been remedied through the abandonment of the Constitutional provision and the passing of legislation which permitted courts to individually assess one's capacity to vote during guardianship proceedings, the Committee recalled that article 29 does not foresee any reasonable restriction, nor does it allow any exception for any group of persons with disabilities. Hence, an exclusion of the right to vote on the basis of a perceived or actual psychosocial or intellectual disability, including a restriction pursuant to an individualised assessment, constitutes discrimination on the basis of disability. The Committee concluded that the State party failed to comply with its obligations under article 29, read alone and in conjunction with article 12 of the Convention.

This is the Committee's first decision on a communication relating to article 29. It reinforces the Committee's concluding observations on the subject and emphasises that judicial capacity assessments on an individual's right to vote are discriminatory in nature and cannot be advanced as a justification to preserve the integrity of the State's political system. It further clarifies that any reading of the European Court of Human Rights judgment in *Alajos Kiss v Hungary* (Application no. 38832/06, 20 May 2010), which suggests that one's right to vote can be legitimately removed on the basis of an individualised judicial evaluation, is not in compliance with articles 29 and 12 of the Convention.

#### ***Szilvia Nyusti & Péter Takács v Hungary (no. 1/2010)***

On 16 April 2013, the Committee adopted its views in an individual communication lodged against Hungary. The case was brought by two Hungarian nationals with visual impairments who had separately concluded contracts for private account services with OTP bank. Despite the obligation for them to pay the same level of fees as other OTP clients, they were denied access on an equal basis with others to the use of their banking services and transactions on account of OTP's inaccessible ATMs, which lacked Braille fonts, audible instructions and voice assistance. The Committee found a violation of article 9(2)(b); that the State party failed to comply with its obligation to ensure accessible banking services for persons with visual impairments, including those provided by OTP and other private financial institutions.



The Committee upheld the obligation incumbent on the State to ensure that private entities that offer facilities and services open or provided to the public take into account all aspects of accessibility for persons with disabilities, and this obligation must be maintained regardless of contractual relationships concluded between individuals and private entities.

***HM v Sweden (no 3/2011)***

This case against Sweden concerns a local municipality's refusal to grant a building permit to a woman with a degenerative illness, who could not leave her home without great risk, for installation of a hydrotherapy pool on her property for the purposes of rehabilitation and maintaining her health. The Committee found that the State failed to provide reasonable accommodation and fulfil its obligations concerning non-discrimination, living independently and being included in the community, health and rehabilitation, resulting in violations of articles 5(1), 5(3), 19(b), 25 and 26, read alone and in conjunction with articles 3(b), (d) and (e) and 4(1)(d) of the Convention.

Guidance published by UN Enable<sup>147</sup> suggests that the chief advantages of the individual complaints procedure are that it:

- Provides an opportunity for specific redress in individual cases when a State violates the rights of persons with disabilities and no remedy can be obtained from national procedures
- Provides the possibility of international recourse for persons with disabilities who have been denied access to justice at the national level
- Allows the Committee to highlight the need for more effective remedies at the national level
- Allows the Committee to develop a new body of jurisprudence on how better to promote and protect the rights of persons with disabilities;
- Assists States in determining the content of their obligations under the Convention and thus assists them in implementing those obligations.

## 4.9. CONDUCTING INQUIRIES INTO ALLEGATIONS OF GRAVE AND SYSTEMIC VIOLATIONS UNDER THE OPTIONAL PROTOCOL

If the CRPD Committee receives reliable information indicating grave or systemic violations of the provisions of the Convention by a State party, the Committee may invite the State to cooperate in the examination of the information by submitting observations. After considering these, and any other reliable information, the Committee may designate one or more of its members to conduct an inquiry and to issue a report urgently. The inquiry may include a visit to the country in question. Having conducted its inquiry, the Committee must transmit its findings and its comments to the State, which has six months to submit its observations to the Committee.

The inquiry procedure is wholly confidential and must be conducted with the full cooperation of the State concerned. Following the six-month period in which it may submit observations, the State may be invited to submit details of measures it has taken to respond to the inquiry. The Committee may at this stage request further information from the State.

147 OHCHR and Inter-Parliamentary Union, *From Exclusion to Equality: Realizing the Rights of Persons with Disabilities. Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*, 2007; available at [www.un.org/disabilities/documents/toolaction/iphb.pdf](http://www.un.org/disabilities/documents/toolaction/iphb.pdf).

The Committee may then publish a summary of its finding in its annual report to the UN General Assembly. With the agreement of the State concerned, the Committee may also publish the full report of its inquiry.

Guidance published in 2007 by UN Enable suggests that the chief advantages of the inquiry procedure are that it:

- Enables the Committee to address systematic and widespread violations of the rights of persons with disabilities
- Allows the Committee to recommend measures to combat the structural causes of discrimination against persons with disabilities
- Gives the Committee an opportunity to set out a broad range of recommendations to achieve greater respect for the rights of persons with disabilities;
- Allows the Committee to work with the State in removing impediments to the full enjoyment of the rights of persons with disabilities.<sup>148</sup>

NHRIs have a vital role to play in assisting Committee members in their inquiries, including providing reliable information and evidence, assisting the Committee with country visits and developing recommendations, as appropriate. However, the Committee has yet to issue guidance on the precise role that NHRIs can play during the inquiry process.

The Committee's Rules of Procedure explain its approach to individual communications and inquiries in detail. This information is available on the Committee's webpage, along with a model complaints form.<sup>149</sup>

There were 18 cases pending in 2016, covering issues such as legal capacity, institutionalisation, voting rights, hospitalisation and appointment of a guardian without consent, legal aid, housing rights, deportation, health care and torture.<sup>150</sup>

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148 Ibid.

149 CRPD/C/5/3/Rev.1.

150 See [www.ohchr.org/EN/HRBodies/CRPD/Pages/Tablependingcases.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Tablependingcases.aspx).

## Section II Other international and regional human rights instruments and disability



**Chapter 5: UN human rights instruments and related processes**

**Chapter 6: Regional human rights instruments and disability**

# Chapter 5:

## UN human rights instruments and related processes

### KEY QUESTIONS

- How are the human rights of persons with disabilities reflected in the wider international and regional human rights framework?
- How do the other UN human rights treaty monitoring bodies deal with disability?
- How do regional instruments and mechanisms deal with disability issues?



Since the two United Nations covenants on human rights<sup>151</sup> and the various UN thematic treaties on human rights are universal in scope, they apply equally to persons with disabilities. What has emerged in the past 20 years or so – and especially since the adoption of the UN CRPD – is that the interpretation of these treaties by their respective treaty monitoring bodies has trended in favour of the rights of persons with disabilities. This can be seen in the various general comments and general recommendations that have crystallised the jurisprudence under these treaties as it relates to disability, directly or indirectly. It can also be seen on the concluding observations of the different treaty monitoring bodies. It would seem that the UN CRPD is exerting a powerful influence on these other treaties, encouraging their interpretation along lines consistent with the UN CRPD.

This general symmetry of interpretation reinforces the principles that underpin the UN CRPD and ensures that these treaties can be, in themselves, powerful forces for change, especially for the few States that have not ratified the UN CRPD. What follows is an overview of the evolving jurisprudence on disability.

### 5.1. THE INTERNATIONAL COVENANT ON CIVIL AND POLITICAL RIGHTS AND DISABILITY

The emergence of disability as a human rights issue first arose from the civil rights model of disability early on in the United States. Civil and political rights are vital for persons with disabilities as they encapsulate a theory of human dignity and autonomy which is essential for human flourishing, as well as protect persons with disabilities against various abuses of power.

Two general comments of the Human Rights Committee, which is responsible for monitoring compliance with the International Covenant on Civil and Political Rights (ICCPR) are especially pertinent in relation to disability: General Comment No. 21 concerning the humane treatment of people deprived of their liberty, including those in psychiatric hospitals,<sup>152</sup> and General Comment No. 25 concerning the right to take part in the conduct of public affairs, the right to vote and to be elected and the right to have access to public service.<sup>153</sup>

151 The International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR).

152 See [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=8&DocTypeID=11](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=8&DocTypeID=11).

153 CCPR/C/21/Rev.1/Add.7.

Following are examples of the evolving jurisprudence of the Human Rights Committee on disability, drawn from various concluding observations issued to States parties.

### **Autonomy: Ensuring legal safeguards regarding denial of legal capacity leading to institutionalisation**

In 2013, the Human Rights Committee expressed concern at the absence of legal safeguards and due process relating to the confinement of persons with disabilities who have been deprived of their legal capacity in the Czech Republic.<sup>154</sup>

### **Autonomy: Ensuring adequate safeguards dealing with the deprivation of liberty**

The Human Rights Committee has expressed concern at the absence or weakness of due process and safeguards with respect to people with psychosocial disabilities being deprived of their liberty. With respect to Latvia, the Committee drew attention to the:

... lack of State regulation of the application of compulsory medical treatment, physical restraints and restrictions of the right to privacy in psychoneurological hospitals.<sup>155</sup>

The Committee also expressed concern at the continuing use of caged beds in psychiatric institutions in the Czech Republic.<sup>156</sup>

### **Political participation: Ensuring the right to vote**

The Human Rights Committee recently recommended that the Czech Republic, Hong Kong (China) and Paraguay review their respective electoral laws to ensure that they do not discriminate against persons with mental, intellectual or psychosocial disabilities by denying them the right to vote for reasons that are disproportionate or that have no reasonable and objective relationship to their ability to vote.<sup>157</sup>

This focus on civil and political rights is vital for persons with disabilities since it spans concepts such as autonomy, equality and participation, especially political participation. NHRIs with a focus on civil and political rights can easily integrate disability perspectives into this work and highlight this in their engagement with the Human Rights Committee.

## **5.2. THE INTERNATIONAL COVENANT ON ECONOMIC, SOCIAL AND CULTURAL RIGHTS AND DISABILITY**

When the UN CRPD was being drafted, economic, social and cultural rights were seen by many participants as being part of the problem. Their goal, then, was to reframe these rights in order to deliver autonomy and dignity of people with disabilities, not entrap them in segregated services with 'compensation' for their absence from the mainstream. This richer understanding of the place and purpose of economic, social and cultural rights also informs the current understanding within the Committee on Economic Social and Cultural Rights (CESCR Committee).

Many of the more important obligations in the UN CRPD are to be achieved progressively. In understanding what this means, including the kind of latitude that States have and the boundaries on this latitude, reference must be made to the CESCR Committee's famous General Comment No. 3 (1991) on the nature of States parties' obligations.<sup>158</sup> Though general in scope, this document is a valuable reference when trying to determine the nature and scope of obligations of 'progressive achievement' in the UN CRPD (of which there are many).

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154 CCPR/C/CZE/CO/3, para. 13.

155 CCPR/C/LVA/CO/3, para. 16.

156 CCPR/C/CZE/CO/3, para. 14.

157 See, for example, CCPR/C/CHN-HKG/CO/3, para. 24.

158 Available at <http://ohchr.org/en/hrbodies/cescr/pages/cescrindex.aspx>.

Two general comments of the CESCR Committee are especially relevant in relation to disability issues. The detailed and comprehensive General Comment No. 5 on the economic, social and cultural rights of persons with disabilities,<sup>159</sup> published in 1994, was an important precursor to the UN CRPD. General Comment No. 4 on the right to adequate housing notes specifically highlights the right to accessible housing for persons with disabilities.<sup>160</sup>

The CESCR Committee has also addressed disability issues in a number of its concluding observations. In 2013, for example, the Committee concluded that the high frequency of compulsory treatment and confinement within the mental health system of persons with psychosocial disabilities in Norway, and the absence of an adequate legal framework regulating the application of coercive treatment, amounted to a violation of the right to the highest attainable standard of health.<sup>161</sup>

In 2014, the Committee expressed concern that Indonesia failed to employ a human rights approach in the way it defined ‘persons with disabilities’ in its anti-discrimination law and that the law does not specify the obligation to provide ‘reasonable accommodation’.<sup>162</sup>

In addition, the Committee noted the continuing high levels of unemployment among persons with disabilities in its recent examinations of Belgium, Bosnia and Herzegovina, Rwanda, Ecuador and Denmark, among others.<sup>163</sup> It has called on States to enhance their employment policies, including in the areas of requalification, local employment initiatives, incentives and tax benefits to employers.

It is clear that the CESCR Committee is now interpreting economic, social and cultural rights in ways that closely accord with the goals and principles of the UN CRPD. NHRIs working on economic, social and cultural rights can easily integrate disability perspectives into that work.

### 5.3. THE CONVENTION FOR THE ELIMINATION OF ALL FORMS OF DISCRIMINATION AGAINST WOMEN AND DISABILITY

The issue of gender and disability – as one example of intersectionality – is explicitly covered by article 6 of the UN CRPD. It is therefore important that there is a strong resonance between the jurisprudence of the Committee on the Elimination of Discrimination against Women (CEDAW Committee) and the CRPD Committee.

The CEDAW Committee was among the first to draw attention to the intersectionality between gender and disability. As far back as 1991, the CEDAW Committee adopted its landmark General Recommendation No. 18 concerning women with disabilities and noted the double discrimination linked to “their special living conditions”.<sup>164</sup> It affirmed the Committee’s support for the World Programme of Action concerning Disabled Persons and recommended that States parties provide information on women with disabilities in their periodic reports, along with measures taken to ensure equal access to education and employment, health services and social security, and to ensure that they can participate in all areas of social and cultural life.

The concluding observations of the CEDAW Committee deal with many gender and disability-related issues. For example, following its examination of the periodic report from India in 2014, the Committee expressed concern that:

... women with intellectual or psychosocial disabilities can be denied legal capacity and committed to institutions without their consent and without recourse to any meaningful remedy or review.<sup>165</sup>

159 Ibid.

160 Ibid.

161 E/C.12/NOR/CO/5, para. 19.

162 E/C.12/IDN/CO/1, para. 11.

163 Available at <http://ohchr.org/en/hrbodies/cescr/pages/cescrindex.aspx>.

164 See [www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm#recom18](http://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm#recom18).

165 CEDAW/C/IND/CO/4-5, para. 36.

The CEDAW Committee has commented on the failure of States to outlaw forced abortions and sterilisation of women with intellectual disabilities. Following its examination of Lithuania in 2014, the Committee said that:

It is seriously concerned about the provisions that allow forced abortion and sterilization of women with intellectual disabilities without court authorization<sup>166</sup>

The Committee called on the State party to:

Investigate claims of undocumented forced abortions and sterilization of women with intellectual disabilities in care institutions, put protocols in place to ensure compliance with the legal requirement of court authorization in such cases and ensure that offenders are punished.

The CEDAW Committee has regularly highlighted the issue of poorer educational opportunities for girls with disabilities. For example, in 2014 it called on Peru to:

Allocate sufficient human and financial resources for the implementation and monitoring of laws and public policies designed to combat discrimination in access to education and to include the use of temporary special measures in promoting the education of girls and women, in particular in rural areas and indigenous communities and among girls with disabilities.<sup>167</sup>

Following its examination of the United Kingdom in 2013, the Committee expressed concern about the impact of public spending cuts, arguing that:

... the austerity measures introduced by the State party have resulted in serious cuts in funding for organizations that provide social services to women, including those that provide services for women only. The Committee is concerned that the cuts have had a negative impact on women with disabilities and older women.<sup>168</sup>

Accordingly, the Committee called on the State party to:

... mitigate the impact of austerity measures on women and the services provided to women, especially women with disabilities and older women.<sup>169</sup>

Both the CEDAW Committee and the CRPD Committee place strong emphasis on intersectionality, specifically on the intersection between women and girls with disabilities. This focus is only set to grow as our understanding develops about the multiple disadvantages experienced by women and girls with disabilities.

## 5.4. THE CONVENTION AGAINST TORTURE AND DISABILITY

One result of segregation – and, in its worst form, institutionalisation – was the relative ‘disappearance’ of persons with disabilities from the community. This segregation placed people with disabilities in situations where they were especially vulnerable to violence, exploitation and abuse, which could take the form of torture or cruel, inhuman or degrading treatment. This abuse was compounded, and perhaps perpetuated, by a lack of oversight of places where persons with disabilities were housed or served. There was also a degree of impunity for those who committed such acts.

An important goal of the UN CRPD is to end such segregation and isolation and, indeed, to close down institutions. It also aims to protect people against torture and degrading treatment. While the UN CRPD incorporates both goals, it places an emphasis on ending the institutionalisation that creates vulnerabilities to abuse. At the same time, there is growing recognition of these issues among the Committee against Torture, to the point that the mere existence of institutionalisation is in itself increasingly being deemed a form of torture.

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166 CEDAW/C/LTU/CO/5, para. 36.

167 CEDAW/C/PER/CO/7-8, para. 30.

168 CEDAW/C/GBR/CO/7, para. 21.

169 Ibid, para. 22.

To mark the International Day in Support of Victims of Torture on 25 June 2009, the Committee against Torture, the Subcommittee on Prevention of Torture, the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, the Committee on the Rights of Persons with Disabilities and the Board of Trustees of the United Nations Voluntary Fund for Victims of Torture issued a joint statement. The statement highlighted the increased risk faced by persons with disabilities of falling victim to abuse and neglect in a number of contexts – in particular institutions, but also at the hands of family members – and called on States to ensure that torture prevention measures recognise the rights and risks faced by persons with disabilities.

The Committee against Torture has called on various States, including Latvia, Japan and the Netherlands, to create viable alternatives to the institutionalisation of persons with psychosocial/psycho-neurological conditions.<sup>170</sup> For example it recommended that Japan take action to ensure that:

... outpatient and community services are developed and the number of institutionalized patients is brought down.<sup>171</sup>

This line of jurisprudence resonates strongly with the interpretation of article 19 of the UN CRPD (on the right to live independently and be included in the community) by the CRPD Committee.

The Committee against Torture has expressed concern regarding the treatment of people with psychosocial disabilities confined to hospitals and institutions. For example, following its examination of the Netherlands, the Committee recommended that the State party:

... use restraints and solitary confinement as a measure of last resort when all other alternatives for control have failed, for the shortest possible time and under strict medical supervision.<sup>172</sup>

The Committee has also recognised the failure to address disability hate crime as a violation of the right to live free from inhuman and degrading treatment. For example it recommended that Poland:

...incorporate offences in its Penal Code to ensure that hate crimes and acts of discrimination and violence that target persons on the basis of their sexual orientation, disability or age are punished accordingly.<sup>173</sup>

The European Union Fundamental Rights Agency is currently working on a project dealing with hate crime against children with disabilities, which should set a benchmark for such research and provide useful policy recommendations.<sup>174</sup>

It is vital that NHRIs refer to the evolving standards and interpretation of the Convention against Torture when working on issues involving abuse and violence against people with disabilities. Even if institutionalisation is ended, there will still be a need to focus on abuse issues, especially in the context of services and, to some extent, in the family environment.

## 5.5. THE CONVENTION ON THE RIGHTS OF THE CHILD AND DISABILITY

Intersectionality between children and disability is specifically addressed in article 7 of the UN CRPD. However, the Committee on the Rights of the Child (CRC Committee) has a long track record of focusing on children with disabilities.

The CRC Committee issued the comprehensive General Comment No. 9 on the rights of children with disabilities in 2007, which remains an important reference point.<sup>175</sup> It is also very engaged on the issue of

170 See CAT/C/LVA/CO/3-5 (2013); CAT/C/JPN/CO/2 (2013); and CAT/C/NLD/5-6 (2013).

171 CAT/C/JPN/CO/2, para. 22.

172 CAT/C/NLD/5-6, para. 21.

173 CAT/C/POL/CO/5-6, para. 25.

174 See <http://fra.europa.eu/en/project/2012/children-disabilities-targeted-violence-and-hostility>.

175 CRC/C/GC/9/Corr.1.

institutionalisation, which reportedly affects eight million children globally.<sup>176</sup> For example, the Committee expressed concern about the widespread institutionalisation of children with disabilities following its examinations of Croatia and Hungary. With respect to Croatia, the Committee noted that:

... the number of children with disabilities in institutional care is increasing and there is a lack of adequate treatment and care in these institutions.<sup>177</sup>

The absence of inclusive education for children with disabilities has also become a focus for the Committee, which accords with article 24 of the UN CRPD. For example the CRC Committee called upon Morocco to:

Set up comprehensive measures to develop inclusive education and ensure that inclusive education is given priority over the placement of children in specialized institutions and classes.<sup>178</sup>

Similarly, the Committee recommended that Germany:

... pursue the establishment of State-wide inclusive education and ensure that the necessary resources are available.<sup>179</sup>

There is a natural overlap between the two conventions, especially with respect to de-institutionalisation and inclusive education. It is only natural that NHRIs focusing on children's rights can and should incorporate a disability perspective in their work.

## 5.6. THE UNIVERSAL PERIODIC REVIEW AND DISABILITY

The Universal Periodic Review (UPR) is a unique process which involves a review of the human rights records of all UN Member States.<sup>180</sup> The right of persons with disabilities feature regularly in these reviews, which provide further opportunity for NHRIs (and for civil society) to influence the scrutiny of their State's performance under international human rights law and standards and to promote ratification of the UN CRPD where their State has not yet done so.

As OHCHR explains:

NHRIs can submit information which can be added to the "other stakeholders" report which is considered during the review. Information they provide can be referred to by any of the States taking part in the interactive discussion during the review at the Working Group meeting.<sup>181</sup>

OHCHR has also issued extremely useful 'Technical Guidance' for NHRIs on the second cycle of UPR (2012–2016).<sup>182</sup> This guidance covers issues such as how NHRIs can intervene and what they should consider when preparing written submissions.

Many NHRIs have taken full advantage of the UPR process to highlight disability issues. For example, the 2015 UPR submission of the **Australian Human Rights Commission** advocated that the State fully fund the new National Disability Insurance Scheme, support an inclusive employment culture and introduce legal protections to ensure no sterilisation of persons with disabilities without their consent.<sup>183</sup> The 2011 submission of the **Irish Human Rights and Equality Commission** recommended that Ireland ratify the UN CRPD.<sup>184</sup>

176 Lumos, *The Time is Now – Ending the Institutionalisation of Children Globally*, 2014; available <https://wearelumos.org/content/time-now-ending-institutionalisation-children-globally-0>.

177 CRC/C/HRV/CO/3-4, para. 42.

178 CRC/C/MAR/CO/3-4, para 53.

179 CRC/C/DEU/CO/3-4, para 51.

180 More information on the UPR is available at [www.ohchr.org/EN/HRBodies/UPR/Pages/UPRMain.aspx](http://www.ohchr.org/EN/HRBodies/UPR/Pages/UPRMain.aspx).

181 See [www.ohchr.org/EN/HRBodies/UPR/Pages/NgosNhris.aspx](http://www.ohchr.org/EN/HRBodies/UPR/Pages/NgosNhris.aspx).

182 Available at [www.ohchr.org/EN/HRBodies/UPR/Pages/NoteNHRIS.aspx](http://www.ohchr.org/EN/HRBodies/UPR/Pages/NoteNHRIS.aspx).

183 Available at [www.ohchr.org/EN/HRBodies/UPR/Pages/AUSession23.aspx](http://www.ohchr.org/EN/HRBodies/UPR/Pages/AUSession23.aspx).

184 Available at [www.ohchr.org/EN/HRBodies/UPR/Pages/IESession12.aspx](http://www.ohchr.org/EN/HRBodies/UPR/Pages/IESession12.aspx).

## 5.7. THE UN SPECIAL RAPPORTEUR ON THE RIGHTS OF PERSONS WITH DISABILITIES

The mandate of the UN Special Rapporteur on the rights of persons with disabilities was established in July 2014 by a Resolution of the General Assembly (26/20).<sup>185</sup> The purpose of the mandate is to “develop a regular dialogue and to consult with States” (para. 2.a). This mandate goes beyond the work of the CRPD Committee in that it involves a mutual dialogue with States about challenges and solutions. It also has a focus on both human rights and development. The current Special Rapporteur is Catalina Devandas Aguiler from Costa Rica.

The Rapporteur is required to consult with other stakeholders, which explicitly includes NHRIs and national monitoring mechanisms established under article 33(2) of the UN CRPD. This explicit inclusion of NHRIs in the mandate is an extremely welcome development as it can greatly support the Special Rapporteur to gather information, make concrete recommendations to States, undertake country visits, arrange advisory services and so on. An annual report of the Special Rapporteur’s activities is prepared for the Human Rights Council and another for the General Assembly.

The Resolution establishing the mandate calls on a range of actors, including NHRIs, to cooperate fully with the Special Rapporteur. The mandate holder interacts with many different UN agencies and bodies, including specifically the CRPD Committee. In a way, the mandate acts an early warning system to the CRPD Committee and other treaty bodies and mechanisms on emerging problems and trends.

The current Special Rapporteur has expressed her intention to promote the establishment and strengthening of national mechanisms for the implementation and monitoring of the UN CRPD, including NHRIs designated as independent monitoring mechanisms under article 33(2).<sup>186</sup>

The various country visits undertaken by the Special Rapporteur provide an important opportunity for engagement by NHRIs. For example, and with respect to her country visit to Moldova in September 2015, she met with and was briefed by the **Centre for Human Rights of Moldova** (the NHRI) and the Council for Combating Discrimination and Assuring Equality.<sup>187</sup> In her mission to Paraguay in November 2015, she highlighted that the appointment of the Ombudsperson or **Defensor del Pueblo** was pending, as well as the importance of ensuring that the institution operates in accordance with the provisions of the Paris Principles.<sup>188</sup> During these visits, NHRIs can play an important role by providing the Special Rapporteur with information about major challenges and possible solutions.

The Special Rapporteur also receives individual claims with a view to raising them with the State concerned. There is no reason why these cannot come from NHRIs. The themes of her recent annual reports have been on effective involvement in decision-making and the need to transform social protection systems in order to make them inclusive of persons with disabilities.<sup>189</sup>

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185 A/HRC/RES/26/20.

186 A/HRC/28/58.

187 A/HRC/31/62/Add.2.

188 See [www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=16811&LangID=E](http://www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=16811&LangID=E).

189 See A/HRC/31/62 and A/70/297.

# Chapter 6: Regional human rights instruments and disability

## KEY QUESTION

- How do the existing regional human rights instruments reflect the move to the human rights frame in the context of disability?



The paradigm shift in disability away from charity and towards human rights has been reflected in the way in which existing regional human rights instruments have been interpreted and applied. This has helped to reinforce the goals and principles of the UN CRPD at a regional level. This chapter provides an overview of some of these interpretive trends.

Only some of the major regional organisations are covered. Before engaging with these instruments, it is important to recall that NHRIs can and have been active on disability issues through their various regional groupings.

## 6.1. REGIONAL GROUPINGS OF NHRIs AND THEIR WORK ON DISABILITY

### European Network of National Human Rights Institutions

The European Network of National Human Rights Institutions (ENNHRI)<sup>190</sup> works on a broad range of human rights issues, including the rights of persons with disabilities (and also the rights of older people where there is some overlap). The regional coordinating body runs an NHRI Academy that provides workshops and training for NHRIs on different aspects of their work. It also established a Convention on the Rights of Persons with Disabilities Working Group in 2010. One of the goals of the Working Group is to “[i]dentify, develop, and promote good practice guidance on the role and actions of NHRIs in promoting, protecting and monitoring implementation of the Convention in the European Network and internationally”. It also promotes ratification of the UN CRPD by States across Europe.

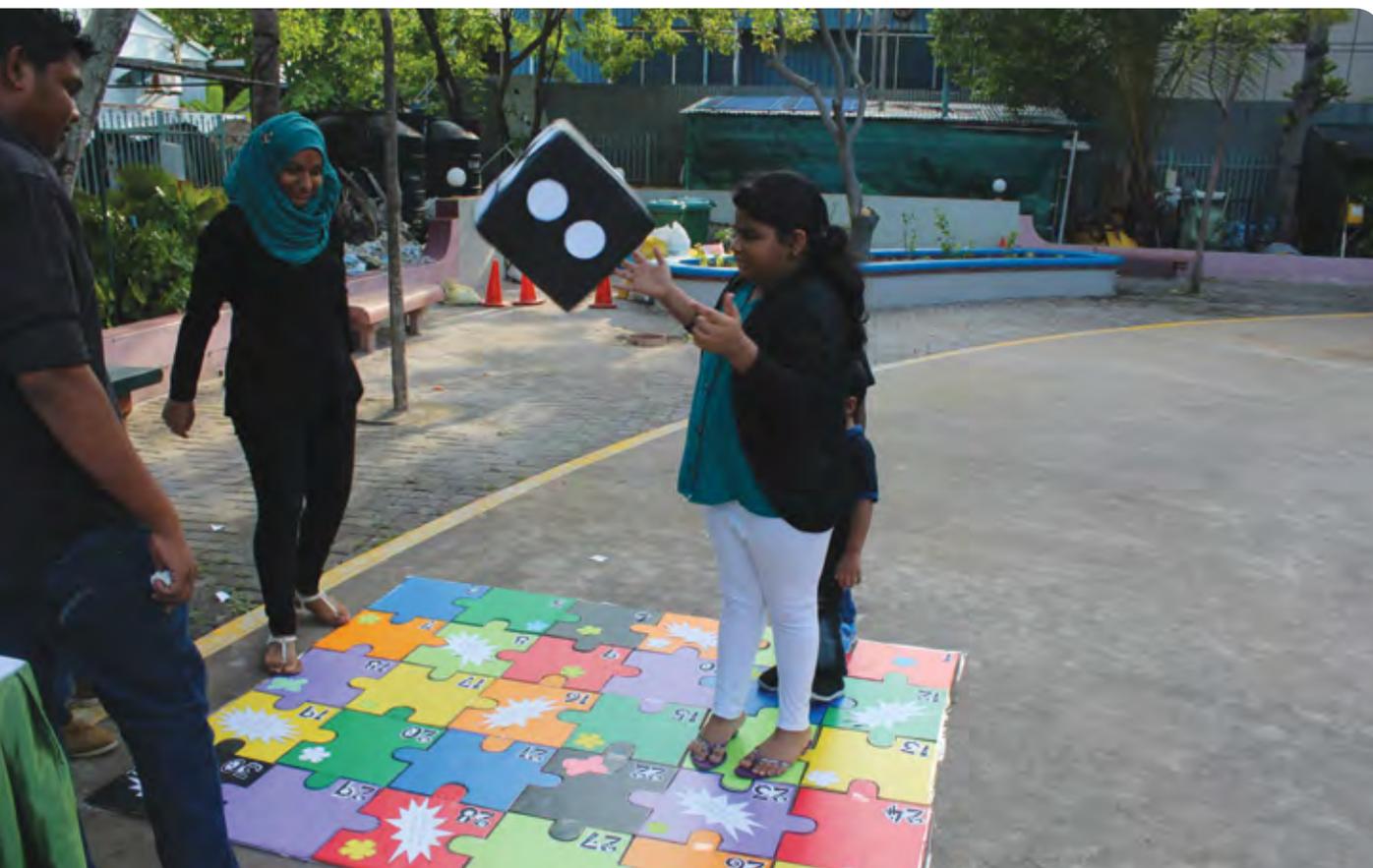
ENNHRI makes regular appearances before the CRPD Committee and submitted a parallel report to the Committee based on the European Union’s Initial Report. It has also organised a number of side panel discussions. It coordinates the input of NHRIs into European-level developments, especially within the European Union, and has begun the practice of submitting joint *amicus curia* briefs before the European Court of Human Rights, including *DD v Lithuania* (2008), involving civil commitment and the loss of legal capacity, and *Gauer v France* (2011), which concerned the forced sterilisation of women with disabilities.

190 More information on ENNHRI is available at <http://ennhri.org>.

## Asia Pacific Forum of National Human Rights Institutions

The Asia Pacific Forum of National Human Rights Institutions (APF)<sup>191</sup> has a long history of involvement in disability issues. It was highly active before and during the negotiations that led to the adoption of the UN CRPD. It established an early Working Group and, even before the negotiations were opened up on drafting a convention, convened a meeting in New Delhi in 2002 to discuss the proposed convention. The meeting proposed many useful recommendations, including some on the role of NHRIs.<sup>192</sup> The APF regularly updated its members on progress to draft the Convention and, in 2007, published a Disability Issues Paper, which placed a heavy emphasis on the roles of NHRIs with respect to promoting, protecting and monitoring rights in the UN CRPD.<sup>193</sup>

Promoting and protecting the rights of persons with disabilities is one of the thematic priorities in the APF's 2015–2020 Strategic Plan.<sup>194</sup> In 2015, the APF published a comprehensive manual on National Human Rights Institutions – their establishment, roles and functions and working methods – which is a valuable reference tool for NHRIs across the globe.<sup>195</sup> It includes a very useful article-by-article analysis of what to look for in monitoring activities; for example, with respect to inclusive education or employment.



Interactive displays on the streets of Male' were used by the Human Rights Commission of the Maldives to build public awareness of its national inquiry into accessible education for children with disabilities. Photo by the Human Rights Commission of the Maldives

191 More information on the APF is available at [www.asiapacificforum.net](http://www.asiapacificforum.net).

192 Available at [www.asiapacificforum.net/resources/apf-7-discussion-paper-proposed-un-convention-disability](http://www.asiapacificforum.net/resources/apf-7-discussion-paper-proposed-un-convention-disability).

193 Available at [www.asiapacificforum.net/resources/apf-12-conference-paper-disability-rights/](http://www.asiapacificforum.net/resources/apf-12-conference-paper-disability-rights/).

194 Available at [www.asiapacificforum.net/resources/apf-strategic-plan-2015-2020](http://www.asiapacificforum.net/resources/apf-strategic-plan-2015-2020).

195 Available at [www.asiapacificforum.net/resources/manual-on-nhris](http://www.asiapacificforum.net/resources/manual-on-nhris).

## Network of African Human Rights Institutions

In March 2016, the Network of African National Human Rights Institutions (NANHRI),<sup>196</sup> with the support of the Swedish Development Cooperation and the Roaul Wallenberg Institute, published *Protecting, Promoting and Monitoring the Rights of Persons with Disabilities: A Guide for African National Human Rights Institutions*.<sup>197</sup> The resource will be extremely useful for NHRIs when monitoring the human rights situation of people with disabilities within their counties and interacting with the regional and international human rights mechanisms, including the CRPD Committee.

In its 2015–2019 Strategic Plan, NANHRI specifically mentions work on persons with disabilities as one of its strategic priorities for the region, albeit under the heading of ‘vulnerable groups’.<sup>198</sup>

## Commonwealth Secretariat

The Commonwealth Secretariat, based in London, has arranged a number of meetings for NHRIs on disability issues. Many NHRIs in countries attached to the Commonwealth (54 countries in all) have done extensive work on disability issues, especially in Australia and New Zealand. The Commonwealth Secretariat Disabled Persons’ Forum has delivered training on the Convention in six of its Member States. In 2012, it held a seminar with 14 Member States on ‘promoting inclusive education and sustainable employment for persons with disabilities’. It has also published a very impressive book on inclusive education.<sup>199</sup>

## 6.2. DISABILITY AND HUMAN INSTRUMENTS IN THE AFRICAN UNION

The African Charter on Human and Peoples’ Rights, also known as the Banjul Charter,<sup>200</sup> is an international human rights instrument that seeks to promote and protect human rights and basic freedoms in the African continent. Oversight and interpretation of the Charter is the task of the African Commission on Human and Peoples’ Rights. A protocol to the Charter was subsequently adopted in 1998 whereby an African Court on Human and Peoples’ Rights was to be created. The protocol came into effect on 25 January 2005.

Article 2 of the Charter concerns the right to freedom from discrimination. Although it does not mention disability specifically, the Charter prohibits discrimination on the ground of “any status”. Article 3 of the Charter concerns equal recognition before the law and equal entitlement to protection by the law. The Charter also highlights the need to pay particular attention to the right to development and to the fact that civil and political rights cannot be disassociated from economic, social and cultural rights, reflecting the approach of the UN CRPD.

In 2014, a draft Protocol on the Rights of Persons with Disabilities in Africa<sup>201</sup> was prepared by a Working Group on older persons and persons with disabilities, under the auspices of the African Commission on Human and Peoples’ Rights. The draft Protocol broadly embodies the articles of the UN CRPD, while “providing an African context to rights of persons with disabilities” by grounding it in the African Charter on Human and Peoples’ Rights and referencing the draft Protocol on the Rights of Older Persons. The introduction to the Protocol says it “should not undermine the letter and spirit of the 2006 United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD). It therefore draws from and is inspired by the CRPD without necessarily adopting all the CRPD’s detail.”

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196 More information on NANHRI is available at [www.nanhri.org](http://www.nanhri.org).

197 Available at [www.nanhri.org/reports](http://www.nanhri.org/reports).

198 See more at [www.nanhri.org/1088-2](http://www.nanhri.org/1088-2).

199 R. Rieser, *Implementing Inclusive Education: A Commonwealth Guide to Implementing Article 24 of the UN Convention on the Rights of Persons with Disabilities*, 2012 (2nd edition).

200 Text available at [www.achpr.org/instruments/achpr](http://www.achpr.org/instruments/achpr).

201 Text available at [www.achpr.org/news/2014/04/d121](http://www.achpr.org/news/2014/04/d121).

## 6.3. DISABILITY AND HUMAN RIGHTS INSTRUMENTS IN EUROPE

### The Council of Europe

The Council of Europe, based in Strasbourg, is an inter-governmental organisation including 47 Member States<sup>202</sup> (28 of which are also members of the European Union). Its primary aims are to advance and protect democracy, the rule of law and human rights. It works largely by adopting treaties and issuing policy recommendations to its Member States.

The Council of Europe's inter-governmental machinery is quite elaborate and allows for intensive cooperation between Member States on particular topics. Disability has been the subject of such cooperation ever since the landmark 1992 Recommendation (92)6.<sup>203</sup> There is now a Council of Europe strategy on disability.<sup>204</sup> The most recent Council of Europe Disability Action Plan (2006–2015) provides guidance to Member States on the following action areas:

- Participation in public and political life
- Participation in cultural life
- Information and communication
- Education
- Employment, vocational guidance and training
- The built environment
- Transport
- Community living
- Health care
- Rehabilitation
- Social protection
- Legal protection
- Protection against violence and abuse
- Research and development
- Awareness raising.<sup>205</sup>

The Council is currently preparing its next Disability Action Plan, which will likely be much more targeted.

The Council of Europe has adopted at least 12 treaties relating to human rights. All 47 Member States are signatories of the European Convention on Human Rights,<sup>206</sup> which is probably the most famous treaty concluded under the auspices of the Council. This instrument seeks to protect civil and political rights, with supervision of the Convention overseen by the European Court of Human Rights.<sup>207</sup> Enforcement of the Court's judgments is left to the Council's Committee of Ministers, a political body.

Article 14 of the European Convention on Human Rights prohibits discrimination with respect to the enjoyment of the rights set out in the Convention. Although it does not explicitly mention discrimination on the grounds of disability, the Convention refers to "other status", which is interpreted to provide protection to persons with disabilities. Protocol 12 to the Convention establishes a freestanding right to non-discrimination. The Protocol has been ratified by 17 of the Council of Europe's 47 Member States and has entered into force in respect to them.

202 More information on the Council of Europe is available at [www.coe.int/en/web/portal/home](http://www.coe.int/en/web/portal/home).

203 Available at <https://wcd.coe.int/com.instranet.InstraServlet?command=com.instranet.CmdBlobGet&InstranetImage=2398057&SecMode=1&DocId=602414&Usage=2>.

204 General information is available at [www.coe.int/en/web/portal/people-with-disabilities](http://www.coe.int/en/web/portal/people-with-disabilities).

205 Available at [www.coe.int/t/dg3/disability/default\\_en.asp](http://www.coe.int/t/dg3/disability/default_en.asp).

206 Text available at [www.echr.coe.int/Documents/Convention\\_ENG.pdf](http://www.echr.coe.int/Documents/Convention_ENG.pdf).

207 More information on the European Court of Human Rights is available at [www.echr.coe.int/Pages/home.aspx?p=home&c](http://www.echr.coe.int/Pages/home.aspx?p=home&c).

The European Court of Human Rights has prepared a very useful dossier on its case law as it relates to persons with disabilities.<sup>208</sup> It has directly cited the UN CRPD several times and especially in its case law on legal capacity, which generally tends to accord with article 12 of the UN CRPD.<sup>209</sup>

The European Revised Social Charter<sup>210</sup> is another Council of Europe treaty which secures social and economic human rights, including housing, health, education, employment, movement of persons, non-discrimination and legal protection. Article 15 of the Charter is specifically dedicated to the rights of persons with disabilities, focusing on independence and integration, education and vocational training, employment and access to services and support. The European Committee on Social Rights oversees States' conformity with the Charter. The Committee has adjudicated on several high-profile disability collective complaints, beginning with the famous case of *International Association Ausisme-Europe v France of 2004*, which deals with the inclusion of children with autism in education. The Committee has published a useful factsheet on its disability jurisprudence.<sup>211</sup>

Similar to the UN system, the Council of Europe has its own Commissioner for Human Rights. The Commissioner has been very active on disability issues and has produced three influential 'issue papers' on the rights of persons with disabilities. They have examined the broad implications of the UN CRPD for Europe<sup>212</sup>, equal recognition before the law<sup>213</sup> and the right to live independently and to be included in the community.<sup>214</sup> Furthermore, the Commissioner has strongly argued against the elaboration of a draft Protocol to the Oviedo Biomedicine Convention, a treaty of the Council of Europe, on the grounds that it would conflict with the CRPD Committee's understanding of the requirements of article 14 (on liberty) of the UN CRPD. This is an interesting spectacle; one part of the Council of Europe arguing against another on the basis of an external treaty. This clearly demonstrates how powerful the UN CRPD has become within the work of regional organisations.

What this brief survey shows is that the relatively old instruments of the Council of Europe are steadily being informed by the standards and principles of the UN CRPD. This has implications for NHRIs who engage with the Strasbourg system in their regular work.

## The European Union

The European Union, which has 28 Member States, is a 'regional integration organisation'. Its Member States have transferred some aspects of their sovereignty to the EU institutions, have shared others with the EU and have reserved many others. Because it enjoys the exercise of transferred or shared sovereignty, the EU has standing to accede to the UN CRPD – and has done so.

The EU Charter on Fundamental Rights<sup>215</sup> enshrines certain political, social, and economic rights for European Union citizens and residents into EU law. The provisions of the Charter are addressed to the institutions and bodies of the European Union and to Member States only when they are implementing EU law. The Charter does not add to existing EU competences. At the end of the day it is these legal competences that matter.

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208 Fact sheets on 'Persons with disabilities and the European Convention on Human Rights' are available at [www.echr.coe.int/Documents/FS\\_Disabled\\_ENG.pdf](http://www.echr.coe.int/Documents/FS_Disabled_ENG.pdf).

209 O. Lewis, 'Advancing Legal Capacity Jurisprudence', *European Human Rights Law Review*, Vol. 6, 2011, pp. 700-714.

210 Text available at [www.coe.int/en/web/conventions/full-list/-/conventions/treaty/163](http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/163).

211 Available at [www.coe.int/t/dghl/monitoring/socialcharter/Theme%20factsheets/FactsheetDisabled\\_en.pdf](http://www.coe.int/t/dghl/monitoring/socialcharter/Theme%20factsheets/FactsheetDisabled_en.pdf).

212 Available at <https://wcd.coe.int/ViewDoc.jsp?p=&id=1355349&direct=true>.

213 Available at <https://wcd.coe.int/ViewDoc.jsp?p=&id=1908555&direct=true>.

214 Available at <https://wcd.coe.int/ViewDoc.jsp?p=&id=1917847&direct=true>.

215 Available at [http://ec.europa.eu/justice/fundamental-rights/charter/index\\_en.htm](http://ec.europa.eu/justice/fundamental-rights/charter/index_en.htm).

Article 21 of the Charter prohibits discrimination, including on the grounds of disability. Article 26 specifically concerns the integration of persons with disabilities:

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

EU treaty law requires mainstreaming of the elimination of all forms of discrimination into all activities and in policy development.<sup>216</sup> An Employment Equality Directive of 2000 – EU legislation requiring Member States to introduce certain measures in their own laws – lays down minimum standards to prohibit direct discrimination, indirect discrimination, harassment, victimisation and instructions to discriminate.<sup>217</sup> It includes discrimination based on disability. It requires that employers and providers of vocational training should be placed under an obligation to provide ‘reasonable accommodation’ to disabled job applicants and employees.<sup>218</sup> In 2008, the European Commission proposed the enactment of an additional Equal Treatment Directive in relation to the provision of goods and services, transport and education and social protection, which would also include disability.<sup>219</sup> The proposed Directive would introduce the concept of ‘anticipatory’ reasonable accommodation into EU law. It has not yet been enacted.

In 2011, the European Union ‘concluded’ (ratified) the UN CRPD in its capacity as a regional integration organisation under article 44 of the Convention. It was the first international human rights treaty to be ratified by the EU. This has implications for law reform at EU level and has already had an impact on regulations governing how EU funds are spent in lesser developed regions of Europe. The CRPD Committee’s assessment of the Initial Report of the European Union was published in 2015. The main features of the concluding observations were that the EU should conduct a thorough review of its legislation to assess its consistency with the Convention, that dialogue with civil society should be further strengthened, that the monitoring mechanism of the EU needs to be changed and that the EU should facilitate the search by its Member States for new models in the field of assisted decision-making. The Committee also recommended speeding up the enactment of a broader equality Directive.

The EU Disability Strategy (2010–2020) is a central vehicle through which the EU pursues implementation of the Convention.<sup>220</sup> The Strategy is focused on eight priority areas of concern to the EU and its Member States (but only when implementing EU law):

- Accessibility
- Participation
- Equality
- Employment
- Education and training
- Social protection
- Health
- External action (international development).

The European Union Agency for Fundamental Rights<sup>221</sup> is tasked with providing evidence-based advice to the European Union and its Member States when implementing EU law on human rights. To do so, the Agency has carried out analysis regarding political participation of persons with disabilities, legal capacity, and the right to live independently and to be included in the community.<sup>222</sup>

216 European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier Free; available at <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:en:PDF>.

217 Council Directive 2000/78/EC OJ L303/16, article 3; available at <http://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A32000L0078>.

218 Ibid, article 2.

219 See <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2008:0426:FIN:EN:PDF>.

220 Available at <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:en:PDF>.

221 More information on the Agency for Fundamental Rights is available at <http://fra.europa.eu/en>.

222 See <http://fra.europa.eu/en/theme/people-disabilities>.

It has developed indicators regarding political participation and is presently developing indicators regarding the right to live independently (see Part III for further details). The Agency has also started to look at the issue of targeted violence and hostility experience by children with disabilities.<sup>223</sup>

The Agency is a central part of the EU monitoring framework for the Convention, which includes the European Parliament, the European Commission, the European Disability Forum and the EU Ombudsman. However, in its 2015 concluding observations to the European Union, the CRPD Committee called on the European Commission to withdraw from the monitoring framework as it is primarily an executive body.

The impact of the UN CRPD in the work of the EU is extremely powerful, which is due in large part to the EU's accession to the Convention. It is also powerful because the instruments used by the EU are themselves powerful. A recent example is in how the Regulations for the EU Structural Funds (a fund to be distributed from richer to poorer EU countries) has been changed to ensure that taxpayer's monies are not spent on opening or even refurbishing institutions, but are spent instead to assist States to transition towards community living models. NHRIs are increasingly engaging with EU institutions, as evidenced by locating the European Network of National Human Rights Institutions in Brussels.

As previously mentioned, the 2015 concluding observations of the CRPD Committee include a recommendation that the European Commission should withdraw from the monitoring framework the EU established under article 33(2) of the Convention. A new framework is expected to be established in 2016. In March 2016, the European Parliament requested an 'Opinion' from the Fundamental Rights Agency on how the monitoring framework might be reconstituted in light of the concerns expressed by the CRPD Committee. This 'Opinion' – an extensive 36-page document – was delivered on 13 May 2016. It makes for compelling reading as it considers the conclusions of the Committee and skilfully applies them to the specific circumstances of the EU as a regional integration organisation. It should be read by anyone interested in how NHRIs can actively contribute to shaping the relevant article 33(2) 'frameworks'.

## 6.4. THE AMERICAS: THE ORGANIZATION OF AMERICAN STATES

The American Convention on Human Rights of the Organization of American States (OAS) is an international human rights instrument which came into force in 1978.<sup>224</sup> The bodies responsible for overseeing compliance with the Convention are the Inter-American Commission on Human Rights and the Inter-American Court of Human Rights,<sup>225</sup> both of which are organs of the OAS.<sup>226</sup> There are presently 23 active parties to the Convention.

Article 1 of the American Convention on Human Rights obliges States to respect human rights without discrimination. Disability is not explicitly mentioned but, as with the African Charter and the European Convention on Human Rights, the list of grounds is not exhaustive by virtue of inclusion of the words "or other social condition". Article 24 of the Convention provides for equal protection before the law. Article 26 of the Convention requires States parties to achieve progressively the economic, social and cultural rights "implicit in the economic, social, educational, scientific, and cultural standards set forth in the Charter of the Organization of American States as amended by the Protocol of Buenos Aires".

The Inter-American Convention on the Elimination of All Forms of Discrimination against Persons with Disabilities,<sup>227</sup> adopted in 1999, is another regional human rights instrument within the OAS. Its stated objectives are "to prevent and eliminate all forms of discrimination against persons with disabilities and to promote their full integration into society".

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223 Ibid.

224 Available at [www.oas.org/dil/treaties\\_B-32\\_American\\_Convention\\_on\\_Human\\_Rights.htm](http://www.oas.org/dil/treaties_B-32_American_Convention_on_Human_Rights.htm).

225 See [www.oas.org/en/iachr](http://www.oas.org/en/iachr).

226 See [www.oas.org/en/default.asp](http://www.oas.org/en/default.asp).

227 Available at [www.oas.org/juridico/english/treaties/a-65.html](http://www.oas.org/juridico/english/treaties/a-65.html).

In 2011, the relevant treaty monitoring body – the Committee for the Elimination of All Forms of Discrimination against Persons with Disabilities – issued a famous general observation in 2011 to the effect that it intended to read the relevant provisions of the OAS Convention dealing with legal capacity issues in line with article 12 of the UN CRPD.<sup>228</sup>

The OAS declared a Decade for the Americas on the rights and dignity of persons with disabilities (2006–2016), which includes a program of action on disability.

## 6.5. ASIA PACIFIC: UN ECONOMIC AND SOCIAL COMMISSION FOR ASIA AND THE PACIFIC

Unlike the African, European and Americas regions, the Asia Pacific region does not possess a regional human rights treaty or human rights body

The 2012 Incheon Strategy to ‘Make the Right Real’ for Persons with Disabilities – concluded between governments under the auspice of UN Economic and Social Commission for Asia and the Pacific – is a regional document that seeks to put into practice the principles and goals of the UN CRPD during the Asian and Pacific Decade of Persons with Disabilities (2013–2022).<sup>229</sup> The Strategy centres on ten goals:

1. Reduce poverty and enhance work and employment prospects
2. Promote participation in political processes and in decision making
3. Enhance access to the physical environment, public transportation, knowledge, information and communications
4. Strengthen social protection
5. Expand early intervention and education for children with disabilities
6. Ensure gender equality and women’s empowerment
7. Ensure disability-inclusive disaster risk reduction and management
8. Improve the reliability and comparability of disability data
9. Accelerate the ratification of the UNCRPD and harmonisation of national legislation with the Convention
10. Advance regional, sub regional and interregional cooperation.

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228 OEA/Ser.L/XXIV.3.1, CEDDIS/doc.12(I-E/11) Rev. 1.

229 More information on the Incheon Strategy is available at [www.unescap.org/resources/incheon-strategy-%E2%80%9Cmake-right-real%E2%80%9D-persons-disabilities-asia-and-pacific](http://www.unescap.org/resources/incheon-strategy-%E2%80%9Cmake-right-real%E2%80%9D-persons-disabilities-asia-and-pacific).

## Further reading for Part II

What follows is a very limited list of some of the best publications on the UN CRPD. These are general publications and do not go into specific fields (like education). The literature with respect to the latter is now voluminous.



### General resource

A useful archive of resources on UN CRPD is hosted by the Harvard Project on Disability, available at: [www.hpod.org/resources/human-rights](http://www.hpod.org/resources/human-rights).



### Significant publications pre-Convention

- M. Saule, *Disabled Persons and International Organizations* (Rome, 1981)
- T. Degener and Y. Koster-Dreese (eds.), *Human Rights & Disabled Persons: Essays and Relevant Human Rights Instruments* (Nijhoff, 1995)
- M. Breslin and S. Yee, *Disability Rights Law and Policy: International and National Perspectives* (Transnational, 2002)
- T. Degener and G. Quinn, *Human Rights and Disability: The Current Use and Future Potential of the United Nations Human Rights Instruments in the context of Disability* (OHCHR, Geneva, 2002)

### Significant publications post-Convention

- M. Schulze and M. Sabbatello, *Human Rights and Disability Advocacy* (University of Pennsylvania Press (2014)
- M. Stein and E. Emens, *Disability & Equality Law* (Ashgate, 2013)
- M. Birtha, 'Nothing about CRPD Monitoring without us: A Case Study on the involvement of the disability movement in policy-making in Zambia', Vol. 1, *African Yearbook on Disability* (2013)
- J. Anderson and J. Philips, *Disability and Universal Human Rights: Legal, Ethical and Conceptual Implications of the Convention on the Rights of Persons with Disabilities* (University of Utrecht, 2012)
- E. Flynn, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities* (Cambridge University Press, 2011)
- M. Schulze, *A Handbook on the Human Rights of Persons with Disabilities: Understanding the UN Convention on the Rights of Persons with Disabilities* (Handicap International, 2010)
- K. Kumpuvuori and M. Scheinin (eds.), *United Nations Convention on the Rights of Persons with Disabilities: Multidisciplinary Perspectives* (Abo Academy Press, 2010)
- S. Tromel, 'A personal perspective on the drafting history of the United Nations Convention on the Rights of Persons with Disabilities', Vol. 1, *European Yearbook of Disability Law* (2009)
- R. Colker, *When is Separate Unequal: A Disability Perspective* (Cambridge 2009)
- O. Arnardottir and G. Quinn, *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Nijhoff, 2009)

- M. Stein and J. Lord, 'Monitoring the UN Convention on the Rights of Persons with Disabilities: Lost Opportunities and Future Potential', *College of William & Mary, Faculty Publications*, No. 1101 (2009)
- G. Quinn, 'The United Nations Convention on the Rights of Persons with Disabilities – towards a new international politics of disability', Vol. 15, *Texas Journal on Civil Liberties & Civil Rights* (2009)
- R. Kayess and P. French, 'Out of the Darkness into Light: Introducing the UN Convention on the Rights of Persons with Disabilities', Vol. 8, No. 1, *Human Rights Law Review* (2008)
- W. Scott, 'Guide to Sources in International & Comparative Disability Law', *Syracuse Journal of International Law & Commerce*, Vol. 34 (2007)
- 'Symposium: The United Nations Convention on the Rights of Persons with Disabilities', *Syracuse Journal of International Law & Commerce*, Vol. 34 (2007)

### YouTube and video resources

- See series of lectures on the Convention on the Rights of Persons with Disabilities at the Centre for Disability Law & Policy International Summer School site: [www.youtube.com/results?search\\_query=CDLP+summer+school](http://www.youtube.com/results?search_query=CDLP+summer+school).

### Disability book series

- Cambridge Disability Law & Policy Series: [www.cambridge.org/us/academic/subjects/law/human-rights/series/cambridge-disability-law-and-policy-series](http://www.cambridge.org/us/academic/subjects/law/human-rights/series/cambridge-disability-law-and-policy-series).

# Part III

## The practice: What NHRIs can do to contribute to the process of change



**Section I: Getting ready to engage**

**Section II: NHRI engagement on disability: Promising practice**

## Introduction to Part III

**Knowing as I do the ineffective impact of law that remains on the books never enforced or implemented, I see NHRIs as an important transmission belt – that stand to ignite and trigger operational and meaningful CRPD compliance.**

**Charlotte Voyiswa McClain-Nhlapo<sup>230</sup>**



International law is not self-executing. It needs to be brought home and ‘translated’ in the local setting in order to drive long-term change. NHRIs are a key part of this translation effort. To the authentic voice of civil society – which is a precondition for legitimate change – NHRIs can add their authoritative voice, creating a potent partnership for progress and reform.

Part III of this Manual focuses on how NHRIs can become effective champions for the rights of persons with disabilities. It sets out the range of possible activities which NHRIs might carry out in partnership with or supported by civil society. It does so against the familiar backdrop of the three core tasks of any national monitoring mechanism: ‘promoting, protecting and monitoring’ the implementation of human rights. These responsibilities apply regardless of ratification of the Convention on the Rights of Persons with Disabilities. However, the Convention crystallises these traditional responsibilities in article 33.

Part III draws on positive examples of engagement by NHRIs in different parts of the world: Section I describes how NHRIs might prepare themselves for effective engagement, while Section II looks at examples of positive engagement and the positive results this has generated.

<sup>230</sup> Representing the International Coordination Committee of National Institutions for the Promotion and Protection of Human Rights (now known as the Global Alliance of National Human Rights Institutions) during the negotiations on the Convention in the UN Ad Hoc Committee.

## Section I Getting ready to engage



**Chapter 7:** The institutional architecture for change and the place of NHRIs

**Chapter 8:** Getting ready to impact change: Internal NHRI organisational development and capacity building

**Chapter 9:** Working in partnership with civil society: 'Nothing about us without us'

**Chapter 10:** Leading by example: Eliminating discrimination and ensuring accessibility in the work of NHRIs

# Chapter 7:

## The institutional architecture for change and the place of NHRIs

### KEY QUESTIONS

- What is meant by ‘promoting, protecting and monitoring’ human rights in the context of disability?
- What role are NHRIs expected to play under article 33 of the Convention as part of a broader national framework to perform these tasks?



### 7.1. WHAT IS MEANT BY ‘PROMOTING, PROTECTING AND MONITORING’ IMPLEMENTATION OF THE RIGHTS OF PERSONS WITH DISABILITIES?

It is important to note that ratification of the UN CRPD is not necessary for NHRIs to engage on human rights issues related to disability. Furthermore, nearly all NHRIs are already engaged in a wide range of activities involving rights or groups that overlap with disability (see Chapter 6 for more information). In fact, there is every reason for NHRIs to embrace disability as a mainstream part of their regular work. The universality of human rights demands nothing less. Nevertheless, if ratification has occurred – and NHRIs have a role in advocating for ratification – then NHRIs are called on to play very particular and significant roles.

As outlined in earlier parts of this Manual, article 33.2 of the UN CRPD requires that a domestic architecture for national implementation and monitoring should be established. This includes providing a “framework, including one or more independent mechanisms, as appropriate” to “promote, protect and monitor implementation of the present Convention”. The membership of the framework can extend much wider than NHRIs. However, the reference to an “independent mechanism” (or more than one) is widely understood as referring to NHRIs. In fact, States parties to the UN CRPD must have regard to “the principles relating to the establishment and functioning of national institutions for the protection and promotion of human rights”. As mentioned in Chapter 3, this is an oblique but unmistakable reference to the Paris Principles. It is certainly the way the CRPD Committee interprets it. The text is ambiguous as to whether NHRIs (as the independent mechanism) ought to perform all three tasks (‘promotion, protection and monitoring’) but most will in fact do so.

The Convention itself does not provide detailed guidance as to what is meant by ‘promoting’, ‘protecting’ and ‘monitoring’ and the CRPD Committee has yet to issue guidance on the matter.<sup>231</sup> However a useful starting point is the 2014 Note on national implementation and monitoring prepared by the Secretariat for the Convention on the Rights of Persons with Disabilities for the Conference of States Parties.<sup>232</sup>

231 For a useful discussion on the requirements of article 33(2), see the 2007 paper prepared by the Australian Human Rights Commission on ‘National human rights institutions and national implementation and monitoring of the Convention on the Rights of Persons with Disabilities’; available at: [www.humanrights.gov.au/national-human-rights-institutions-and-national-implementation-and-monitoring-convention-rights](http://www.humanrights.gov.au/national-human-rights-institutions-and-national-implementation-and-monitoring-convention-rights).

232 ‘National Implementation and Monitoring: Matters relating to the Implementation of the Convention’; available at [www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf](http://www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf).

### Promotion:

Promotion of the implementation of the Convention covers a broad range of activities, including not only awareness-raising activities, as highlighted in article 8 of the Convention, but also a more strategic engagement to advance implementation. This could include scrutiny for compliance of existing national legislation, regulations and practices, draft bills and other proposals, in order to ensure consistency with the requirements of the Convention; and the provision of technical advice to public authorities or other agencies in construing and applying the Convention, including on the basis of observations and recommendations and general comments issued by the Committee on the Rights of Persons with Disabilities.<sup>233</sup>

### Protection:

Under the Convention, 'protection' can include a broad range of different activities, including the investigation and examination of individual and group complaints, taking cases to court, conducting inquiries and issuing reports.<sup>234</sup>

### Monitoring:

... monitoring the implementation of the Convention can be approached in a number of ways, including through the assessment of progress, stagnation or retrogression in the enjoyment of rights over a certain period of time. The development of indicators and benchmarks is a particularly effective way to monitor implementation, particularly with regard to the progressive realization of economic, social and cultural rights, as set out in the Convention. Another approach with which many human rights institutions are familiar is that of monitoring human rights violations, a common methodology of which to collect or maintain records of the complaints filed by alleged victims before relevant judicial or quasi-judicial complaints mechanisms. Considering the specific barriers persons with disabilities have traditionally faced in accessing justice, such data can be integrated with information on violations provided by other sources, such as civil society organizations and organizations of persons with disabilities participating in the framework.<sup>235</sup>

In practice, the functions of 'promoting, protecting and monitoring' implementation are often interlinked. For example, strategic litigation might be used to draw attention to and promote awareness regarding systemic violations, in addition to allowing an individual claim to be pursued. Indeed, some inquiries and investigations conducted by NHRIs may amount to monitoring, whereas others might be regarded as protecting the rights of persons with disabilities. The most effective strategy for NHRIs is to employ their powers and functions in combination to maximise their impact.

Very often the question of which task to perform or which power to use will depend on the NHRI's theory of change. That change could be short-term, intermediate or long-term. It will also depend on the obstacles to change, such as a lack of understanding, political apathy, inefficient or insensitive service arrangements, or the need to make laws and practical provisions that support implementation. NHRIs will have to face and address these obstacles in partnership with others, especially civil society. NHRIs must also have an eye to long-term change which often involves a re-framing of disability (see Part I). Although this work does not yield immediate results, it is necessary to pursue as it helps create space for other change to occur.

## 7.2. THE ROLE OF NHRIs AS PART OF A FRAMEWORK TO PROMOTE, PROTECT AND MONITOR IMPLEMENTATION

NHRIs ought, ideally, to be designated to perform the 'independent' role in the framework described in article 33(2) of the Convention. This does not mean that the framework cannot have other 'less independent' elements. As the Australian Human Rights Commission has advised, the oblique reference to the Paris Principles in article 33(2):

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233 Ibid.

234 Ibid.

235 Ibid.

... does not mean however that the only mechanisms which should be included in a framework are NHRIs complying with the “Paris Principles”. While States agree to take these Principles into account in establishing or designating a mechanism for the purposes of Article 33, they will have clearly done so if such an NHRI is included as one of the mechanisms within the framework while retaining its independence.<sup>236</sup>

Many countries will have subject-specific commissions like a disability policy commission. Ideally, such bodies should also sit alongside NHRIs in the broader framework. Nor should one ‘independent mechanism’ predominate:

Article 33, paragraph 2, appears also to allow States to designate multiple mechanisms by thematic divisions of responsibility so that, conceivably, a plurality of such mechanisms might be engaged depending on the function to be performed.<sup>237</sup>

For example, in addition to NHRIs some States have a Children’s Commissioner; a Data Protection Commissioner; a national preventive mechanism under the Optional Protocol to the Convention against Torture, including bodies that inspect prisons, psychiatric institutions or care settings; an Independent Police Complaints Commission; an anti-discrimination body; an equality tribunal; ombuds offices covering national and local government and the health system; bodies that regulate the media; bodies regulating schools; bodies overseeing health and safety law and regulation; bodies regulating the built environment and transportation, and so on.

Many countries also have an active network of civil society organisations and disabled people’s organisations, in particular, which perform a critical function in promoting, protecting and monitoring the rights of persons with disabilities. There is no *a priori* reason why they should not be included in the framework. Indeed, article 4(3) of the UN CRPD would strongly point to the need to directly involve civil society in this work.

While NHRIs have been identified as the “natural core entities of the monitoring framework at the national level”,<sup>238</sup> the precise role and responsibilities that NHRIs will assume and the activities they undertake will be highly dependent on the existence and effectiveness of this wider framework, as well as the limits of their own mandate and powers.

In some cases this means that it will not be necessary, appropriate or realistic for NHRIs to carry out the full range of functions and activities associated with promoting, protecting and monitoring implementation of the rights of persons with disabilities, where other agencies or institutions are better placed to do so. The strength and effectiveness of these bodies and partnerships will influence the strategic thinking of NHRIs as to which powers to use, when and how.

Of course, if these synergies are weak then this has direct implications for the role of NHRIs. In some States, significant gaps or weaknesses may exist in the framework and NHRIs should view it as their role to advocate steps for these gaps and weaknesses to be addressed through the development of an appropriate institutional architecture. This may include the NHRI itself seeking a more expansive mandate and powers; for example, powers of entry to inspect institutions for people with intellectual or psychosocial disabilities. In other situations, it may be advantageous for NHRIs to form working partnership arrangements with other bodies to address these gaps. In all cases, NHRIs should assess and continually monitor the existence and effectiveness of the framework as a whole.

Even if an NHRI is not formally designated by the State as a part – much less, the ‘independent’ part – of a national framework, it will continue to have a role to promote and protect the rights of persons with disabilities as part of its broader responsibilities and should advocate for a robust and effective national framework.

236 See [www.humanrights.gov.au/national-human-rights-institutions-and-national-implementation-and-monitoring-convention-rights](http://www.humanrights.gov.au/national-human-rights-institutions-and-national-implementation-and-monitoring-convention-rights).

237 ‘National Implementation and Monitoring: Matters relating to the Implementation of the Convention’; available at [www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf](http://www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf).

238 OHCHR, ‘Thematic Study by the Office of the United Nations High Commissioner for Human Rights on the Structure and Role of National Mechanisms for the Implementation and Monitoring of the Rights of Persons with Disabilities’, AHRC/13/29, para. 78.



*Twenty Years: Twenty Stories:* The Australian Human Rights Commission and the Sydney Community Foundation hosted an event to celebrate the 20th anniversary of the Disability Discrimination Act. Photo by the AHRC/Francesca Diaco Photography, reproduced under a CC BY 2.0 licence

### 7.3. THE POSSIBILITY OF MULTIPLE ‘INDEPENDENT MECHANISMS’ WITHIN FEDERAL STATES

Article 33(2) does allow for the possibility that ‘one or more independent mechanisms’ may be designated by the State. This, coupled with article 4(5) which stipulates that its provisions “shall extend to all parts of federal States without any limitation or exception,” creates the possibility of several ‘independent mechanisms’ co-existing, especially within federated states. As the Secretariat for the Convention on the Rights of Persons with Disabilities noted:

Article 33, paragraph 2, also foresees the possibility that more than one independent mechanism might be appointed in the framework, as appropriate, with the effect that States would in fact establish a “mechanism of mechanisms” to promote, protect and monitor implementation. This possibility seems to address States parties with multiple levels of government, such as federal States and analogous entities.<sup>239</sup>

It goes onto suggest that:

Based on the particular constitutional structure and other political and geographic considerations in a State, the independent mechanism of a federal State could arguably be either a unified federal body or a system with multiple bodies. Designation could come from either the federal Government and/or a devolved administration within the limits of its territorial jurisdiction and competence.<sup>240</sup>

In the United Kingdom, for example, the Equality and Human Rights Commission (England & Wales), the Northern Ireland Human Rights Commission and the Equality Commission for Northern Ireland (all established by the Parliament of the United Kingdom) and the Scottish Human Rights Commission (established by the Scottish Parliament) have all been designated by the Government of the United Kingdom, reflecting the devolved jurisdictions in Scotland and Northern Ireland.

While such bodies should have the flexibility and sensitivity to respond to their local environment, they should nevertheless cooperate to harmonise an overall approach. At the end of the day, the federated State is answerable in the international arena for implementation at the sub-federal level.

239 ‘National Implementation and Monitoring: Matters relating to the Implementation of the Convention’; available at [www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf](http://www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf).

240 Ibid.

### A SAMPLE OF ARRANGEMENTS UNDER ARTICLE 33.2

- The New Zealand Government designated the **New Zealand Human Rights Commission**, the **New Zealand Ombudsman** and the ‘Convention Coalition’ group of six national DPOs as the ‘framework’ under article 33(2)
- The Spanish Government designated the **Spanish Committee of Representatives of Persons with Disabilities (CERMI)**, which is the national DPO for Spain, and the Spanish Ombudsman, which is an ‘A status’ NHRI, as the ‘independent mechanism’
- The Danish Government designated the **Danish Institute for Human Rights (DIHR)**, the Danish Disability Council and the Parliamentary Ombudsman as the framework to promote, protect and monitor the Convention, with the DIHR occupying the role of ‘independent mechanism’.



### NHRIs SHAPING THE WIDER MONITORING FRAMEWORK

The **Human Rights Commission of Sierra Leone (HRCSL)** urged its national government to establish and then assisted them in establishing the National Commission for Persons with Disability, a specialist body. The HRCSL has worked in partnership with the new Commission to support its activities, including joint handling of complaints and celebrating the International Day of Persons with Disability, and to provide technical advice.

## 7.4. THE PROCESS OF BECOMING DESIGNATED AS THE ‘INDEPENDENT MECHANISM’

Article 33(2) of the UN CRPD obliges States to “*maintain, strengthen, designate or establish* a framework including one or more independent mechanisms”. The Convention does not provide further guidance on what action, processes or practices might make up each option. The answer to this question is therefore a matter for States to determine in the current absence of specific guidance from the CRPD Committee.

In its Note to the 2014 Conference of States Parties, the Secretariat for the Convention on the Rights of Persons with Disabilities advised that “few States have taken formal steps to designate their national human rights institutions as the independent mechanism of the framework”. It goes on to suggest that:

The process of formally designating a national human rights institution can reflect the adequacy of the mandate of the institution for the purpose of article 33, which, in some cases, might reveal opportunities for strengthening compliance with the Paris Principles. In other cases, a review of how persons with disabilities participate in existing national human rights institutions can highlight the need to revise the composition of the institution and strengthen pluralism. It should also be noted that the designation of a national human rights institution as the independent mechanism will most likely require internal structural changes and that additional financial and human resources will almost always be required.<sup>241</sup>

Based on this advice and the language of article 33(2), it might reasonably be expected that governments will take the following steps:

- Conduct a public consultation, especially with persons with disabilities and with the NHRI and other ‘implicated organisations’, regarding proposed arrangements under article 33(2)
- Make a public statement, including a written statement to the parliament, regarding arrangements under article 33(2)

241 Ibid.

- Amend the founding statute of the NHRI, if necessary and if part of the designated framework, to remove any obstacles to it assuming this role and/or to clarify specifically its role in relation to the Convention and to empower it to carry out this role effectively
- Provide additional, adequate resources to assume the role of independent mechanism, including administrative and program-related costs
- Create a new body, where necessary, capable of meeting the principles relating to the establishment and functioning of national institutions for the protection and promotion of human rights, including through the reform or integration of existing institutions.

### THE PROCESS OF DESIGNATING THE INDEPENDENT MECHANISM

- The Government of the United Kingdom laid an ‘Explanatory Memorandum’ before Parliament on the occasion of ratifying the UN CRPD in July 2009, which detailed the ‘independent mechanisms’ under article 33(2). These arrangements had been previously agreed with the four designated organisations (the **Equality and Human Rights Commission**, the **Scottish Human Rights Commission**, the **Northern Ireland Human Rights Commission** and the **Equality Commission for Northern Ireland**). The Government did not, however, consult with persons with disabilities before determining the independent mechanisms for the United Kingdom and nor were any of the designated organisations provided with any general increase in funding to assume this role.<sup>242</sup>
- On ratifying the UN CRPD in 2009, the Danish Government also laid an explanatory memorandum before the Danish Parliament stating that “the Ministry for the Interior and Social Affairs will initiate a study in cooperation with the Ministry of Finance to determine how the existing structures in the field may be developed to conduct monitoring of the implementation of the Convention. Finally, the Government will continue the cooperation with the organisations who represent persons with disabilities” (Parliamentary Decision B194/2009). Following an examination of the different options for a framework under article 33(2) and discussions in the Intra-Ministerial Committee on Civil Servants on Disability Matters, the Ministry for Social Affairs formulated a Proposal for a Parliamentary Decision on “the promotion, protection and monitoring of the implementation of the UN Disability Convention on the Rights of Persons with Disabilities”, which was adopted on 17 December 2010. The Parliamentary Decision appointed the **Danish Institute for Human Rights (DIHR)** with the task to “promote, protect and monitor the implementation of the CRPD”. Although the concept of ‘independent mechanism’ is not mentioned specifically in the Parliamentary Decision, it is clear from the wording that the DIHR has the leading role and is the independent mechanism. The explanatory note to the Parliamentary Decision provides that the Danish Institute for Human Rights, the Danish Disability Council and the Parliamentary Ombudsman constitute the framework to promote, protect and monitor the Convention. The DIHR has also been provided with approximately 620,000 Euros annually to carry out this task.



242 Discussed in OHCHR/G. De Beco, ‘Implementation of Article 33 of the United Nations Convention on the Rights of Persons with Disabilities in Europe’, 2013; available at [http://europe.ohchr.org/Documents/Publications/Art\\_33\\_CRPD\\_study.pdf](http://europe.ohchr.org/Documents/Publications/Art_33_CRPD_study.pdf).

## 7.5. THE POSITIVE IMPLICATIONS OF DESIGNATION

Designation as a national mechanism under article 33(3) can tangibly assist NHRIs with their accreditation or re-accreditation at the international level. NHRIs are organised both regionally and globally.<sup>243</sup> At the global level, they must first gain accreditation with the Global Alliance of National Human Rights Institutions (GANHRI)<sup>244</sup> to be recognised as an NHRI. General Observation 2.9 of GANHRI's Sub-Committee on Accreditation deals with the criteria for accreditation of NHRIs as national protection mechanisms and national monitoring mechanisms.<sup>245</sup> Its states that:

Where, pursuant to an international human rights instrument, a national human rights institution has been designated as, or as part of, a national preventive or monitoring mechanism, the Sub-Committee on Accreditation will assess whether the application has provided sufficient information to demonstrate that it is carrying out its functions in compliance with the Paris Principles. Depending on the specific roles and functions ascribed to the NHRI, in undertaking this assessment the Sub-Committee will consider, as appropriate:

- Whether a formal legal mandate has been provided;
- Whether the mandate has been appropriately defined to encompass the promotion and protection of all relevant rights contained in the international instrument
- Whether the staff of the NHRI possess the appropriate skills and experience
- Whether the NHRI has been provided with additional and adequate resources
- Whether there is evidence that the NHRI is effectively undertaking all relevant roles and functions as may be provided in the relevant international instrument.

The Sub-Committee may also consider, as it thinks appropriate, any guidance that has been developed by the relevant treaty body.

The Sub-Committee further noted that:

... its role is to assess an NHRI against the Paris Principles, whereas the relevant Treaty Body undertakes its assessment of the national preventive or monitoring mechanism against the relevant international instrument on which it is based.

By way of example, in its periodic assessment of the Canadian Human Rights Commission in 2011, the Sub-Committee stated that:

... the provisions in Part II and Part III of the [Canadian Human Rights] Act that provide the CHRC with a mandate to undertake activities in relation to human rights and freedoms. It notes however that this mandate could be more clearly elaborated in the enabling legislation. The SCA encourages the CHRC to advocate for amendments to more clearly establish a broad mandate to promote and protect all human rights, including monitoring implementation of UPR recommendations and the national monitoring mechanism under article 33 of the CRPD. The SCA refers to Paris Principles A.2: "A national institution shall be given as broad a mandate as possible, which shall be clearly set forth in a constitutional or legislative text, specifying its composition and its sphere of competence."<sup>246</sup>

243 Information about the Global Alliance of National Human Rights Institutions is available at <http://nhri.ohchr.org/EN/Pages/default.aspx>.

244 Formerly known as the International Coordinating Committee of National Institutions for the Promotion and Protection of Human Rights (ICC).

245 Available at <http://nhri.ohchr.org/EN/AboutUs/ICCAccreditation/Pages/SCAGeneralObservations.aspx>.

246 Available at <http://nhri.ohchr.org/EN/News/Lists/News/DispForm.aspx?ID=38>.

# Chapter 8: Getting ready to impact change: Internal NHRI organisational development and capacity building

## KEY QUESTION

- How can NHRIs ideally develop their organisation and grow their capacities to engage effectively on the disability issue?



In an ideal world, NHRIs would engage in considerable planning and development in order to ensure they can have maximum impact on disability issues, either as part of their general program of work or as part of the framework for monitoring implementation of the UN CRPD.

It is not possible or desirable to propose a single approach to organisational design and development for NHRIs that have either assumed or are considering assuming the role of ‘independent mechanism’ under article 33(2), or for those NHRIs that wish to improve their performance with respect to the rights of persons with disabilities. NHRIs and their operating contexts are hugely diverse and what works for one may not work for another. However, in preparing to engage on disability issues, NHRIs should consider the following questions:

- **Which activities:** What are the activities that we will need to performed? What is our level of experience of performing such activities? Do these activities exceed our existing mandate? What is the current capacity and likelihood of performing these activities?
- **Knowledge gaps:** What knowledge and expertise is required to perform these activities? To what degree is this knowledge and expertise already available within the organisation? Can the NHRI plug any gaps through training and development of existing staff or is there a need to hire new staff or contract out work?
- **Relationship building:** How will the NHRI build the close and mutually beneficial relationship with civil society required by the Convention?
- **Resource gaps:** Does the NHRI need to expand its financial and human resources to carry out these activities? Will the government make such resources available? Can the NHRI access resources elsewhere, such as through philanthropy or partnerships?
- **Strategy to grow:** Based on the above, what is the best way to organise the NHRI for this work: a specialist free-standing unit, increase the capacity of the organisation as a whole with respect to the rights of persons with disabilities, or a mixed approach?



The Special Rapporteur on the rights of persons with disabilities at a public talk hosted by the New Zealand Human Rights Commission at the Museum of New Zealand | Te Papa Tongarewa in 2016. Photo: Douglas Hancock/New Zealand Human Rights Commission

## 8.1. OPTIMAL ORGANISATIONAL DESIGN WITHIN NHRIs

A number of NHRIs have, on assuming the role of ‘independent mechanism’, established specialist or lead units on human rights and disability. This may be the most appropriate approach for some NHRIs, at least in the short-term.

### Should a specialist unit be considered?

Many NHRIs lack experience in disability issues and they may struggle to assume these responsibilities without dedicated resources. A specialist unit within the NHRI may also help raise the profile of its work on the Convention and help build awareness and understanding of the human rights-based approach to disability.

Nevertheless, in taking this approach, it is useful to recall the point made by CRPD Committee member Theresia Degeners that “it is important that disability rights are mainstreamed in the general human rights movement”.<sup>247</sup> In other words, NHRIs need to ensure that they also consider the rights of persons with disabilities in relation to other sets of rights for which they are responsible; for example, under the Convention against Torture, the International Covenant on Economic, Social and Cultural Rights or the Convention on the Elimination of All Forms of Discrimination against Women. The establishment of a specialist unit within the NHRI should raise the profile of and focus on the rights of persons with disabilities across the institution as a whole.

247 T. Degener, ‘Disability Rights are Human Rights’, 9 May 2014; available at [www.opensocietyfoundations.org/voices/disability-rights-are-human-rights](http://www.opensocietyfoundations.org/voices/disability-rights-are-human-rights).

In this sense, specialist units may be regarded most usefully as ‘focal points’ and ‘coordinating mechanisms’ *within* NHRIs (although the practicality of this proposal will depend considerably on the size of the institution). That is to say, they should provide leadership on matters concerning the rights of persons with disabilities, supporting and being supported by colleagues from other units of the NHRI, rather than operating as a ‘stand-alone’ body within the NHRI.

### Should responsibility be spread broadly within the NHRI?

An alternative to creating a specialist unit may be to appoint or designate a lead Director and distribute responsibilities across existing teams and staff members, or creating dedicated posts within existing units responsible for functions such as legal interventions, policy and education.

#### APPROACHES TO ORGANISATIONAL DESIGN

- The **German Institute for Human Rights** hosts the National CRPD Monitoring Body that “promotes respect of the rights of persons with disabilities and implementation of the UN Convention on the Rights of Persons with Disabilities in Germany”.
- In March 2011, the **National Human Rights Commission of Mexico**, in its capacity as independent mechanism under article 33(2), created the General Directorate of Attention to Disability.
- In 2013, the **Public Defender of Georgia**, in its capacity as independent mechanism under article 33(2), established the Centre on the Protection of the Rights of Persons with Disabilities.
- The **Danish Institute for Human Rights** initially mainstreamed responsibility for the rights of persons with disabilities within its Equal Treatment Department, but has since re-organised the department around the three mandates of ethnicity, gender and disability, with a team designated to each mandate.
- The **British Equality and Human Rights Commission** appointed a Disability Programme Director to support its Disability Committee. The Director acts as a focal point and coordinating mechanism within the Commission, establishing, leading or advising on strategy, work programs, policy and legal interventions.
- In 2008, the **Human Rights Commission of Sierra Leone** appointed a Different Abilities and Non-Discrimination Officer to advise the Commission on policy decisions related to persons with disabilities and other minority groups; to develop and implement programs that protect and promote the rights of persons with disabilities and other minority groups; to collaborate with government and related organisations working to implement policies and program that improve the wellbeing of persons with disabilities and other minority groups; and to collaborate and carry out capacity building activities with organisations working on disability rights.



## 8.2. GETTING THE RIGHT PEOPLE: STAFF TRAINING AND DEVELOPMENT

Where NHRIs lack in-house knowledge and experience in relation to promoting, protecting and monitoring the rights of persons with disabilities, they should consider implementing a comprehensive program of staff training and development. Such a program should ideally include:

- General disability equality training for all Commissioners and staff (see text box below on the difference between disability equality training and disability awareness training)
- Technical training on the specific articles of the UN CRPD and any relevant national or regional legislation
- Training for staff on how to ensure non-discriminatory practices – including making reasonable accommodations – and accessibility in the context of employment and service delivery
- Opportunities for training and development in relation to technical skills, such as sign language or preparing easy-to-read information.

Even organisations with experience in promoting the rights of persons with disabilities should consider running a program of continuous professional development to ensure that staff remain up to date with relevant case law, legislative developments, and the jurisprudence and policies of the UN treaty monitoring bodies.

### WHAT IS THE DIFFERENCE BETWEEN DISABILITY EQUALITY TRAINING AND DISABILITY AWARENESS TRAINING?

**Choices and Rights Disability Coalition**, a civil society group in the United Kingdom which is fully run and controlled by people with disabilities, provides the following distinction between disability equality training and disability awareness training:

“On the whole, Disability Awareness Training tends to focus on the individual impairment or condition and will often use simulation exercises (such as putting people in wheelchairs or blindfolding them) to encourage non-disabled people to have an idea of what it may be like to have that specific disability. Their trainer may discuss medical details, which may be connected with specific conditions, and will cover issues such as etiquette and language.

Someone may offer the training with no personal experience of disability.

Disability Equality Training explores the concept of people being disabled by society’s barriers and attitudes, highlighting the role of the organisation in the removal of those barriers and in the changing of attitudes. The training may include an element of ‘awareness’ – customer care, etiquette and appropriate language for instance – but it is unlikely that simulation exercises will be used, save perhaps as a means of illustrating particular barriers.

The training will always be provided by a person with personal experience of disability.”<sup>248</sup>



248 See [www.choicesandrights.org.uk/disability-equality-training/](http://www.choicesandrights.org.uk/disability-equality-training/).

## EXAMPLES OF NHRIs INSTITUTING TRAINING AND DEVELOPMENT PROGRAMS

The **Human Rights Commission of Sierra Leone** has arranged for all staff and Commissioners to receive ‘Disability Mainstreaming Training’ from an international expert on disability issues.

In November 2013, the **South African Human Rights Commission**, with the assistance of the United Nations Department of Economic and Social Affairs, held a workshop to train its provincial managers and advocacy officers on the content and implementation of the Convention. The rationale behind the workshop was to equip the provincial managers and advocacy officers with information about the Convention so that they could, in turn, go to their respective provinces to educate and train disabled persons’ organisations, stakeholders, service providers and the public about the content and implementation of the Convention.

The **African Network of Human Rights Institutions** established a structured approach to capacity building regarding the rights of persons with disabilities across its members. NHRIs were asked to nominate persons within their institutions with expertise in particular areas concerning persons with disabilities. Individuals then complete a comprehensive development and accreditation process, including being assigned a mentor, participating in a series of workshops, train-the-trainer sessions, giving lectures, facilitating workshops at their NHRIs and undergoing vetting by a committee. To date, five NHRI staff members have been accredited.



### 8.3. SECURING ADDITIONAL RESOURCES

The Secretariat for the Convention on the Rights of Persons with Disabilities, in its note to the 2014 Conference of States Parties, has suggested that “additional financial and human resources will almost always be required” by bodies assuming the role of ‘independent mechanism.’<sup>249</sup> However, a 2011 survey led by the Canadian Human Rights Commission found that “only a third of the States that have designated a NHRI to have sole or shared responsibility have provided additional funding for them to carry out this role”.<sup>250</sup>

The reluctance of States to provide additional resources to NHRIs to carry out the functions set out in article 33(2) of the UN CRPD poses a dilemma for NHRIs. On the one hand, the capacity of NHRIs to be effective in the role of ‘independent mechanism’ will be significantly influenced by the resources available to them and some NHRIs may feel unable to take on any additional responsibilities without additional resources. On the other hand, the Convention is a response to the often profound and systemic human rights violations and discrimination that many persons with disabilities encounter and by the failure of the international human rights system to respond.

The lack of additional resources should not, in itself, excuse NHRIs from giving *any* attention to the rights of persons with disabilities. It is important for NHRIs to avoid treating the rights of persons with disabilities as exceptional. Therefore, any additional resources sought by NHRIs should be commensurate with the *exceptional costs* of assuming the role of ‘independent mechanism,’ such as hiring expert staff, staff training and development, the costs associated with involving and consulting persons with disabilities, the costs of research and the costs of engaging with the regional and international human rights systems.

249 ‘National Implementation and Monitoring: Matters relating to the Implementation of the Convention’; available at [www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf](http://www.un.org/disabilities/documents/COP/COP7/CRPD.CSP.2014.3.E.pdf).

250 Global Alliance of National Human Rights Institutions, ‘Survey of National Human Rights Institutions on Article 33.2 of the Convention on the Rights of Persons with Disabilities’; available at <http://nhri.ohchr.org/EN/Themes/PersonsDisabilities/DocumentsPage/SurveyReport33.2.pdf>.

### NHRIs RECEIVING ADDITIONAL FINANCIAL SUPPORT FROM THE STATE

- The **Danish Institute for Human Rights** has been provided with approximately USD 780,000 annually to carry out its responsibilities under article 33(2).
- The **German Institute for Human Rights** was allocated USD 626,000 annually to establish and run a national monitoring mechanism.
- The **New Zealand Human Rights Commission** was provided with an additional USD 240,000 annually to carry out its responsibilities under article 33(2).



Some NHRIs have also looked beyond their governments to secure resources, either in cash or in kind, such as collaborating with other organisations. For example, the Open Society Foundation for East Africa supported the development of a briefing paper on the steps required to implement article 12 of the UN CRPD (on legal capacity) in Kenya,<sup>251</sup> which was requested by the Kenya National Commission on Human Rights. With funding from the Swedish International Development Cooperation Agency (SIDA) the African Network of National Human Rights Institutions worked in collaboration with the Raoul Wallenberg Institute of Human Rights and Humanitarian Law to develop a monitoring guide to assist Africa's NHRIs as they monitor implementation of the Convention.<sup>252</sup> The European Network of Human Rights Institutions has collaborated with the European Disability Forum to host seminars on the UN CRPD. Civil society groups do not, as such, have additional resources to bring to bear and should not be expected to co-fund relevant NHRI activities. However, there would seem to be much untapped potential to connect with philanthropic bodies, as well as development assistance programs, to help bolster the capacities of NHRIs.

251 Available at [www.knchr.org/Publications/ThematicReports/GroupRights.aspx](http://www.knchr.org/Publications/ThematicReports/GroupRights.aspx).

252 Available at <http://nhri.ohchr.org/EN/Themes/PersonsDisabilities/Documents/Briefing%20Note.pdf>.

# Chapter 9: Working in partnership with civil society: 'Nothing about us without us'

## KEY QUESTION

- How can and should NHRIs partner with, and actively involve, civil society to maximise their impact?



## 9.1. THE LEGAL OBLIGATION OF NHRIs TO INVOLVE AND ENABLE THE FULL PARTICIPATION OF CIVIL SOCIETY

NHRI engagement with civil society is not just a matter of good practice to enhance impact. It is legally required by article 33(3) of the UN CRPD, and implied by article 4(3).

Article 33(3) states clearly that:

[C]ivil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.

On first reading, this would seem to confine civil society engagement to the 'monitoring' tasks of the framework and the independent mechanism. But a broader reading, consistent with the spirit of both article 33 and article 4(3), would suggest that such engagement should be with respect to *all* of the core tasks of the framework and NHRIs under article 33. In other words, it extends beyond monitoring to also include promotion and protection activities.

Different levels or lines of engagement can be broadly categorised as follows:

- **Co-production:** What can civil society and NHRIs do together and how can it be done in an equal, reciprocal and impactful relationship?
- **Involvement:** Can civil society identify worthwhile activities of the NHRI that would address real issues?
- **Mutual convening power:** How can NHRIs provide a neutral platform for civil society and how can both attract difficult-to-reach disability groups and broader allies for change?
- **Consultation:** What does civil society think about the NHRI's proposed actions or draft position?

While it is critical that NHRIs inform and consult persons with disabilities and their representative organisations about their plans, actions and positions, this approach alone is unlikely to satisfy the requirements of the UN CRPD. It is clear that the Convention proposes a deeper model of involvement and participation, one which embodies the paradigm shift whereby persons with disabilities are no longer regarded as 'objects' and can instead participate fully as equal citizens.

NHRIs should therefore seek to ensure – both in the context of their own activities and more widely – that persons with disabilities and their representative organisations play an active, ongoing and influential role to implement and monitor the operation of the Convention at both the domestic and international level. This level of engagement may be new or unfamiliar to NHRIs. However, it is no longer an option but a legal requirement.

## 9.2. THE MUTUAL BENEFIT OF INVOLVING PERSONS WITH DISABILITIES

In addition to ensuring compliance with the UN CRPD and, where they exist, national laws, deeper partnerships have the potential to provide many benefits for both civil society and NHRIs.

**Achieving better impact.** Working with and through networks of persons with disabilities will help NHRIs to amplify their impact; for example through disabled persons' organisations (DPOs) citing the policy positions of NHRIs in their own advocacy, or as a vehicle for reaching marginalised persons with disabilities with information about their rights and the support available from the NHRI.

**Civil society engagement enables synergies to be achieved.** Involving persons with disabilities will help NHRIs ensure that they are focusing their efforts and resources on the issues that matters most. Work on both sides can and should be complementary, allowing NHRIs to focus on critical inputs to important debates.

**Civil society as a source of insight, intelligence, expertise and understanding for NHRIs.** Persons with disabilities are the experts regarding their own lives and, as such, offer invaluable insight, intelligence and expertise in identifying emerging issues and priorities and in generating solutions that work.

As Bokankatla Joseph Malatji, Commissioner for Disability Rights at the South African Human Rights Commission said during a side event at the 2014 Conference of States Parties:

I refer to disabled persons' organizations as the foot soldiers of the NHRI. Without DPOs, we would not know much. The DPOs, I believe, are in touch with reality. DPOs are in touch with people in grass-roots organizations. It is only through them that the NHRIs are updated and know where there are violations. They know where they must improve, where they must monitor.

**Civil society engagement enhances the legitimacy and credibility of NHRIs.** NHRIs will struggle to establish the moral authority and credibility necessary to call others to account for their compliance with the UN CRPD unless they themselves are, and are seen to be, a model of best practice in relation to the involvement and full participation of persons with disabilities.

**Civil society engagement increases the profile and voice of NHRIs in disability policy debates.** Many persons with disabilities and their representative organisations may have little awareness of the NHRI or the role it could play in advancing their rights. Involvement provides a way to promote awareness and is particularly important for NHRIs that provide assistance to individuals through, for example, advice and information, complaints handling or strategic litigation.

**Better working relationship with persons with disabilities.** By working closely with persons with disabilities to identify priorities and deliver activities, NHRIs are likely to enjoy more positive and productive working relationships with persons with disabilities.

### 9.3. PRACTICAL STRATEGIES TO ENGAGE CIVIL SOCIETY

There are a wide variety of ways that NHRIs can involve persons with disabilities in their operations and work programs. The default position should always be to view civil society as full and equal partners. Short of that, there are still many ways that NHRIs can engage people with disabilities and their representative organisations for mutual benefit.

**As equal partners:** NHRIs should regard organisations of persons with disabilities as potential partners and explore opportunities for formal collaboration and mutual support. For example, there are significant benefits when NHRIs and DPOs work together to gather evidence and identify priorities for the purpose of making submissions to treaty monitoring bodies ahead of the State party review. NHRIs and DPOs might also establish mutual capacity building arrangements, such as DPOs providing training for NHRI staff on disability equality in return for training from NHRIs on domestic and international law and the international human rights system.

**As Commissioners:** In a number of countries, persons with disabilities have been appointed to NHRIs as the lead Commissioner on the rights of persons with disabilities.

- In **Britain**, the founding statute of the Equality and Human Rights Commission requires there to be at least one Commissioner who is or has been a person with a disability.
- In **Australia**, the founding statute of the Australian Human Rights Commission requires there to be a Disability Rights Commissioner.
- In **New Zealand**, the first Commissioner with formal responsibility for disability rights was appointed to the New Zealand Human Rights Commission in September 2011.
- In **Denmark**, the founding statute of the Danish Institute for Human Rights was amended in 2013 to require that the Board of the Institute should have a member nominated by organisations of persons with disabilities.



**As staff:** Whether NHRIs strive to promote, protect and monitor implementation of the rights of persons with disabilities through a dedicated unit or team, through building the capacity of the organisation as a whole or by using a mixed approach, they should strive to hire more suitably qualified persons with disabilities. For example, the Sierra Leone Human Rights Commission specifically recruited a person with a disability, involved in disability rights advocacy, to the post of Different Abilities and Non-Discrimination Officer to lead its work on the UN CRPD. NHRIs could also recruit people with disabilities as interns, providing them with valuable experience that they can use in their future careers.

**As members of standing or *ad hoc* committees and advisory groups:** NHRIs should consider the establishment of standing committees, *ad hoc* committees and advisory groups of persons with disabilities as a way to ensuring their close involvement in the work of the NHRI. For example:

- The Equality Act 2006 includes provision for a statutory Disability Committee to advise the British Equality and Human Rights Commission. At least half of the Committee's members and the Chairperson must be a person who is or has been a person with a disability.<sup>253</sup>

<sup>253</sup> Further information is available at [www.equalityhumanrights.com/about-us/about-commission/commissioners/disability-committee](http://www.equalityhumanrights.com/about-us/about-commission/commissioners/disability-committee); see also Equality Act 2006 (United Kingdom) Schedule 1, part 5, s. 49; available at [www.legislation.gov.uk/ukpga/2006/3/pdfs/ukpga\\_20060003\\_en.pdf](http://www.legislation.gov.uk/ukpga/2006/3/pdfs/ukpga_20060003_en.pdf).

- The South African Human Rights Commissioner for disability rights has established a committee consisting of DPOs which advises that office in respect of disabilities and any issue regarding the promotion, protection and implementation of the Convention.

**As active participants in research, inquiries and investigations:** NHRIs should actively involve persons with disabilities in the design of research, inquiries and investigations. This could include developing participatory research methodologies, employing persons with disabilities as investigators, calling persons with disabilities as witnesses or inviting persons with disabilities to sit on expert inquiry panels or on advisory groups.

**As monitors:** Persons with disabilities should be actively involved in specific activities of monitoring, including the design of indicators and monitoring frameworks, gathering evidence, identifying priorities and reporting to national parliaments and human rights treaty monitoring bodies.

**As 'preferred contractors':** NHRIs should consider adopting a policy whereby any contracts concerning the rights of persons with disabilities that are outsourced – such as research, consultation exercises or the elaboration of policy positions – give preference to consultants with direct personal experience of disability, alongside other relevant qualifications and experience.

**As beneficiaries of capacity building and funding:** Where NHRIs offer capacity building services or make grants or otherwise provide funding to third parties, they should strive to direct this support towards disabled persons' organisations.



The Commission talks with parents, teachers and students as part of its study on improving access to education for children with learning disabilities. Photo by the Human Rights Commission of Malaysia

## 9.4. KEY CONSIDERATIONS WHEN PLANNING TO INVOLVE PERSONS WITH DISABILITIES

The deep level of engagement that article 33(3) envisages requires forethought on the part of NHRIs. The following are some of the factors that NHRIs might need to consider when planning their engagement with civil society.

**Balancing involvement with maintaining independence:** Some NHRIs have expressed concern about the impact of involving persons with disabilities on their 'de facto' independence, as required by the Paris Principles. However, others suggest that such involvement helps NHRIs to maintain their independence, in particular from government. Perceptions of a lack of independence, or more accurately, a surrender of independence because of the presence of civil society might, in the eyes of some, taint any recommendations for change that emerge from the partnership. There is no inherent necessity why this should be so.

Setting out clear terms of reference in advance in relation to any mode of involvement will help NHRIs manage the expectations of persons with disabilities and their representative organisations, as well as allow NHRIs to demonstrate to others that such involvement is not compromising their independence.

**Preferring organisations 'of' persons with disabilities as against organisations 'for' persons with disabilities:** In many countries, persons with disabilities have historically been the object of charitable organisations and NGOs 'for' persons with disabilities. These groups have frequently spoken on behalf of persons with disabilities without their consent. Many such organisations have sought to reform their own approaches, increasing the degree to which persons with disabilities are involved in their governance and the delivery of their services. NHRIs will likely find themselves engaging with these organisations. Nevertheless, NHRIs should always prioritise engagement with organisations 'of' persons with disabilities; that is, organisations led and run by persons with disabilities.

**Reaching out to hidden voices:** As noted in Part I of this Manual, the term 'persons with disabilities' encompasses a large and highly diverse section of the population, both in terms of the nature of people's impairments and health conditions, their age, gender, ethnicity, socioeconomic status and other characteristics, and the particular circumstances, barriers and human rights risks they face.

NHRIs should strive to reach out to the widest possible community of persons with disabilities, both directly and through their representative organisations, if they exist. There are many 'hidden voices' in the broad disability community. Strenuous efforts should be made by NHRIs to reach out and include these voices. These include persons with psychosocial or intellectual disabilities confined to institutions, disabled prisoners, people who are 'non-verbal,' people who are 'hidden' within their communities, children with disabilities, those living in rural communities, and persons with disabilities in minority ethnic and indigenous communities. NHRIs should take concrete steps to ensure that the voices of this broad range of persons with disabilities are heard. This may require the NHRI to commission expert support, including from organisations of persons with disabilities.

**Maintaining 'open channels' to the broader community:** The modes of involvement developed by the NHRI must be accessible to all persons with disabilities. For example, information should be available in alternative formats; presentations should be delivered in an accessible way, mindful both of people with sight impairments and intellectual disabilities; provision should be made for people who use hearing aids or sign language; and meetings should be held in accessible venues with accessible transport links.

If technology is available and reliable, web-conferencing and web-casting can be powerful ways to involve persons with disabilities who might otherwise be unable to travel to meetings. It is also a particularly useful way to reach people in isolated areas. NHRIs should consider how to offer 'open channels' of communication for persons with disabilities who may live in situations of vulnerability, such as psychiatric or social care institutions, or with abusive partners or family members, and who will not be in a position to participate in more formal processes.

For example, this could involve offering a confidential telephone number, email address or text-messaging service, or by establishing a system of ‘third party reporting’ where persons with disabilities can report their experiences and concerns to recognised advocates who pass this information onto the NHRI.

**Remuneration, expenses and recognition:** Persons with disabilities should not be expected to provide their advice and expertise for free or to bear the costs of doing so. NHRIs should at the very least cover reasonable expenses incurred by persons with disabilities. Where persons with disabilities are involved with the NHRI on an ongoing basis, such as on an advisory committee, the NHRI should consider remunerating them for their time (while being mindful of the impact such payment may have on any social security entitlements). NHRIs should also consider other forms of recognition which may be of assistance to persons with disabilities in relation to, for example, securing employment, such as endorsements.

**Referrals to support and counselling:** NHRIs should establish referral mechanisms to support and counselling, as appropriate, for persons with disabilities. The latter may be particularly important when NHRIs are engaging with victims of human rights violations, such as violence, abuse and mistreatment, disability hate crime or discrimination and harassment. For example, NHRIs might establish referral arrangements with organisations supporting children with disabilities, women fleeing violence or organisations supporting people with psychosocial disabilities.

**Respecting privacy and confidentiality:** NHRIs should give careful attention to matters of privacy and confidentiality when seeking or benefiting from the involvement of persons with disabilities. Monitoring the human rights of persons with disabilities will often involve reviewing highly sensitive personal information and NHRIs must ensure that this is not revealed to third parties without the informed consent of the individuals concerned. The opportunity to provide information anonymously may be the only way some persons with disabilities – in particular, those who are most at risk of human rights violations – will be prepared to engage with the NHRI.

**Guarding against reprisals:** In 2013, the United Nations Human Rights Council expressed concern at:

...the continued reports of intimidation and reprisals against individuals and groups who seek to cooperate or have cooperated with the United Nations, its representatives and mechanisms in the field of human rights, and at the seriousness of reported reprisals, including violations of the right of the victim to life, liberty and security of person, and violations of obligations under international law prohibiting torture and cruel, inhuman or degrading treatment.<sup>254</sup>

Where NHRIs are seeking to involve persons with disabilities who are in situations of vulnerability, such as people confined to institutions, a clear protocol is required to mitigate against the risk of reprisals and to act swiftly if evidence of reprisals emerges as a consequence of their involvement with the NHRI.

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254 A/HRC/24/29.

# Chapter 10: Leading by example: Eliminating discrimination and ensuring accessibility in the work of NHRIs

## KEY QUESTION

- What practical steps can NHRIs take to identify and end discriminatory practices and ensure accessibility in the way they operate?



## 10.1. THE IMPORTANCE OF NHRIs LEADING BY EXAMPLE

Good practice alone would suggest that NHRIs should aim to be role models in the way they treat people with disability. Doing so significantly enhances the credibility and legitimacy of NHRIs in the broader world where harsh truths may need to be brought to light. Moreover, NHRIs themselves have clear legal duties arising from the Convention and, in some countries from national laws, to refrain from discriminating against persons with disabilities, including the denial of ‘reasonable accommodation’ and an affirmative duty to be accessible.

The question of non-discrimination and accessibility relate to all levels and all dimensions of the NHRI’s activities and operations:

- Organisational ethos and culture
- Awareness, attitudes and behaviours of staff and Commissioners
- Physical accessibility
- Governance
- Employment
- Services that are delivered to the public
- Involvement and consultation with external stakeholders
- Information and communication
- Procurement.

## 10.2. NHRI CHECKLIST FOR ELIMINATING DISCRIMINATION AND ENSURING ACCESSIBILITY

To achieve exemplary practice in accessibility for persons with disabilities, NHRIs should:

- Conduct a baseline review of their current operations
- Develop and implement an action plan with a timeline and statement of what resources are to be devoted and a review/monitoring mechanism
- Periodically review the plan, especially with regards to feedback received from persons with disabilities
- Actively involved persons with disabilities, including staff and those external to the organisation, at all stages of this process.

NHRIs should also consider engaging, as consultants, persons or organisations with specific technical expertise in different aspects of this process. In particular, specialist advice with respect to physical access to the premises where NHRIs operate is critical. Similarly, specialist advice regarding policy and practice on accessible information and communication, including website accessibility, can prevent NHRIs from instituting poor or substandard practices, as well as help generate imaginative and affordable solutions.

### ACCESS AUDITING

In 2012, the **National Human Rights Commission of Mexico**, through its General Directorate of Attention to Disability, working with Libre Acceso AC – a Mexican disability organisation promoting and advising on accessibility – conducted an accessibility audit of each of its regional offices to enhance ease of access and internal movement of persons with disabilities within the facilities.<sup>255</sup>

### ACCESSIBLE INFORMATION

The **Danish Institute for Human Rights** has created an internal strategy for accessibility that covers events, websites, publications and other documents.<sup>256</sup> It has also co-produced information on the UN CRPD, including videos, in partnership with organisations of persons with disabilities. All the videos include sub-titles and audio descriptions for persons with visual impairments. In addition, the text relating to a number of, but not all, articles in the Convention has been sign-language interpreted. Another section provides information with pictures and ‘easy to read’ text to persons with intellectual disabilities.

In 2013, the **Uganda Human Rights Commission** produced its Annual Report in Braille for people with visual impairment.



255 Further information is available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

256 Available at [www.humanrights.dk/sites/humanrights.dk/files/strategies/tilgaengelighedsstrategi\\_2014\\_uk.pdf](http://www.humanrights.dk/sites/humanrights.dk/files/strategies/tilgaengelighedsstrategi_2014_uk.pdf).

## CHECKLIST

Issue or area	Key questions
<b>Organisational ethos and values</b>	Has our organisation made a clear statement regarding its commitment to respect the rights of persons with disabilities? Have we thought about the values and behaviours that ensure that we will meet this commitment in practice? Do we have processes in place to measure whether we are living up to our ethos and values (such as staff and customer surveys, reviewing complaints)?
<b>The awareness, attitudes and behaviours of staff and Commissioners</b>	<p>Have our staff and commissioners received disability equality training?</p> <p>Do our staff understand the concepts of reasonable accommodation and accessibility and are they supported to apply them in their work?</p>
<b>Physical access</b>	<p>Are the premises from which we operate physically accessible to existing or potential staff and to visitors with physical, sensory, intellectual or mental impairments?</p> <p>Can persons with disabilities get to our premises using public transportation? Do we have car parking spaces designated for car users with disabilities?</p> <p>If our premises are not presently accessible, have we identified other ways to employ, engage with or provide services to persons with disabilities?</p>
<b>Accessible information and communication</b>	<p>Do we provide our information in alternative formats including large print, audio, Braille and 'easy to read'?</p> <p>Can persons with disabilities access and navigate our website and read our emails?</p> <p>Can we readily communicate with people who use sign language or people whose language is non-verbal?</p> <p>Do we have viable alternatives to communicate with people who do not use the telephone?</p>
<b>Governance</b>	Do or can our governance processes enable the full participation of persons with disabilities? For example, where meetings are held, the organisation of agendas and paperwork.
<b>Employment</b>	<p>Are we confident of non-discriminatory practice in the way we design job roles and descriptions, recruit, develop and retain staff and in our day-to-day employment practices?</p> <p>Do we consistently offer reasonable accommodation?</p> <p>Have we considered taking steps to increase the representation and career development of persons with disabilities in our workforce?</p>

Issue or area	Key questions
<p><b>Providing advice, handling complaints and providing assistance to individuals</b></p>	<p>How do we ensure non-discrimination and equality of access in the way we provide advice, handle complaints and provide assistance to individuals?</p> <p>With respect to handling complaints and providing assistance to individuals with intellectual or psycho-social disabilities in courts and tribunals, how do we address matters concerning the perceived competence, capacity, credibility, and reliability of witnesses? What action do we take to ensure witnesses with disabilities can withstand the court or tribunal process?</p>
<p><b>Involvement and consultation</b></p>	<p>Can persons with disabilities participate fully in consultations and activities to involve stakeholders, such as meetings, seminars and conferences?</p> <p>Can persons with disabilities report human rights violations to us without experiencing barriers?</p> <p>Do we undertake outreach to ensure we hear from the most marginalised persons with disabilities, such as those confined to institutions and those whose communication is non-verbal?</p>
<p><b>Complaints</b></p>	<p>Is our complaints procedure accessible to persons with disabilities? For example, can people make complaints via a range of media or do we insist on some complaints being in writing? Do we respond to complaints in a manner that is accessible to persons with disabilities?</p>
<p><b>Research, investigations and inquiries</b></p>	<p>When we carry out research, investigations and inquiries that include engaging with and involving individuals, are we confident that our methodologies are accessible and appropriate for persons with disabilities? For example, public polling, focus groups, participatory research, seeking witness statements and holding hearings.</p>
<p><b>Procurement and contracting</b></p>	<p>Can persons with disabilities and their representative organisations bid for tenders and carry out contracts on our behalf without experiencing barriers or disadvantages?</p> <p>Do we promote the rights of persons with disabilities via procurement and contracting? For example by demanding that contractors ensure non-discriminatory practices and accessibility.</p>

## Section II NHRI engagement on disability: Promising practice



**Chapter 11:** Promoting implementation of the rights of person with disabilities

**Chapter 12:** Protecting the rights of persons with disabilities

**Chapter 13:** Monitoring implementation of the rights of persons with disabilities

# Chapter 11:

## Promoting implementation of the rights of persons with disabilities

### KEY QUESTION

- What practical steps can NHRIs take to promote the rights of persons with disabilities?



### 11.1. ADOPTING A CLEAR STRATEGY ON PROMOTION

Since the paradigm shift from the ‘medical model’ to the ‘social model’ and onwards to the ‘human rights model’ of disability is still at an early stage in most parts of the world, the task of promoting the rights of persons with disabilities is particularly important.

As recommended earlier in Part III, NHRIs should develop a strategic approach to promoting implementation of the UN CRPD. Not everything can be done at once. Factors to consider when deciding what to focus on and the approach to take include:

- The priorities identified by persons with disabilities and their representative organisations through involvement and consultation
- Evidence of grave and systemic violations of the human rights of persons with disabilities, including the failure of States to take action to realise economic, social and cultural rights
- Areas of policy or legal non-compliance with international human rights law and standards, including the Convention
- What other agencies and organisations are or could/should be doing and whether the NHRI has a unique contribution to make either working alone, by providing assistance or collaborating with others, or through monitoring and enforcing action
- The powers available to the NHRI and where these are likely to be most effective in achieving change
- The resources available to the NHRI.

A ‘one size fits all’ approach is unlikely to be successful in generating sustained change and different strategies will be needed in relation to different issues, different sectors and institutions. For example, influencing the practices of business requires different strategies, tools and approaches to influencing the practices of government and public bodies.

Action and activities that NHRIs can take with respect to promoting implementation of the rights of persons with disabilities include:

- Raising awareness among persons with disabilities and among duty-bearers
- Promoting ratification of the Convention
- Leading and participating in the elaboration of action plans
- Assessing and advising on compliance of existing or proposed national legislation, regulation and practices
- Providing technical advice to government, public authorities and other agencies
- Building the capacity of civil society to promote, protect and monitor implementation of the Convention.

### A STRATEGIC APPROACH TO PROMOTION

To define its approach, the **Tanzanian Commission for Human Rights and Good Governance** undertook a mini-survey in December 2009 to gauge understanding of the rights of persons with disabilities among key stakeholders. This included evaluating levels of public awareness regarding the situation of persons with disabilities and the preparedness of key players in the legal and administrative landscape shaping Tanzanian law and policy on disability. The ultimate objective of the survey was to identify the most appropriate and effective role for Commission to play.<sup>257</sup>



## 11.2. PREPARING AND ADOPTING AN ACTION PLAN

Action planning can be a helpful way to identify the steps necessary to implement the rights of persons with disabilities, to set goals, measure progress and ensure accountability. It can include action to reform law and policy, to change practices and include desired changes in outcomes. It is important that action plans are linked to monitoring and measurement tools and programs.

A number of States have developed disability action plans to implement their obligations under the Convention and NHRIs have participated in the development of these plans. In other States, the rights of persons with disabilities have been addressed as part of national human rights plans, the development of which is sometimes led by NHRIs. There are also examples of NHRIs elaborating action plans to address specific human rights concerns and negotiating commitments from key actors.

It is critical that persons with disabilities are closely involved in the development of these plans and that the plans genuinely act as a program of action, including firm milestones and measures.

257 Information provided by the Network of African National Human Rights Institutions for the preparation of this Manual.

## NATIONAL DISABILITY ACTION PLANS

A number of countries have developed national disability action plans. The **Australian Human Rights Commission** engaged with its government in the development of the Australian Disability Action Plan. It welcomed the initiative overall and, in particular, its grounding in the UN CRPD. However, the Commission also offered extensive recommendations to enhance the Action Plan.<sup>258</sup>

## THE RIGHTS OF PERSONS WITH DISABILITIES IN THE CONTEXT OF NATIONAL HUMAN RIGHTS PLANS

The **Scottish Human Rights Commission** has led the development of a National Action Plan for Human Rights in Scotland which includes a series of actions concerning the rights of persons with disabilities. These actions relate to health inequalities, social care practices, autonomy and independent living, transportation and the affordability of pursuing legal redress.<sup>259</sup>



## ACTION PLANS REGARDING SPECIFIC ISSUES

Some NHRIs have developed action plans concerning specific issues. Following its 2009–10 inquiry into disability-related harassment, **Britain's Equality and Human Rights Commission** produced a manifesto – *Out in the open* – in 2011, which brought together all of the formal responses from government and other agencies with the Commission's final recommendations. The Commission has published updates in 2012 and 2012 concerning the progress being made.<sup>260</sup>

## 11.3. PROMOTING RATIFICATION OF THE UN CRPD

NHRIs can and should engage on disability issues regardless of whether their State has ratified the UN CRPD. But ratification gives focus to these activities. A survey in 2011 found that States with accredited NHRIs are almost 25 per cent more likely to have signed and ratified the Convention than are States that do not have an accredited NHRI.<sup>261</sup>

There are a number of ways that NHRIs can seek to influence States to sign and ratify the Convention and its Optional Protocol, including:

- Publishing reports on the situation of persons with disabilities (highlighting deficiencies and pointing to the Convention as a key tool for advancing change).
- Engaging with the parliament on disability issues (see text box below).
- Creatively harness the regional and international human rights system to highlight the situation of persons with disabilities in the context of other regional or international human rights law, such as the Convention against Torture, the International Covenant on Economic, Social and Cultural Rights or through the Universal Periodic Review.

258 The submission of the Australian Human Rights Commission on the National Disability Strategy (November 2008) is available at [www.humanrights.gov.au/publications/national-disability-strategy-australian-human-rights-commission-submission](http://www.humanrights.gov.au/publications/national-disability-strategy-australian-human-rights-commission-submission).

259 The Scottish National Action Plan for Human Rights (December 2010) is available at [www.scottishhumanrights.com/scotlands-national-action-plan/](http://www.scottishhumanrights.com/scotlands-national-action-plan/).

260 Available at [www.equalityhumanrights.com/legal-and-policy/our-legal-work/inquiries-and-assessments/inquiry-disability-related-harassment/recommendations](http://www.equalityhumanrights.com/legal-and-policy/our-legal-work/inquiries-and-assessments/inquiry-disability-related-harassment/recommendations).

261 Global Alliance of National Human Rights Institutions, 'Survey of National Human Rights Institutions on Article 33.2 of the Convention on the Rights of Persons with Disabilities'; available at <http://nhri.ohchr.org/EN/Themes/PersonsDisabilities/DocumentsPage/SurveyReport33.2.pdf>.

## **GUIDANCE FOR PARLIAMENTARIANS ON PROMOTING RATIFICATION OF THE CONVENTION**

The following guidance for parliamentarians was produced by UN Enable. NHRIs can play a key role in encouraging and supporting parliamentarians to pursue these actions, as appropriate:

Check whether your Government has the intention of signing and ratifying the Convention and the Optional Protocol. If not, use parliamentary procedure to determine the reasons for such inaction and encourage the Government to start the signing and ratification process without delay. For example, put an oral or written question to your Government to determine its intention to ratify or the reasons for any Government inaction. Consider your right to submit a private member's bill on the matter. Encourage parliamentary debate on the question. Mobilize public opinion through public-awareness campaigns and disseminate information promoting ratification of the Convention and Optional Protocol. If a signing procedure is underway, check whether the Government intends to make reservations to the Convention or Optional Protocol and, if so, determine whether the reservations are necessary and compatible with the object and purpose of the Convention or Optional Protocol. If you conclude that they are groundless, take action to ensure that the Government reverses its position. If ratification has taken place, check whether any reservations made by your Government are in force and whether they are still necessary. If you conclude that they are not, take action for their withdrawal. Make sure that public officials, State agents and the general public are aware that the State has ratified or acceded to the Convention and Optional Protocol. If your country has ratified or acceded to the Convention but has not yet ratified the Optional Protocol, determine why this is the case and take action to ensure that obstacles to ratifying the Optional Protocol are removed or remedied and encourage prompt ratification of the Optional Protocol.<sup>262</sup>



## **11.4. PROMOTING AWARENESS OF THE RIGHTS OF PERSONS WITH DISABILITIES**

The obligation to promote awareness of the rights of persons with disabilities, as set out in article 8 of the UN CRPD, ultimately falls to States parties. However, the Paris Principles also require NHRIs to include within their mandate powers to:

... publicize human rights and efforts to combat all forms of discrimination, in particular racial discrimination, by increasing public awareness, especially through information and education and by making use of all press organs.<sup>263</sup>

In a number of States, promoting awareness, understanding and support for human rights are tasks that have been formally assigned to NHRIs through their founding legislation. Even where this is not the case, raising awareness and improving understanding of the rights of persons with disabilities is instrumental to promoting implementation of the Convention, including promoting the development of a viable and active framework under article 33(2). An excellent – pre-Convention example – is the 2005 Disability Manual of the National Human Rights Commission of India.

262 OHCHR and Inter-Parliamentary Union, *From Exclusion to Equality. Realising the Rights of Persons with Disabilities: Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities and its Optional Protocol*, 2007; available at [www.un.org/disabilities/documents/toolaction/ipuhb.pdf](http://www.un.org/disabilities/documents/toolaction/ipuhb.pdf).

263 General Assembly resolution 48/134 3(g); available at [www.asiapacificforum.net/resources/paris-principles/](http://www.asiapacificforum.net/resources/paris-principles/).

Further, the obligation on NHRIs to involve persons with disabilities in their own work and to contribute to ensuring the involvement and full participation of persons with disabilities and their representative organisations in monitoring implementation of the Convention also presents a clear need for action to raise awareness and promote understanding.

There are a number of issues to consider when promoting the rights of persons with disabilities,

**Capture people's attention and imagination:** Think about how to inspire and engage audiences through the use of case studies and examples which show how a human rights-based approach to disability has enabled people to secure justice, transformed their lives or improved the delivery of services. It is important to ground human rights and the UN CRPD in everyday situations, using real life examples.

**Know your audience:** Who are you trying to reach? Who are they already in contact with? Who are they most likely to pay attention to? Can you work with these organisations? How does your target audience self-identify and how is this reflected in your messages and language?

**Using accessible language, formats and modes of communication:** Can all persons with disabilities access the materials that you plan to produce, whether written or audio-visual? Do they make sense to people who are unfamiliar with human rights language and concepts?

**Focus on what it is useful for people to know:** Most people do not need to know all the details of the UN CRPD. Consider how to provide guidance on the specific implications or opportunities presented by the Convention – and related domestic laws, policy and practice – in relation to issues that concern them, such as the rights of people with mental health problems, accessible transportation or the right to vote.



Representatives from the National Human Rights Commission of Nepal and civil society organisations collaborate at a training initiative on human rights and mental health. Photo by the National Human Rights Commission of Nepal

## RAISING AWARENESS AND PROMOTING UNDERSTANDING OF THE RIGHTS OF PERSONS WITH DISABILITIES

- In 2010, the **British Equality and Human Rights Commission** published and disseminated a guide for persons with disabilities and their representative organisations: *The United Nations Convention on the Rights of Persons with Disabilities: What does it mean for you*<sup>264</sup>. The publication was prepared on behalf of the Commission by a disabled persons' organisation, Disability Rights UK.
- The **Scottish Human Rights Commission**<sup>265</sup> and the **Danish Institute for Human Rights**<sup>266</sup> have both produced short animated films to introduce persons with disabilities to the Convention.
- The **Scottish Human Rights Commission** in collaboration with the **British Equality and Human Rights Commission** has delivered a program of events to promote awareness and understanding among persons with disabilities and their representative organisations, including a general awareness-raising and involvement event about the Convention, followed by a series of online 'webinars' in 2012 covering issues identified by persons with disabilities in the initial awareness raising session, such as disability rights in a recession; access to justice; independent living; and the rights of children with disabilities. In 2012, the Commission hosted a participation event on the Convention and mental health with mental health service users.<sup>267</sup>
- The General Directorate to the Attention of Disability of the **National Human Rights Commission of Mexico** has carried out an extensive program of awareness-raising. Between being established in 2011 and 2013, it held 363 promotional events, trained 45,356 people and held 569 meetings with civil society organizations, public servants and local human rights organisations. It also produced a variety of information materials targeting persons with disabilities, including *We Have Human Rights: A Human Rights Handbook for People with Developmental Disabilities* and an 'easy to read' version of the Convention.<sup>268</sup>
- The **National Commission for Human Rights of Rwanda** has organised training workshops on the rights of persons with disabilities targeting persons with disabilities, public officials and the wider population and plans to develop a teaching module on the rights of persons with disabilities.<sup>269</sup>
- The **Ugandan Human Rights Commission** worked in partnership with the **Australian Human Rights Commission** to organise a joint Workshop on Rights of People with Disabilities for NHRIs and disabled persons' organisations on the theme 'Working Together to Promote and Protect the Rights of People with Disability'. The workshop was designed to build the capacity of NHRIs and DPOs on how to engage effectively with each other and with government to promote and protect the rights of people with disabilities in their respective countries.



264 Available at [www.equalityhumanrights.com/publications/reading-lists/disability-reading-list](http://www.equalityhumanrights.com/publications/reading-lists/disability-reading-list).

265 Available at [www.youtube.com/watch?v=uUwHlbQFszU](http://www.youtube.com/watch?v=uUwHlbQFszU).

266 Available at [www.youtube.com/watch?v=TpgV2P\\_e3GM](http://www.youtube.com/watch?v=TpgV2P_e3GM).

267 Information supplied by the Scottish Human Rights Commission for the preparation of this Manual.

268 Further information is available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

269 Information provided by the Network of African National Human Rights Institutions for the preparation of this Manual.

Participants came from NHRIs and DPOs from six East African countries: Uganda, Tanzania, Kenya, Rwanda, Burundi and South Sudan.<sup>270</sup>

- The **New Zealand Human Rights Commission** and the Office of the Ombudsman published a guide on reasonable accommodation in 2015, as well as a variety of information materials for the private sector and persons with disabilities.<sup>271</sup>
- The **South African Human Rights Commission** authored a toolkit for the private sector called *Promoting the Right to Work of Persons with Disabilities*.<sup>272</sup>

## 11.5. PROMOTING THE RIGHTS OF PERSONS WITH DISABILITIES WHEN ASSESSING EXISTING OR PROPOSED NATIONAL LEGISLATION

Most NHRIs are experienced in assessing the compliance or human rights implications of existing or proposed national policies, legislation, regulations and practices. The proposed or existing laws may be generic across a field – for example, sanitation – but have implications for people with disabilities or specific to people with disabilities. In both cases, NHRIs have an important role to play.

It is critical that NHRIs involve persons with disabilities in this work, seeking their views on problems with existing law, policy and practice and involving them in drafting recommendations. Some NHRIs, such as the German Institute for Human Rights, have established a systematic law-screening program.<sup>273</sup> Others take a more thematic approach.<sup>274</sup>

Following is a selection of examples of NHRIs working to promote the rights of persons with disabilities on a range of themes addressed in the UN CRPD.

### Equal recognition before the law (article 12)

A number of NHRIs are developing advice on the legal and practice reforms required in their States to comply with article 12 of the Convention on equal recognition before the law. The Kenyan National Commission for Human Rights prepared a briefing paper in 2013 ('How to implement Article 12 of the CRPD regarding legal capacity in Kenya') with the support of the Open Society Foundation for East Africa.<sup>275</sup>

The Danish Institute for Human Rights has made recommendations for reform to Danish law, policy and practice regarding legal capacity,<sup>276</sup> as has the German Institute for Human Rights.<sup>277</sup>

270 Ibid.

271 Available at [www.hrc.co.nz/your-rights/people-disabilities/our-work](http://www.hrc.co.nz/your-rights/people-disabilities/our-work).

272 Available at [www.sahrc.org.za/index.php/focus-areas/disability-older-persons](http://www.sahrc.org.za/index.php/focus-areas/disability-older-persons).

273 Information about this systematic law screening program (in German) is available at [www.institut-fuer-menschenrechte.de/monitoring-stelle-un-brk/](http://www.institut-fuer-menschenrechte.de/monitoring-stelle-un-brk/).

274 For instance, see the approach of the Danish Institute for Human Rights, at [www.humanrights.dk/our-work/our-work-denmark/disability](http://www.humanrights.dk/our-work/our-work-denmark/disability).

275 Available at [www.knchr.org/Publications/ThematicReports/GroupRights.aspx](http://www.knchr.org/Publications/ThematicReports/GroupRights.aspx).

276 'Self Determination and Guardianship in Denmark'; available at <http://humanrights.dk/publications/self-determination-guardianship-denmark>.

277 'Submission of the CRPD Monitoring Body of Germany to CRPD Committee on the Rights of Persons with Disabilities on the Occasion of the Preparation of a *List of Issues* by the Committee in the Review of Germany's Initial Report in 2014'; available at [www.institut-fuer-menschenrechte.de/uploads/tx\\_commerce/Submission\\_of\\_the\\_National\\_CRPD\\_Monitoring\\_Body\\_of\\_Germany\\_to\\_the\\_CRPD\\_Committee\\_on\\_the\\_occasion\\_of\\_the\\_preparation\\_of\\_a\\_list\\_of\\_issues\\_by\\_the\\_Committee\\_in\\_the\\_review\\_of\\_Germanys\\_Initial\\_Report\\_2014.pdf](http://www.institut-fuer-menschenrechte.de/uploads/tx_commerce/Submission_of_the_National_CRPD_Monitoring_Body_of_Germany_to_the_CRPD_Committee_on_the_occasion_of_the_preparation_of_a_list_of_issues_by_the_Committee_in_the_review_of_Germanys_Initial_Report_2014.pdf).

All have recommended the repeal of laws which deprive people of their legal capacity and the replacement of systems of substitute decision-making with those modelled on supported decision making. A number have also sought reform in other areas of law, such as electoral law, to ensure that people deprived of their legal capacity are still permitted to vote in elections.

### **De-institutionalisation of people with psychosocial disabilities (article 19)**

The National Human Rights Commission of Mexico has recommended strengthening inclusive practices with respect to persons with psychosocial disabilities, including measures to discourage the establishment of centres of segregation and to promote the deinstitutionalisation process through short-term and long-term projects.<sup>278</sup>

### **Use of coercive measures in psychiatry (articles 15 and 17)**

The Danish Institute for Human Rights published a report in September 2013 with recommendations on the reduction of coercive measures in psychiatry.<sup>279</sup> Referring to case law of the European Court of Human Rights and the Convention on the Rights of Persons with Disabilities, the report recommended that restraint be shown in using coercive measures, where according to the doctors there is a need for treatment but where the person with a psycho-social disability does not pose a danger to their own person or others. It also recommended that an absolute limit be placed on the duration of immobilisation. The report noted that despite goals for reducing this practice, the use of long-term immobilisations increased between 2011 and 2012.

### **Disability-related harassment and hate crime (articles 8 and 16)**

The British Equality and Human Rights Commission conducted an inquiry into disability-related harassment and hate crime in 2009–10. The final report, *Hidden in Plain Sight*,<sup>280</sup> found that harassment is a commonplace experience among persons with disabilities but that a culture of disbelief and systemic institutional failures prevented it from being tackled effectively. As well as reporting on the extent of harassment, the report also made recommendations to public authorities to help them address the problems uncovered.

### **The right to water and sanitation (article 28)**

State parties to the UN CRPD are required to ensure equal access by persons with disabilities to clean water services and to ensure access to appropriate and affordable services, devices, and other assistance for disability-related needs. Some communities in South Africa continue to be deprived of the right to water and sanitation, which impinges on their right to a dignified life and to other rights, such as the right to education, health, safety and an environment that is not harmful to human health. It also increases the vulnerability of certain groups, including persons with disabilities. The South African Human Rights Commission has described the particular barriers facing persons with disabilities:

...sanitation developments in some communities are outdoors and inaccessible due to the small size and uneven land. Pipes in some communities for water collection can be a long distance away from homes. And taps are often at the low level, making them inaccessible to persons with disabilities. The affordability of water is also an essential element of accessibility for persons with disabilities, as they are often more marginalized and poorer than those without disabilities.<sup>281</sup>

278 Available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

279 Available at [www.humanrights.dk/publications/use-compulsory-measures-psychiatric-treatment](http://www.humanrights.dk/publications/use-compulsory-measures-psychiatric-treatment).

280 Available at [www.equalityhumanrights.com/en/publication-download/hidden-plain-sight-inquiry-disability-related-harassment](http://www.equalityhumanrights.com/en/publication-download/hidden-plain-sight-inquiry-disability-related-harassment).

281 Presentation by Bokankatla Joseph Malatji, Commissioner for Disability Rights at the South African Human Rights Commission, to a side event at the 2014 Conference of States Parties.

The Commission investigated the situation and produced its *Report on the Right to Access Sufficient Water and Decent Sanitation in South Africa: 2014*.<sup>282</sup> It identified the lack of a human rights-based approach to the delivery of water and sanitation as an underlying problem and, in particular, the absence of transparency and public participation in the delivery of basic services. It recommended a national human rights campaign to address budgets and integrated development plans and the need for the government to have meaningful consultation with communities in order to address vulnerability to violations arising from discrimination and prejudices based on race, sex, gender class, disability, age and sexual orientation, and to ensure that the voices of vulnerable groups are heard.

### **The right to inclusive education (article 24)**

The National Human Rights Commission of Mexico, highlighting the right to education and access to information, emphasised the need to ensure access to reading, learning and information for persons with disabilities, as well as the implementation of specific educational materials to ensure the inclusion of children with disabilities. As a result of this recommendation, the Mexican Government provided listening and Braille system materials to more than 78,000 students in basic education with visual impairment.<sup>283</sup>

### **Right of persons with disabilities to decent work (article 27)**

The Palestinian Independent Commission on Human Rights is conducting an inquiry into the rights of persons with disabilities to decent work. In 2013, the Commission published the findings and recommendations of a field study which found that 78 per cent of respondents were unemployed and that 57 per cent had never worked. Common to other countries, it found that people with physical disabilities had the best labour market outcomes, with a participation rate of 59 per cent, while people with mental disabilities had the lowest participation rate. The report makes extensive recommendations aimed at all sections and levels of government, employers and the voluntary sector.<sup>284</sup>

### **Right to accessibility and universal design (article 9)**

A number of NHRIs have undertaken work to promote accessibility and universal design. The National Commission for Human Rights of Rwanda, jointly with the National Council of Persons with Disabilities and other stakeholders, carried out a national accessibility audit on how the right to accessibility is respected in the country.<sup>285</sup>

In 2009, the National Human Rights Commission of Mexico – working with Arquitectos de la República Mexicana A. O. and Asociación Libre Acceso A. C. – carried out a national assessment of accessibility with a view to “to promote a culture of respect and promotion of the rights of vulnerable groups, especially people with disabilities”.<sup>286</sup>

In 2012–13, the Danish Institute for Human Rights conducted a study to assess whether Danish law meets the requirements of article 9, as well as to identify other structural barriers that hinder accessible construction.<sup>287</sup> The study made a series of recommendations including the need to focus on accessibility in Denmark’s disability action plan, to prohibit discrimination in relation to newly-built facilities, to review building regulations, to enhance the knowledge of all actors in the construction process and to enforce accessibility regulations.

282 Available at [www.sahrc.org.za/home/21/files/FINAL%204th%20Proof%204%20March%20-%20Water%20%20Sanitation%20low%20res%20\(2\).pdf](http://www.sahrc.org.za/home/21/files/FINAL%204th%20Proof%204%20March%20-%20Water%20%20Sanitation%20low%20res%20(2).pdf).

283 Further information is available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

284 Available at [www.ichr.ps/en/2/12/1165/The-Independent-Commission-for-Human-Rights-Launched-its-Field-Study-on-The-Right-of-Persons-with-Disabilities-to-Decent-Work-in-Palestine-The-Independent-Commission-for-Human-Rights-Launched-its-Field-Study-on-The-Right-of-Persons-with-Disabilities-to-Decent-Work-in-Palestine.htm](http://www.ichr.ps/en/2/12/1165/The-Independent-Commission-for-Human-Rights-Launched-its-Field-Study-on-The-Right-of-Persons-with-Disabilities-to-Decent-Work-in-Palestine-The-Independent-Commission-for-Human-Rights-Launched-its-Field-Study-on-The-Right-of-Persons-with-Disabilities-to-Decent-Work-in-Palestine.htm).

285 Information provided by the Network of African National Human Rights Institutions for the preparation of this Manual.

286 Further information is available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

287 See [www.humanrights.dk/publications/come](http://www.humanrights.dk/publications/come).

The South African Human Rights Commission plans to prioritise work on business and human rights, with a particular focus on promoting universal design. The British Equality and Human Rights Commission has worked with the business sector to advance the rights of persons with disabilities, including through the development of an online training course in 'digital accessibility' and guidance on accessible tourism, developed with Visit Britain.<sup>288</sup>

## 11.6. PROVIDING TECHNICAL ASSISTANCE TO GOVERNMENT, PUBLIC BODIES AND OTHER AGENCIES

Many NHRIs are involved in providing technical assistance to their governments, public bodies and other agencies, including regulatory bodies and business, regarding the rights of persons with disabilities. Some have established formal working relationships with regulatory bodies, such as those relating to the health and social care systems, prisons or telecommunications and the media.

**The Scottish Human Rights Commission and the British Equality and Human Rights Commission** are helping building capacity and knowledge within the Scottish Government of the Convention, ahead of the United Kingdom's examination by the CRPD Committee. The Commissions are delivering seminars for government policy leaders in relation to articles in the Convention that fall within their responsibilities.<sup>289</sup>

The **British Equality and Human Rights Commission** has established a 'memorandum of understanding' with the Care Quality Commission (CQC), the body responsible for inspecting health, social care and mental health services, including hospitals, to facilitate cooperation. The Commission worked with CQC to review its inspection criteria and to train inspectors on human rights issues and to revise the criteria regarding the registration of private and voluntary sector service providers.<sup>290</sup>



## 11.7. PROMOTION AT THE INTERNATIONAL AND REGIONAL LEVELS

NHRIs have a significant contribution to make to the development of regional and international policy guidance and standards regarding the rights of persons with disabilities.

Examples include the general comments and guidance of the CRPD Committee and those produced by other treaty bodies relating to persons with disabilities. It is important that NHRIs contribute to the relevant policy and legal debates across the broad UN system. These standards are in a constant state of evolution and the input of NHRIs is critically important in maintaining forward momentum.

Regional groupings of NHRIs should also be active at the regional level since regional instruments are also evolving and it is important to maintain the highest level of consistency with the UN CRPD. These organisations include, among others, the Council of Europe, the European Union, the Organization for Security and Cooperation in Europe, the African Human Rights Commission, the Commonwealth Secretariat and the Inter-American Commission on Human Rights.

288 See [www.visitbritain.com/gb/en/plan-your-trip/getting-around-britain/accessible-britain](http://www.visitbritain.com/gb/en/plan-your-trip/getting-around-britain/accessible-britain).

289 Information supplied by the Scottish Human Rights Commission for the preparation of this Manual.

290 Information available at [www.equalityhumanrights.com/en/care-and-support/guidance-care-quality-commission-inspectors](http://www.equalityhumanrights.com/en/care-and-support/guidance-care-quality-commission-inspectors).

Several NHRIs contributed to the development of the CRPD Committee's General Comment on article 12 on equal recognition before the law, attending the 'days of discussion' in Geneva and submitting formal responses. They included the **Australian Human Rights Commission**, the **Danish Institute for Human Rights**, the **Netherlands Institute for Human Rights**, the **Scottish Human Rights Commission**, the **British Equality and Human Rights Commission**, the **Northern Ireland Human Rights Commission** and the **Finnish Human Rights Centre**.<sup>291</sup>



<sup>291</sup> For more information on the development of draft general comments, including submissions, see [www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx](http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticles12And9.aspx).

# Chapter 12: Protecting the rights of persons with disabilities

## KEY QUESTION

- What practical steps can NHRIs take to protect the rights of persons with disabilities?



## 12.1. PROTECTING BY PREVENTING: PREVENTIVE ACTION TO AVOID THREATS TO RIGHTS

Protection involves a continuum of actions intended to either avoid violations or provide a remedy for violations. Preventive action that anticipates potential threats to the rights of persons with disabilities and seeks to avoid them can include:

- Seeking to ensure that advocacy is available to persons with disabilities in community settings and places of detention, such as prisons, psychiatric departments, children's homes and social care institutions
- Conducting inspections, inquiries and investigations
- Using legal powers, such as judicial review or constitutional litigation, to challenge discriminatory policies or decisions
- Ensuring regulatory and inspection bodies – in relation to areas such as prisons, psychiatric facilities, social care and schools – are attentive to protecting the rights of persons with disabilities
- Promoting access to justice by building the capacity of the civil and criminal justice systems to respect, protect and promote the rights of persons with disabilities.

## CHALLENGING DISCRIMINATORY POLICIES

The **National Human Rights Commission of Mexico** has used its legal powers to challenge the constitutional compliance of policies adversely affecting the rights of persons with disabilities. It challenged the General Health Law, which employed segregationist language to refer to persons with disabilities; the Law for Persons with Disabilities in the Federal District, which did not include people with temporary impairments; and the Law of Municipal Government and Public Administration of the State of Jalisco, which permitted members of the local government to be removed from their jobs as a result of acquiring a permanent physical disability, violating the right to non-discrimination, rehabilitation and to have a reasonable adjustment in the workplace.<sup>292</sup>



292 Further information is available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

## BUILDING THE CAPACITY OF THE JUSTICE SYSTEM

The **Danish Institute for Human Rights** holds dialogue meetings with the Danish Court Administration, the Board of Equal Treatment, the Impartial Consultative Service for People with Disabilities, local legal aid institutions and other relevant institutions in relation to the protection of the human rights of persons with disabilities.<sup>293</sup>



Consultations organised by the Human Rights Commission of Malaysia with representatives of disabled persons' organisations. Photo by the Human Rights Commission of Malaysia

## 12.2. PROTECTING BY SECURING LEGAL REDRESS OR RESOLUTION FOR VIOLATIONS

Redress or resolution of human rights violations against people with disabilities can include:

- Directly handing complaints (if that is within the power of the NHRI)
- Providing assistance to persons with disabilities in domestic courts. This can be done directly by independent mechanisms, such as ombuds offices, or by providing financial assistance in cases of strategic importance that can set legal precedents; for instance, allocating funds for the provision of legal expertise or to support legal costs
- Taking legal action in the name of victims of alleged violations of the Convention on the Rights of Persons with Disabilities in domestic courts.
- Assisting persons with disabilities to introduce complaints before regional and international bodies and tribunals, including the CPRD Committee.

<sup>293</sup> Information provided by the Danish Institute for Human Rights for the preparation of this Manual.

## COMPLAINT HANDLING

The **National Human Rights Commission of Mexico** has received complaints from persons with disabilities and their advocates regarding discrimination and abuse; violations of the right to health of women with disabilities caused by pressure to practice sterilisation; denial of reasonable adjustments in the workplace; restrictions on the right of education due to the lack of infrastructure and appropriate materials to ensure learning; and the limited adoption of institutional mechanisms to ensure equal opportunities for people with pervasive developmental disorders and people with psychosocial disabilities.<sup>294</sup>

## ENCOURAGING PERSONS WITH DISABILITIES TO BRING COMPLAINTS

The **South African Human Rights Commission** facilitates annual dialogues between disabled persons' organisations and government departments. These dialogues provide a platform for DPOs to air some of the challenges that result in the denial of rights to disabled persons and to build awareness of the Commission's complaints handling system. The dialogues have, as a result, attracted a number of disability rights complaints for investigation, including the non-provision of sign language interpreters, lack of funding for centres that care for children with disabilities, lack of accurate assessment tests to determine whether a child is eligible for a disability grant, discrimination in the workplace, lack of legal representation, lack of funding for assistive devices, lack of a dedicated plan and focus for implementation of the Convention and the lack of accreditation for some special needs schools within Northwest Province.<sup>295</sup>



A number of NHRIs have a specific mandate in relation to anti-discrimination laws. It is important that such powers are used by NHRIs to effectively protect persons with disabilities from discrimination by State and non-State actors, including business and civil society organisations. This anti-discrimination mandate is very important since equality and non-discrimination are central to the human rights framing of disability and the objectives of the UN CRPD.

The **British Equality and Human Rights Commission** supported David Allen, a teenager who uses a wheelchair, to bring a case against a bank that he was unable to access as a result of the entrance being at the top of four steps. The bank had sought to discuss personal details with Mr Allen in the street outside. However, after considering the case, the Court ordered the bank to install a ramp at its entrance and Mr Allen was awarded the highest compensation yet in a case involving failure to make reasonable adjustments.<sup>296</sup>



294 Further information is available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

295 Information provided by the Network of African National Human Rights Institutions for the preparation of this Manual.

296 See [www.equalityhumanrights.com/en/legal-casework/our-legal-work-action](http://www.equalityhumanrights.com/en/legal-casework/our-legal-work-action).

## 12.3. PROTECTING BY USING POWERS OF INSPECTION, INVESTIGATION AND INQUIRY

Some NHRIs have duties and powers of inspection, investigation and inquiry. While these might also be considered to be monitoring tools, they are useful for revealing human rights violations, whether on a systemic scale or with respect to certain individuals, which is a precondition for launching specific redress procedures.

These may concern places of detention, such as psychiatric hospitals or in prison. They may also include educational establishments, such as schools, colleges and universities, or workplaces, such as sheltered factories. They may further concern the right of persons with disabilities to vote during elections, access to justice or access to services available to the wider community, such as healthcare.

Some NHRIs act as part of the national preventive mechanism under the Optional Protocol to the Convention against Torture (OPCAT), while others are linked with national inspectorate bodies; for example, the British Equality and Human Rights Commission has established a working relationship with the Care Quality Commission.

The APF has produced a manual for NHRIs on preventing torture<sup>297</sup> which provides extensive guidance on monitoring places of detention. However, it does not offer specific guidance on monitoring the situation of persons with disabilities, which may pose particular challenges in relation to interviewing ‘detainees’, patients or residents with psychosocial or intellectual disabilities. Accordingly, NHRIs may wish to refer to the ITHACA *Toolkit for Monitoring Human Rights and General Health Care in Mental Health and Social Care Institutions*.<sup>298</sup>

The UN CRPD also requires States to implement effective legislation and policies to ensure that violence, exploitation and abuse are “identified, investigated and, where appropriate, prosecuted”.<sup>299</sup> This assumes that some entity or a mix of entities – including NHRIs – have the full spread of competences to enable them do so.

### INSPECTION, INQUIRIES AND INVESTIGATIONS

- The Commissioners of the **Austrian Ombudsman Board** hold conversations with patients or dwellers in (psychiatric) institutions in a protected, non-coercive and anonymous setting. They are supported by peer-counsellors. The Commissioners also provide ‘easy to read’ leaflets about the AOB’s mandate and monitoring role and can be accompanied by interpreters and persons experienced in non-verbal and/or facilitated communication. The AOB promotes the establishment of self-advocates in institutions and has often criticised the absence of ‘anonymous complaint boxes’ and the lack of adequate complaint procedures.<sup>300</sup>



297 APF, OHCHR and the Association for the Prevention of Torture, *Preventing Torture: An Operational Manual for National Human Rights Institutions*, 2010; available at: [www.asiapacificforum.net/resources/preventing-torture-operational-manual-national-human-rights-institutions](http://www.asiapacificforum.net/resources/preventing-torture-operational-manual-national-human-rights-institutions).

298 Institutional Treatment, Human Rights and Care Assessment (ITHACA) Project, 2010; available at [www.thl.fi/documents/189940/1878598/2.4\\_Ithaca\\_Toolkit\\_English.pdf/bbd4594f-a221-48be-822a-9c5fac843454](http://www.thl.fi/documents/189940/1878598/2.4_Ithaca_Toolkit_English.pdf/bbd4594f-a221-48be-822a-9c5fac843454).

299 Article 16(5).

300 More information is available at <http://volksanwaltschaft.gv.at/en/preventive-human-rights-monitoring>.

- In 2009–10, the **British Equality and Human Rights Commission** conducted an inquiry into the responses of public agencies, including the police and prosecutors, to disability-related harassment and hate crime, which resulted in the *Hidden in Plain Sight* report.<sup>301</sup>
- The **National Human Rights Commission of Sierra Leone** and the **National Commission for Human Rights of Rwanda** have conducted monitoring of the rights of persons with disabilities during elections.<sup>302</sup>
- The **National Human Rights Commission of Mexico** conducted a ‘National Assessment of Accessibility’ to establish the accessibility status of certain facilities where the Federal Administration is allocated. It did so in partnership with the *Federación de Colegio de Arquitectos de la República Mexicana A.O.* and *Asociación Libre Acceso A.C.*<sup>303</sup>
- In 2010, the **Irish Human Rights Commission** held a major inquiry into the ‘operation of a residential and day-care centre for persons with a severe to profound disability’. Among other things, the report directly linked abuses within the institution to underlying deficiencies with respect to economic, social and cultural rights.<sup>304</sup>

## 12.4. PROTECTION AS PART OF THE WIDER PROCESS OF SYSTEMIC CHANGE

Individual complaints of human rights violations commonly reveal deep systemic problems. These are often best addressed through parallel action by NHRIs, utilising their general powers of investigation and inquiry. This broader vantage point enables NHRIs to mount the case for systemic change and thereby reduce the number of individual violations over time.

NHRIs with powers to enforce laws should strive to align the focus of their activities with other interventions, such as making recommendations for policy or legislative reform. NHRIs should also regard themselves as custodians and promoters of human rights law, providing expert submissions to courts and tribunals to inform judgments that will guide jurisprudence in relation to the rights of persons with disabilities.

### USING INDIVIDUAL COMPLAINTS TO IDENTIFY AND HIGHLIGHT SYSTEMIC PROBLEMS

During the course of its work, the **Austrian Ombudsman Board** has received numerous complaints about legal guardianship. The issues raised in the complaints have been reported to the Austrian Government, leading the Ministry of Justice to establish a working group for the reform of legal guardianship based on a model of supported decision-making.



301 Available at [www.equalityhumanrights.com/en/publication-download/hidden-plain-sight-inquiry-disability-related-harassment](http://www.equalityhumanrights.com/en/publication-download/hidden-plain-sight-inquiry-disability-related-harassment).

302 Information provided by the Network of African National Human Rights Institutions for the preparation of this Manual.

303 Further information is available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

304 The report is available at [www.ihrec.ie/download/pdf/reporte3.pdf](http://www.ihrec.ie/download/pdf/reporte3.pdf).

In 2009, the **United Kingdom's Parliamentary and Health Services Ombudsman** (which is not an NHRI) presented a report to the Parliament, *Six Lives: the provision of public services to people with learning disabilities*.<sup>305</sup> The report identified common findings that emerged from investigations into the premature deaths of six people with learning disabilities who, at the time of their deaths, were in National Health Service or local authority care, indicating that the problems identified may place others at risk. The report received widespread publicity, formal responses and action by central and local government.

### STRATEGIC LITIGATION TO PROMOTE SYSTEMIC CHANGE

The **British Equality and Human Rights Commission** supported the case of Sharon Coleman, which was heard in the European Court of Justice (ECJ).<sup>306</sup> Ms Coleman had been refused permission by a British employment tribunal to commence a claim of disability discrimination because, although she was the mother of a disabled child, she herself was not a disabled person. The ECJ found that the United Kingdom Government had failed to properly implement European Union anti-discrimination law, which required the prohibition of direct disability discrimination irrespective of whether or not the victim was disabled. British anti-discrimination law now clearly prohibits disability discrimination on grounds of association with a person with a disability or where a person is wrongly perceived to have a disability.



### PREPARING SUBMISSIONS TO THE COURTS

The **European Network of National Human Rights Institutions** collectively intervened in the case of *DD v Lithuania*, which concerned a woman with mental health problems who had been stripped of her legal capacity and confined to a social care institution. Although the European Court of Human Rights did not find that the women's human rights were breached in the act of her institutionalisation, it did find that her fair trial rights had been breached in the context of proceedings concerning the identity of her guardian.<sup>307</sup>

The **British Equality and Human Rights Commission** intervened in a Judicial Review at the United Kingdom's High Court concerning the British Government's decision to close the Independent Living Fund, a scheme dispersing funding to persons with disabilities with high support needs to enable them to live in the community. The Commission argued that a policy which adversely affects the right to live independently and to be included in the community, as protected under article 19 of the UN CRPD, was likely to breach the Government's domestic positive legal duty to both respect the rights of persons with disabilities and to advance them (provided in the *Equality Act 2010*).<sup>308</sup>

305 Available at [www.gov.uk/government/publications/six-lives-the-provision-of-public-services-to-people-with-learning-difficulties-2008-to-2009](http://www.gov.uk/government/publications/six-lives-the-provision-of-public-services-to-people-with-learning-difficulties-2008-to-2009).

306 Case C-303/06 *Coleman v. Attridge Law & Steve Law* (2008) ECJ in which the European Court of Justice determined a mother of a disabled person was protected under the provisions of Directive 2000/78.

307 More information is available at [www.ihrec.ie/european-national-human-rights-institutions-welcome-judgment-of-the-european-court-of-human-rights-on-mental-capacity-and-human-rights/](http://www.ihrec.ie/european-national-human-rights-institutions-welcome-judgment-of-the-european-court-of-human-rights-on-mental-capacity-and-human-rights/).

308 See 'Bracking and others v Secretary of State for Work and Pensions' at [www.equalityhumanrights.com/en/legal-casework/human-rights-legal-cases](http://www.equalityhumanrights.com/en/legal-casework/human-rights-legal-cases).

# Chapter 13: Monitoring implementation of the rights of persons with disabilities

## KEY QUESTION

- What practical steps can NHRIs take to monitor respect for the rights of persons with disabilities?



## 13.1. WHY MONITOR?

Promoting the rights of persons with disabilities can and should lead to better compliance. Protecting these rights can provide relief for human violations and highlight systemic failings. Monitoring provides a reality check over time.

Monitoring can perform a number of roles. It provides the basis for the development of a targeted and effective national action plan on disability. It can and should identify human rights risks and violations for the purpose of strategic planning and prioritisation. Once benchmarks have been set, especially in national action plans, they can be used to assess progress and identify obstacles to realising the rights of persons with disabilities. This also helps with the periodic adjustment and re-framing of priorities.

Such monitoring can and should inform any parallel reports that NHRIs produce for regional or international treaty monitoring bodies, including the CRPD Committee. In addition, monitoring can be a precursor to legal action and can inform *amicus curiae* submissions by NHRIs to assist courts or tribunals.

Monitoring can utilise a range of methodologies, including indicator development, policy and legislative evaluation, qualitative and quantitative research, conducting inspections, investigations and inquiries, calls for evidence and public consultation.

## 13.2. MONITORING EFFECTIVELY: DEVELOPING INDICATORS AND FRAMEWORKS TO MEASURE PROGRESS

The practice of developing human rights measurement indicators and monitoring frameworks remains in its infancy. Nevertheless, a number of interesting approaches have emerged or are in development with respect to the rights of persons with disabilities, led by NHRIs and others. For example, OHCHR has produced general guidance on human rights monitoring<sup>309</sup> that identifies structural indicators (the laws, policies in place), process indicators (how the system actually works) and outcome indicators (how individuals actually experience their rights). To do this work effectively, it is important to monitor at different levels, ensuring that appropriate legislation and policies are in place (structures) and that they are proactively implemented and monitored (processes). Moreover, it is also critical to monitor the lived experiences of persons with disabilities in order to assess the impact of policy, legislation and programs (outcomes).

309 *Human Rights Indicators: A Guide to Measurement and Implementation*, 2012; available at [www.ohchr.org/EN/Issues/Indicators/Pages/HRIndicatorsIndex.aspx](http://www.ohchr.org/EN/Issues/Indicators/Pages/HRIndicatorsIndex.aspx).

## EXAMPLE: LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY (ARTICLE 19 OF THE CONVENTION)<sup>310</sup>

ISSUE: ACCESS TO SUPPORT SERVICES		
Structural indicators	Process indicators	Outcome indicators
<p>Is there a legal provision setting out a right for persons with disabilities, irrespective of age and type of impairment, to receive community support services to live independently?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> <li>• personal assistance</li> <li>• residential</li> <li>• in-home</li> <li>• other (informal support, peer support, day care, voluntary work, etc.)</li> </ul> <p>Does the legal provision specify the scope of support services? For example:</p> <ul style="list-style-type: none"> <li>• number of hours provided</li> <li>• type of services</li> <li>• spheres of life (that is, in-home, access to leisure and cultural activities,</li> <li>• access to medical services, employment, education, etc.)</li> </ul>	<p>How much budget has been allocated, annually since 2010, for community support services to live independently?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> <li>• personal assistance</li> <li>• residential</li> <li>• in-home</li> <li>• other (informal support, peer support, day care, voluntary work etc.)?</li> </ul> <p><i>Provide information by:</i> <i>Type of support service</i></p>	<p>How many persons with disabilities were using some type of community support service to live independently, annually since 2010?</p> <p><i>Provide information by:</i> <i>Type of support service, type of impairment, level of support needs, age, gender</i></p>

310 European Union Agency for Fundamental Rights, 'Human Rights Indicators on Article 19 of the CRPD'; available at <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>.

ISSUE: ACCESS TO SUPPORT SERVICES		
Structural indicators	Process indicators	Outcome indicators
<p>Is there a legal provision setting out a right for families of children with disabilities to receive support services, irrespective of type of impairment?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> <li>• family support (counselling, respite care, early intervention)</li> <li>• residential</li> <li>• in-home</li> <li>• other (informal support, peer support, day care, etc.)</li> </ul> <p>Does the legal provision specify the scope of support services? For example:</p> <ul style="list-style-type: none"> <li>• number of hours provided</li> <li>• type of services</li> <li>• spheres of life (that is, in-home, access to leisure and cultural activities, access to medical services, employment, education, etc.)</li> </ul>	<p>How much budget has been allocated, annually since 2010, for families of children with disabilities?</p> <p>Types of support service include:</p> <ul style="list-style-type: none"> <li>• family support (counselling, respite care, early intervention)</li> <li>• residential</li> <li>• in-home</li> <li>• other (informal support, peer support, day care, etc.)</li> </ul> <p><i>Provide information by: Type of support service</i></p>	<p>How many families of children with disabilities received some type of family support services, annually since 2010?</p> <p><i>Provide information by: Type of support service, type of impairment, level of support needs, gender</i></p>
<p>Is there a legal provision setting out a right for persons with disabilities, irrespective of age and impairment, to receive personal budgets/direct payments?</p> <p>Does the legal provision setting out personal budgets/direct payments specify the scope of services that can be purchased, for example:</p> <ul style="list-style-type: none"> <li>• number of hours provided</li> <li>• type of services</li> <li>• spheres of life</li> </ul>	<p>How much budget has been allocated, annually since 2010, for personal budgets/direct payments?</p>	<p>How many persons with disabilities received personal budgets/direct payments, annually since 2010?</p> <p><i>Provide information by: type of impairment, level of support needs, gender</i></p>

With respect to collecting evidence against indicators, OHCHR recommends that this should include:

- **Evidence regarding alleged violations or denial of the human rights of persons with disabilities.** For example, this might include evidence of instances of inhuman or degrading treatment in psychiatric institutions.
- **Statistical data regarding the situation of persons with disabilities.** For example, this might include data regarding enrolment of children with disabilities in schools, or the employment rate of persons with disabilities.
- **The perceptions and opinions of persons with disabilities.** For example, polling a representative sample of persons with disabilities regarding their views on the accessibility of public transportation. Particular attention is also required to ensure that any methodologies used to measure perceptions and opinions are accessible and inclusive.
- **The combined assessments of the human rights situation of persons with disabilities conducted with the assistance of 'informed experts'.** In the context of monitoring the rights of persons with disabilities, it is critical that 'informed experts' include persons with disabilities and their representative organisations.<sup>311</sup>

In many countries, unfortunately, there is a paucity of official data concerning the rights of persons with disabilities. Speaking at a conference in October 2014, Lynne Featherstone MP, the United Kingdom's then Minister for International Development noted that:

It's a sad truth that in many developing countries people with disabilities simply don't count .... No data is collected on their disabilities nor their abilities, so it's as if they just don't exist.<sup>312</sup>

The Minister went on to argue:

As we prepare for the post-2015 development framework and the principle of 'leaving no one behind', we must be sure that everyone is accounted for. This includes the one billion-plus people living with disability. Only by having the right information from the start will we be able to do this properly.

Accordingly, article 31 of the UN CRPD places obligations on States to:

... undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention' and that 'information collected in accordance with this article shall be disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights.

The development of indicators to measure implementation of the Convention provides a powerful way to identify 'evidence gaps' and to work with government agencies, such as national statistical authorities, to begin to plug them.

Ethical considerations must be at the heart of indicator selection. OHCHR highlights three key human rights principles in relation to data-collection processes:

- **Self-identification:** People should have the option of self-identifying when confronted with a question seeking sensitive personal information related to them.
- **Participation:** All sections of the population, including vulnerable and marginalized groups, as well as human rights and other relevant institutions, to actively join in decision-making. The nature of the data to be collected should be based on public participation and understanding of the implications of how such data could potentially be used.

311 *Human Rights Indicators: A Guide to Measurement and Implementation*, 2012; available at [www.ohchr.org/EN/Issues/Indicators/Pages/HRIndicatorsIndex.aspx](http://www.ohchr.org/EN/Issues/Indicators/Pages/HRIndicatorsIndex.aspx).

312 See 'People with disabilities "don't count" in many developing countries', *The Guardian*, 23 October 2014; available at [www.theguardian.com/global-development/2014/oct/23/people-disabilities-dont-count-developing-countries-lynn-featherstone](http://www.theguardian.com/global-development/2014/oct/23/people-disabilities-dont-count-developing-countries-lynn-featherstone).

- **Privacy:** In accordance with the right to privacy set out in the International Covenant on Civil and Political Rights, the principle of data protection requires action to prevent the abuse of sensitive data.<sup>313</sup>

## GOLD INDICATORS

The **Danish Institute for Human Rights** and the **Danish National Centre for Social Research** (SFI) worked together to identify a set of ten ‘gold statistical outcome indicators’ to measure the implementation of the UN CRPD in Denmark.<sup>314</sup>

The ambition is that these gold indicators can be used to highlight the main challenges facing people with disabilities in Denmark in terms of enjoying the rights set out in the Convention. The gold indicators, however, are not intended as a guide to Denmark’s compliance with the Convention; they provide only a benchmark for assessing progress and developments. Rather, the gold indicators are intended to help initiate debate, set a political agenda and stimulate action. Accordingly, the gold indicators relate only to the outcome level and not to the issue of whether the rights in the Convention are otherwise protected by Danish law (structure or process indicators).

A Danish Steering Group was set up to ensure that there was consensus among the main stakeholders for the ten gold indicators. The steering group consisted of relevant state authorities, which varied to some extent depending on the indicator, and disability organisations. The steering group was involved in determining the purpose of the project, the method for selecting the indicators, evaluation of individual indicators and selection of those areas that the indicators should illuminate. Part of the steering group’s role was to identify the concerns and disadvantages that may arise when using selected indicators.

Criteria were developed for the selection of indicators, including indicators that can be measured against the Convention’s definition of disability; the possibility of drawing international comparisons; relevance to Convention rights and to persons with disabilities and duty bearers; whether data will be updated to track change over time; the reliability and precision of the indicator; and the ability to disaggregate data.

The project is presently national, but the long-term goal is to achieve European and, if possible, international recognition of the gold indicators so that they can be used as a basis for comparison among countries that have ratified the UN CRPD.



313 *Human Rights Indicators: A Guide to Measurement and Implementation*, 2012; available at [www.ohchr.org/EN/Issues/Indicators/Pages/HRIndicatorsIndex.aspx](http://www.ohchr.org/EN/Issues/Indicators/Pages/HRIndicatorsIndex.aspx).

314 More information is available at [www.humanrights.dk/activities/our-work-denmark/disability/gold-indicators-crpd](http://www.humanrights.dk/activities/our-work-denmark/disability/gold-indicators-crpd).

## GUIDEBOOK ON MONITORING THE RIGHTS OF PERSONS WITH DISABILITIES

The **African Network of Human Rights Institutions** has published a guidebook on monitoring the rights of persons with disabilities with the support of the Raoul Wallenberg Institute. Preliminary research was conducted by prominent Kenyan disability rights activist Commissioner Lawrence Mute, who developed a skeleton framework. The draft framework was developed further at a workshop organised in Uganda for African NHRIs. The first day of the workshop was devoted to introducing the UN CRPD, the second to monitoring human rights generally and the third to monitoring the Convention using the monitoring tool. This allowed the tool to be contextualised in the realities of different countries; for example, by considering what the right to supported decision making might mean in rural Zambia. As part of the workshop, participants visited a school, a health centre, a mental health institution and the Ministry of Social Security to test the tool and returned with feedback on how it might be further developed. Participants further refined the tool on the final day of the workshop. In September 2015, the NHRIs as well as representatives from disabled persons' organisations met in Nairobi, to validate the guidebook. It was published in March 2016.<sup>315</sup>

## MEASURING THE RIGHT TO POLITICAL PARTICIPATION AND THE RIGHT TO LIVE INDEPENDENTLY AND TO BE INCLUDED IN THE COMMUNITY

Working with the **European Commission** and the **Academic Network of European Disability Experts**, the **European Union Agency for Fundamental Rights** has developed 28 indicators to assess the political participation of persons with disabilities in the European Union. The indicators are grouped under four themes:

- Lifting legal and administrative barriers
- Increasing rights awareness
- Making political participation more accessible
- Expanding opportunities for participation.<sup>316</sup>

The indicators and the background to their development are contained in the report, *The right to political participation by persons with disabilities: human rights indicators* (2014).

The Agency has also developed indicators to measure implementation of article 19 of the UN CRPD on the right to live independently and to be included in the community. The indicators focus on the transition from institutions to community based services.<sup>317</sup>



315 Available at [www.nanhri.org/reports](http://www.nanhri.org/reports).

316 Available at <http://fra.europa.eu/en/publications-and-resources/data-and-maps/comparative-data/political-participation>.

317 Available at <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>.

## ZERO PROJECT

The Zero Project was initiated by the Essl Foundation in 2010 and is run in partnership with the World Future Council and the European Foundation Centre. The project's mission is 'a world without barriers', which mirrors the goals of the UN CRPD. In addition to identifying innovative policy and practices globally, the project has developed social indicators to measure implementation of the Convention and the current situation regarding implementation across the world.

The social indicators presently consist of 20 questions on the general implementation of the Convention, in addition to 12 further questions looking specifically at accessibility. Responses to the questionnaire have enabled the Zero Project to amass data concerning over 80 per cent of States parties to the Convention.

The results, which include the use of infographics, are presented on the Zero Project website: <http://zeroproject.org>.



## 13.3. HIGHLIGHTING SPECIFIC CHALLENGES THROUGH THEMATIC STUDIES AND RECOMMENDATIONS

Many NHRIs have extensive research programs and can therefore make a valuable contribution towards more effective monitoring of the situation of persons with disabilities in their respective countries. This would also help close the global data and evidence gap regarding the rights of persons with disabilities.

The **European Union Agency for Fundamental Rights** has carried out an extensive program of research regarding the situation of persons with disabilities across the Member States of the European Union. The research has focused on legal capacity of persons with mental health conditions and intellectual disabilities, the right to independent living and the right to political participation. The studies have underpinned the development of indicators.<sup>318</sup>



## 13.4. USING ANNUAL REPORTS TO FOCUS ATTENTION

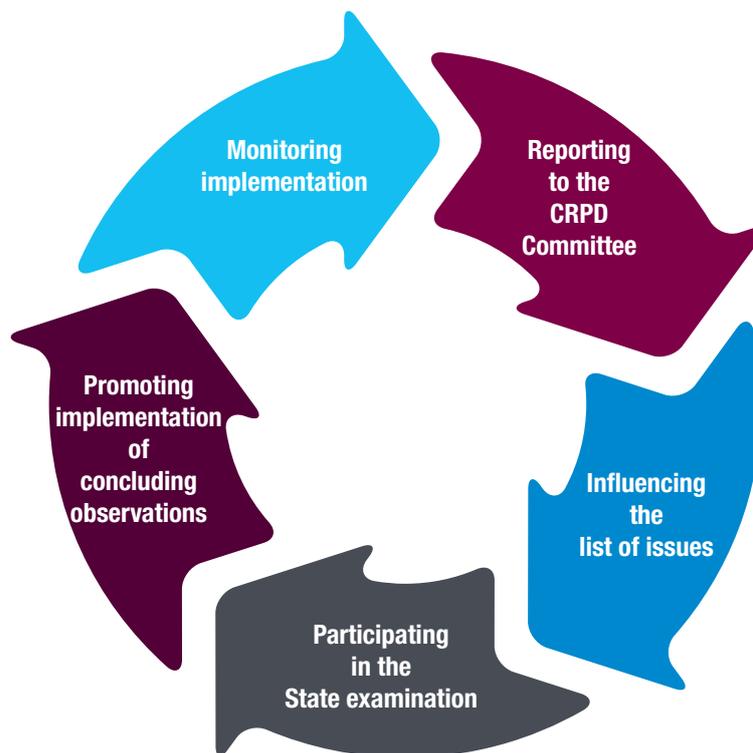
In compliance with the Paris Principles, NHRIs produce annual reports that detail both their own activities and provide an overview of the national human rights situation. These reports are broadly read and are a useful platform to draw general attention to deficits in the field of disability. NHRIs are encouraged to follow the example of the South African Human Rights Commission and the Ugandan Human Rights Commission and include a specific chapter or section regarding the human rights situation of persons with disabilities.<sup>319</sup>

318 More information is available at <http://fra.europa.eu/en/theme/people-disabilities>.

319 The annual reports of the South African Human Rights Commission are available at [www.sahrc.org.za/index.php/sahrc-publications/annual-reports](http://www.sahrc.org.za/index.php/sahrc-publications/annual-reports); and the annual reports of the Ugandan Human Rights Commission are available at [www.uhrc.ug/reports](http://www.uhrc.ug/reports).

## 13.5. CONTRIBUTING TO THE UN CRPD REPORTING PROCESS TO REINFORCE DOMESTIC PROGRESS

The various stages in the State examination process under the UN CRPD are set out in Chapter 4 of this Manual. NHRIs have a vital role to play in the international monitoring process established by the Convention and in using this involvement to drive the process of change back at home. They are both mutually reinforcing.



The specific contributions that NHRIs can make through the monitoring cycle include:

**Ensuring effective State reports:** NHRIs can provide technical assistance and advice to States regarding their initial and periodical reports to the CPRD Committee, including ensuring that persons with disabilities are involved in their preparation and providing feedback to their governments in response to public consultations on the reports. For example, the four NHRIs that together form the United Kingdom Independent Mechanism contributed to the development of the United Kingdom Government’s Initial Report and recommended that it sought additional time to submit its report in order to address gaps and weaknesses. It is very important to stress, however, that NHRIs do not take responsibility for their State’s report – that is solely the responsibility of the State.

**Submitting parallel reports:** NHRIs can – and many do – prepare and submit parallel reports to the CPRD Committee, offering an independent account of the national situation regarding the rights of persons with disabilities. Some NHRIs have also supported organisations of persons with disabilities to prepare comprehensive parallel reports, with the NHRI submitting a shorter and more focused report.

**Assisting the Committee to identify the list of issues:** NHRIs can assist the CRPD Committee to identify the ‘list of issues’ ahead of the examination of a State report in a number of ways. NHRIs might consider preparing short reports specifically recommending the issues and questions for the Committee to ask the State under examination, as was the approach of the German Independent Monitoring Mechanism.<sup>320</sup> NHRIs are also encouraged to develop a working relationship with the Committee member assigned as country rapporteur and to support them. Further, NHRIs should seek to attend and participate in the Committee sessions where the list of issues is discussed and agreed.

**Contributing to the Committee’s examination:** NHRIs can assist the CRPD Committee in its examination of State parties in a number of ways. These include submitting further independent evidence related to list of issues and assisting Committee members to identify questions and draft recommendations. NHRIs should also seek to attend the Committee sessions and support Committee members during the constructive dialogue with their States. This was done to good effect by the Danish Institute for Human Rights and the New Zealand Human Rights Commission in their respective country’s dialogue with the Committee.<sup>321</sup>

**Promoting implementation of the concluding observations:** NHRIs can promote and disseminate the concluding observations of the Committee, incorporate them as appropriate into their monitoring frameworks and action plans, and produce their own periodic reports on progress of implementation to reinforce the process and pace of change at home.



Opening of the Ninth Session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities.  
UN Photo/JC McIlwaine

320 The submission is available at [www.institut-fuer-menschenrechte.de/uploads/tx\\_commerce/Submission\\_of\\_the\\_National\\_CRPD\\_Monitoring\\_Body\\_of\\_Germany\\_to\\_the\\_CRPD\\_Committee\\_on\\_the\\_occasion\\_of\\_the\\_preparation\\_of\\_a\\_list\\_of\\_issues\\_by\\_the\\_Committee\\_in\\_the\\_review\\_of\\_Germanys\\_Initial\\_Report\\_2014.pdf](http://www.institut-fuer-menschenrechte.de/uploads/tx_commerce/Submission_of_the_National_CRPD_Monitoring_Body_of_Germany_to_the_CRPD_Committee_on_the_occasion_of_the_preparation_of_a_list_of_issues_by_the_Committee_in_the_review_of_Germanys_Initial_Report_2014.pdf).

321 Information on the participation of the NHRIs of Denmark and New Zealand (15 September-3 October 2014) is available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

## 13.6. PUTTING THE ‘VOICE’ OF PERSONS WITH DISABILITIES AT THE HEART OF THE MONITORING PROCESS

As has already been stressed, NHRIs must ensure the involvement and full participation of persons with disabilities in their monitoring activities. They should also support persons with disabilities and their representative organisations to engage independently in monitoring implementation of the Convention. A number of examples of how NHRIs are involving persons with disabilities generally are provided in Chapter 11. Following are examples of NHRIs involving persons with disabilities specifically in their monitoring activities.

### INVOLVING PERSONS WITH DISABILITIES IN MONITORING

The **South African Human Rights Commission** convenes annual dialogues between disabled persons’ organisations and government departments to evaluate how provincial departments are implementing the Convention. They also help forge greater collaboration between DPOs and government to secure effective implementation. In addition, the provincial dialogues create a platform through which the Commission can hold meetings with various governmental departments and DPOs to monitor compliance with national, regional, and international treaties.<sup>322</sup>

The German National CRPD Monitoring Body, housed by the German Institute for Human Rights, hosts Civil Society Consultations in Berlin three times each year. The consultations are set up in an inclusive event format to encourage the open exchange of experiences and information between the National CRPD Monitoring Body and civil society disability advocacy organisations in Germany.<sup>323</sup>

The **Scottish Human Rights Commission** and the **British Equality and Human Rights Commission** jointly prepared and disseminated a questionnaire in November 2013 to consult with persons with disabilities and their representatives ahead of the United Kingdom Independent Mechanism report to inform the ‘list of issues’ stage of the United Kingdom’s first examination by the CRPD Committee. This was followed by a civil society roundtable to ensure that the priorities of persons with disabilities and their representatives were adequately reflected in the Independent Mechanism’s parallel report.<sup>324</sup>

During 2011, the **Danish Institute for Human Rights** organised roundtable meetings with all disability organisations in Denmark. In five different meetings, over 40 organisations had the opportunity to inform the Institute about the biggest challenges facing their members and to explore how the Institute could assist them.<sup>325</sup>

The **National Human Rights Commission of Mexico** has hosted a wide range of seminar and events to promote the Convention and to gather information regarding alleged human rights violations. These events have focused on themes such as political participation, accessibility and legal capacity, as well as events to review progress on implementation of the UN CRPD.<sup>326</sup>



322 Information provided by the Network of African National Human Rights Institutions for the preparation of this Manual.

323 Information provided by the German Institute for Human Rights for the preparation of this Manual.

324 Information provided by the Scottish Human Rights Commission for the preparation of this Manual.

325 Information provided by the Danish Institute for Human Rights for the preparation of this Manual.

326 Further information is available at [http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/SessionDetails1.aspx?SessionID=935&Lang=en).

## Further reading for Part III

- M. Birtha, 'A Chance to Pioneer or a Lost Opportunity? Monitoring Disability Rights Effectively and Independently in the EU in Line with Article 33 of the UN CRPD', Vol. 5, *European Yearbook of Disability Law* (2015)
- G. De Beco, *Article 33 of the UN Convention on the Rights of Persons with Disabilities, National Structures for Implementing and Monitoring the Convention* (Nijhoff, 2013)
- National Commission on Human Rights of Mexico, *National Monitoring Mechanisms of the Convention on the Rights of Persons with Disabilities* (Mexico, 2008)
- G. De Beco, 'Article 33 of the UN Convention on the Rights of Persons with Disabilities: Practice and Evaluation', Vol. 5, *European Yearbook of Disability Law* (2014)
- G. De Beco, 'Article 33(2) of the UN Convention on the Rights of Persons with Disabilities: Another role for national human rights institutions', Vol. 29, *Netherlands Quarterly on Human Rights* (2011)



## Epilogue

Many extremely important developments have taken place even within the relatively short period of time spent compiling this Manual between late 2014 and May 2016.

For one thing, the jurisprudence of the CRPD Committee has now crystallised both with respect to certain key rights – such as the right to legal capacity (article 12) and the right to live independently and be included in the Community (article 19) – and with respect to article 33 itself.

For another, the UN system is undergoing a highly visible transformation in generating more space and receptiveness for the engagement of NHRIs. This is exemplified by the General Assembly Resolution of December 2015, which marks the next logical development of more openness and receptiveness for NHRIs within the UN system. While the real work – and hopefully change – happens at home, these enhanced rights of audience mean that NHRIs can contribute more effectively in the UN treaty system and other settings, especially the CRPD Committee, and that they are well positioned to understand and advocate for implementation of the relevant concluding observations at home. This should make the ideal of a virtuous circle between international engagement and domestic change more of a reality.

In 2014, the CRPD Committee issued important Guidelines on the engagement of civil society and DPOs with its own workings. As described in Part II (Chapter 4, 4.5.), a similar set of Guidelines was adopted by the CRPD Committee in August 2016 on its engagement with NHRIs. These historic Guidelines will confirm best practice and set the stage for even more engagement.

It is clear that NHRIs are not just valued as key agents of change at home in their own countries (and increasingly in their own regions) but within the UN system as a whole. NHRIs from every corner of the world have been stepping up their engagement with disability issues. They can – especially through regional arrangements and disability working groups – also assist each other.

The challenge in the decade ahead will be to find ways of working collaboratively with civil society so that the authentic voices of the people, and especially the many hidden voices, can be combined with legal analysis to drive genuine and lasting change.

All in all, it is clear that a new era of opportunity for NHRIs is now opening up. We hope this Manual plays a part in helping NHRIs prepare to engage in the new politics of disability opened up by these many welcome changes.





**ASIA PACIFIC FORUM**  
ADVANCING HUMAN RIGHTS IN OUR REGION

**Asia Pacific Forum of National Human Rights Institutions**

GPO Box 5218  
Sydney NSW 1042  
Australia

E: [apf@asiapacificforum.net](mailto:apf@asiapacificforum.net)  
W: [www.asiapacificforum.net](http://www.asiapacificforum.net)