

CHAPTER 3

THE ROLE OF NATIONAL HUMAN RIGHTS INSTITUTIONS IN ADVANCING ARTICLE 19 OF THE UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

Elizabeth Kamundia and Faizah Sidi***

Summary

National Human Rights Institutions (NHRIs) established in accordance with the Principles relating to the Status of National Institutions (Paris Principles) have been identified as an essential pillar in the promotion and protection of the rights of persons with disabilities under article 33(2) of the CRPD. This article examines how NHRIs can leverage their respective mandates to address concerns on implementation of article 19 of the CRPD on the right to live independently in the community. Article 19 is especially important in the African context where persons with disabilities lack access to a range of in-home, residential and other state funded community support services as highlighted by the Committee on the Rights of Persons with Disabilities in concluding observations to African states. The article looks into the role played by NHRIs in realising article 19 of the CRPD, with reference to Kenya where the National Human Rights Institution has been designated as the monitoring agency under article 33(2) of the CRPD. The article also explores the potential role of NHRIs in promoting article 19.

* Assistant Director, Research, Advocacy and Outreach Directorate, Kenya National Commission on Human Rights, PhD (University of Pretoria), LLM (National University of Ireland Galway), LLB (University of Nairobi) Advocate of the High Court of Kenya. Email: elkamundia@gmail.com

** Senior Human Rights Officer, Research, Advocacy and Outreach Directorate, Kenya National Commission on Human Rights, LLB (Catholic University of Eastern Africa), Advocate of the High Court of Kenya. Email faizahsidi@gmail.com

1 Introduction

National Human Rights Institutions (NHRIs) established in accordance with the Principles relating to the Status of National Institutions (Paris Principles) have been identified as a critical pillar in the promotion and protection of the rights of persons with disabilities.¹ Article 33(2) of the United Nations Convention on the Rights of Persons with Disabilities (CRPD or Convention) requires state parties to designate one or more independent mechanisms to promote, protect and monitor the implementation of the Convention, taking into account the Paris Principles. Article 33 of the Convention has been recognised as one of the milestones of the CRPD in outlining institutional changes to facilitate implementation and monitoring of the rights of persons with disabilities.² However, the potential and role of NHRIs in advancing the right of persons with disabilities to live independently in the community in view of article 33(2) of the CRPD is rarely canvassed. Knowledge of good practices or initiatives undertaken by NHRIs in order to promote, protect and monitor the right of persons with disabilities to live independently in the community is still very limited.³ The lacuna in information on the role of NHRIs comes at a time when there are 21 African countries with NHRIs accredited as fully compliant with the Paris Principles.⁴ Moreover, discussions at national level on the right of persons with disabilities to live independently in the community are often driven by organisations of persons with intellectual or psychosocial disabilities with little to no investment by the state to fulfil its obligations under article 19 of the CRPD.⁵

- 1 GD Beco 'Article 33(2) of the United Nations Convention on the Rights of Persons with Disabilities: Another role for national human rights institutions' (2011) 29 *Netherlands Quarterly of Human Rights* 84 at 93.
- 2 M Birtha 'Nothing about CRPD monitoring without us: A case study on the involvement of the disability movement in policy making in Zambia' (2013) 1 *African Disability Rights Yearbook* 115 at 2.
- 3 To illustrate, general guides on the CRPD and on the role of NHRIs in advancing the rights of persons with disabilities make no reference to the potential role of NHRIs in advancing article 19 of the CRPD eg: Network of African National Human Rights Institutions *Guide for African national human rights institutions on the implementation of the Convention on the Rights of Persons with Disabilities* (2014) at 2; United Nations Office of the High Commissioner for Human Rights *The Convention on the Rights of Persons with Disabilities training guide professional series no 19* (2014) at 2.
- 4 The following African countries have National Human Rights Institutions accredited as fully compliant with the Paris Principles as at 1 March 2020: Cameroon, Democratic Republic of Congo, Egypt, Ghana, Kenya, Liberia, Madagascar, Malawi, Mauritius, Morocco, Namibia, Niger, Rwanda, Sierra Leone, South Africa, Tanzania, Togo, Uganda, Zambia and Zimbabwe. Global Alliance of National Human Rights Institutions 'Chart of the status of national institutions' (27 November 2019) at 3-7 <https://nhri.ohchr.org/EN/AboutUs/GANHRIAaccreditation/Documents/Status%20Accreditation%20-%20Chart%20%28%2027%20November%202019%29.pdf> (accessed 1 March 2020).
- 5 See generally, Inclusion International 'Global report on the right to decide' (2014) at 2.

This article explores how NHRIs can leverage their respective mandates to address concerns on implementation of article 19 of the CRPD on the right to live independently in the community, using the Kenyan NHRI as a case study. Article 19 has been selected as a test case for NHRIs because it blurs the traditional divide in the human rights discourse between the established civil and political rights and economic, social and cultural rights.⁶ Article 19 exemplifies the interrelation, interdependence and indivisibility of all human rights,⁷ and therefore challenges the ability of NHRIs to drive the process of change forward.

The section that follows examines the import of article 19 of the CRPD on the right to live independently in the community. The section lays the foundation for discussion on the role on NHRIs in advancing the rights of persons with disabilities to live independently in the community.

2 The import of the right to live independently in the community

2.1 The UN Convention on the Rights of Persons with Disabilities

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) provides for the right for all persons with disabilities to live in the community as equal citizens. The right of all persons with disabilities to live in the community is not explicitly provided for in any treaty prior to the CRPD.⁸ However, the right to live in the community is not a new right but rather, a creative interpretation of existing rights that has been specially tailored to apply to the context of persons with disabilities.⁹ In particular, the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities provides that:¹⁰

Persons with disabilities are members of the society and have the right to remain within their local communities. They should receive the support they

6 MA Stein, J Feffer & JE Lord 'Ratify the UN disability treaty' (9 July 2009) https://fpif.org/ratify_the_un_disability_treaty/ (accessed 23 July 2020).

7 CRPD General Comment 5: Article 19: Living independently and being included in the community (2017) UN Doc CRPD/C/GC/5 dated 29 August 2017 para 7.

8 European Coalition for Community Living 'Focus on article 19 of the UN Convention on the Rights of Persons with Disabilities' (Focus Report 2009) <http://community-living.info/wp-content/uploads/2014/02/ECCL-Focus-Report-2009-final-WEB.pdf> (accessed 27 October 2019).

9 E Kamundia 'Choice, support and inclusion: Implementing article 19 of the Convention on the Rights of Persons with Disabilities in Kenya' (2013) 56 *African Yearbook on Disability Rights* 49 at 50.

10 United Nations, Department of Economic and Social Affairs 'Standard rules on the equalization of opportunities for persons with disabilities' <https://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html> (accessed 27 October 2019).

need within ordinary structures of education, health, employment and social services.

Additionally, General Comment 9 of the Committee on the Rights of the Child (2006) states that young children should never be institutionalised solely on the grounds of disability.¹¹ It is worth noting, however, that General Comment 9 of the Committee on the Rights of the Child does not prohibit institutionalisation absolutely. In this regard, General Comment 9 calls for state parties to ‘use the placement in institution only as a measure of last resort, when it is absolutely necessary and in the best interests of the child’.¹² This underscores the fact that institutions are generally not best suited to provide care for children. It is now necessary to turn to the content of article 19 of the CRPD.

Article 19 of the CRPD calls upon state parties to ensure that:

- Persons with disabilities have the equal opportunity to choose where and with whom to live;
- A range of community-based services is availed to persons with disabilities to support inclusion; and
- Services and facilities available for the general population are available to persons with disabilities and responsive to their needs.

The UN Committee on the Rights of Persons with Disabilities has developed a General Comment on article 19 of the CRPD.¹³ Although General Comments provide expert interpretations to treaty provisions,¹⁴ it is worth noting that they lack binding legal force.¹⁵ Nevertheless, General Comments are useful in clarifying state obligations in relation to the specified treaty provisions.

The General Comment on article 19 of the CRPD¹⁶ identifies eight core elements of the article. The first is the right to exercise legal capacity in determining where and with whom to live.¹⁷ Secondly, is the principle of non-discrimination in accessing accessible housing.¹⁸ Thirdly, is the requirement to expand options for persons with disabilities to live independently in the community, beyond the support provided by family.¹⁹ The fourth core element of article 19 is the requirement to ensure

11 CRC General Comment 9: The rights of children with disabilities (2006) UN Doc CRC/C/GC/9 dated 27 February 2007.

12 General Comment 9 (n 11) para 47.

13 General Comment 5 (n 7).

14 Dag Hammarskjöld ‘What is the purpose of the Human Rights Treaty Bodies general comments?’ 06 January 2020 <https://ask.un.org/friendly.php?slug=faq/135547> (accessed 26 July 2020).

15 A Nollkaemper ‘The legal status of decisions by human rights treaty bodies in national law’ (2011) ACIL Research Paper No 2011-02.

16 General Comment 5 (n 7).

17 General Comment 5 (n 7) para 38(a).

18 General Comment 5 (n 7) para 38(b).

19 General Comment 5 (n 7) para 38(c).

that basic mainstream services are accessible to persons with disabilities in both law and practice.²⁰ Fifth is the requirement to develop a concrete action plan on implementing personalised, rights-based disability-specific support services.²¹ The sixth core element requires that states ensure non-retrogression in achieving the content of article 19 unless in accordance with international law.²² The seventh element requires the collection of quality data on persons with disabilities, regardless of their place of residence.²³ The eighth and final core element calls for the use of any available funding, including regional funding and funding for development cooperation, to develop inclusive and accessible independent living services.²⁴

The core elements identified above underscore the interrelation and interdependence of rights, and of particular interest for present purposes is the relationship between articles 12 and 19 of the CRPD. As is stated in the General Comment on article 19 of the CRPD,²⁵ the right to ‘choose and decide how, where and with whom to live is the central idea of the right to live independently and be included in the community’.²⁶ This clearly entails an exercise of legal capacity. A question that may arise in this regard is whether one can exercise legal capacity to live in an institution. It is the view of the authors that all too often, there is a lack of options to choose from, and therefore, currently, the ‘choice’ to live in an institution is not a real choice as it is driven by a lack of alternatives. Furthermore, as the General Comment elucidates, individual choice includes:²⁷

all aspects of a person’s living arrangements: the daily schedule and routine as well as the way of life and lifestyle of a person, covering the private and public spheres, every day and in the long term.

It is difficult to fathom how the above aspects of individual choice may be achieved in an institutional setting.

At the same time, it is worth acknowledging that the full realisation of article 19 depends on ‘progressive achievement’ of those parts of article 19 that are progressively applicable (economic, social and cultural rights). These are article 19(b) and (c).²⁸ In this regard, state parties have an immediate obligation to design concrete strategies, and resources to develop support services as well as making existing, and new, general services inclusive for persons with disabilities.²⁹

20 General Comment 5 (n 7) para 38(d).

21 General Comment 5 (n 7) para 38(e).

22 General Comment 5 (n 7) para 38(f).

23 General Comment 5 (n 7) para 38(g).

24 General Comment 5 (n 7) para 38(h).

25 General Comment 5 (n 7).

26 General Comment 5 (n 7) para 24.

27 General Comment 5 (n 7) para 24.

28 General Comment 5 (n 7) para 39.

29 General Comment 5 (n 7) para 39.

2.2 The Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa

In addition to the CRPD, the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa provides for the right of persons with disabilities to live in the community under article 14. While the Protocol has not yet come into force,³⁰ it is important to compare article 14 of the Protocol with article 19 of the CRPD in order to clarify similarities and/or differences between the two provisions and resultant state obligations. Notably, the text of the Protocol is largely similar to that of the Convention, except for a few critical elements as discussed in this sub-section.

Unlike the CRPD, the Protocol *explicitly* provides for the right of persons who require intensive support to have access to respite care services/caregivers.³¹ This is critical, in the light of the fact that most African countries lack support for living in the community as will be discussed below under section 3 entitled: 'Issues of concern on implementing the right to live independently in the community in selected African states'.

An additional difference between the Protocol and the CRPD is that the Protocol requires that Community Based Rehabilitation (CBR) should be provided in ways that enhance the inclusion of persons with disabilities in the community³² (in other words, CBR should not be based on a medical model approach of 'fixing' the person). Unlike the CRPD, the Protocol also requires that community living centers organised or established by persons with disabilities be supported to provide training and peer support, among other services to persons with disabilities.³³

As stated in the introduction, article 19 of the CRPD entails civil and political as well as economic, social and cultural rights. In this regard, the principle of progressive realisation of rights as outlined in article 4(2) of the CRPD is critical. Article 4(2) of the CRPD makes a distinction between rights that are to be progressively realised and those that are immediately applicable. It states that in relation to economic, social and cultural rights, each state party shall take measures to the maximum of its available

30 Article 38 of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa provides that the protocol shall enter into force 30 days after the deposit of the 15th instrument of ratification. As at 18 December 2019, the Protocol had not been ratified by any country, but had already registered six signatures namely by Burkina Faso, Central African Republic, Gabon, Rwanda, South Africa and Togo.

31 Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa Art 14(2)(b).

32 Art 14(2)(e).

33 Art 14(2)(f).

resources, with a view to achieving progressively the full realisation of these rights. The Protocol does not make this distinction expressly. Article 4(a) of the Protocol calls upon states to adopt 'appropriate measures for the full and effective implementation of the rights recognised in the present Protocol'. Under the Protocol, the language of progressive realisation is only expressly utilised in relation to articles 15(2) on accessibility and 16(3)(d) on the right to education.

3 Issues of concern on implementing the right to live independently in the community in selected African states

The UN Committee on the Rights of Persons with Disabilities (CRPD Committee) has as at 30 March 2020 issued Concluding Observations to 13 African states.³⁴ Of the 13 African states examined so far, only one state (Tunisia) did not receive Concluding Observations on article 19.³⁵ Some common issues of concern have arisen in the Concluding Observations issued by the CRPD Committee on article 19 to African states. These issues present a starting point for understanding the challenges faced by African states on the right to live independently in the community and therefore introducing proposals about the role that National Human Rights Institutions (NHRIs) can play in advancing this right.

34 Concluding Observations on the Initial Report of Kenya, Committee on the Rights of Persons with Disabilities (30 September 2015) UN Doc CRPD/C/KEN/CO/1 (2015); Concluding Observations on the Initial Report of Mauritius, Committee on the Rights of Persons with Disabilities (30 September 2015) UN Doc CRPD/C/MUS/CO/1 (2015); Concluding Observations on the Initial Report of Uganda, Committee on the Rights of Persons with Disabilities (12 May 2016) UN Doc CRPD/C/UGA/CO/1 (2016); Concluding Observations on the Initial Report of Gabon, Committee on the Rights of Persons with Disabilities (2 October 2015) UN Doc CRPD/C/GAB/CO/1 (2015); Concluding Observations on the Initial Report of Tunisia, Committee on the Rights of Persons with Disabilities (13 May 2011) CRPD/C/TUN/CO/1 (2011); Concluding Observations on the Initial Report of Ethiopia, Committee on the Rights of Persons with Disabilities (4 November 2016) UN Doc CRPD/C/ETH/CO/1 (2016); Concluding Observations on the Initial Report of South Africa, Committee on the Rights of Persons with Disabilities (23 October 2018) UN Doc CRPD/C/ZAF/CO/1 (2018); Concluding Observations on the Initial Report of Senegal, Committee on the Rights of Persons with Disabilities (13 May 2019) UN Doc CRPD/C/SEN/CO/1 (2019); Concluding Observations on the Initial Report of Rwanda, Committee on the Rights of Persons with Disabilities (3 May 2019) UN Doc CRPD/C/RWA/CO/1 (2019); Concluding Observations on the Initial Report of Niger, Committee on the Rights of Persons with Disabilities (1 May 2019) UN Doc CRPD/C/NER/CO/1 (2019); Concluding Observations on the Initial Report of Morocco, Committee on the Rights of Persons with Disabilities (25 September 2017) UN Doc CRPD/C/MAR/CO/1 (2017); Concluding Observations on the Initial Report of Algeria, Committee on the Rights of Persons with Disabilities (27 June 2019) UN Doc CRPD/C/DZA/CO/1 (2019); Concluding Observations on the Initial Report of Sudan, Committee on the Rights of Persons with Disabilities (10 April 2018) UN Doc CRPD/C/SDN/CO/1 (2018).

35 Concluding Observations on the Initial Report of Tunisia, Committee on the Rights of Persons with Disabilities (13 May 2011) UN Doc CRPD/C/TUN/CO/1 (2011).

The first and most prevalent issue of concern relates to the prevalence of institutionalisation of persons with disabilities.³⁶ In terms of institutionalisation, the CRPD Committee has expressed concern regarding, in particular, the institutionalisation of children.³⁷ In this regard, the Committee, in its Concluding Observations to Mauritius expressed concern that children are removed from family settings and placed in residential institutions, where they lack care and psychological support and are sometimes subjected to cruel, inhuman and degrading treatment.³⁸ The Committee has also expressed concern about the lack of a well-defined national strategic and legislative framework on deinstitutionalisation.³⁹

The second issue of concern highlighted by the CRPD Committee is the absence of community support services that provide for inclusion of persons with disabilities in society.⁴⁰ The Committee notes that the lack of provision of essential services affects in particular persons with psychosocial and/or intellectual disabilities who are marginalised from everyday life as a result of lack of these services.⁴¹ Furthermore on persons with psychosocial disabilities, in the context of Sudan, the CRPD Committee expressed concern that persons with psychosocial disabilities are still forced to live in reformatories without their consent, ostensibly in the interests of ensuring close supervision and providing access to better healthcare and treatment.⁴² In the context of Ethiopia, the Committee expressed concern at the lack of availability and accessibility of personal assistance services for persons with disabilities.⁴³

The third critical issue of concern is the fact that there are persons with disabilities living in social isolation and segregated from their families and the community.⁴⁴ The CRPD Committee expressed concern about the lack of measures aimed at persons with disabilities who do not have

36 Concluding Observations on the Initial Report of Uganda (n 34) para 38; Concluding Observations on the Initial Report of Kenya (n 34) para 37; Concluding Observations on the Initial Report of Morocco (n 34) para 38(a); Concluding Observations on the Initial Report of Algeria (n 34) para 32.

37 Concluding Observations on the Initial Report of Morocco (n 34) para 38(a); Concluding Observations on the Initial Report of Mauritius (n 34) para 31.

38 Concluding Observations on the Initial Report of Mauritius (n 34) para 31.

39 Concluding Observations on the Initial Report of South Africa (n 34) para 34; Concluding Observations on the Initial Report of Morocco (n 34) para 38(d); Concluding Observations on the Initial Report of Sudan (n 34) para 39.

40 Concluding Observations on the Initial Report of Uganda (n 34) para 38; Concluding Observations on the Initial Report of Kenya (n 34) para 37; Concluding Observations on the Initial Report of Ethiopia (n 34) para 43; Concluding Observations on the Initial Report of Morocco (n 34) para 38(b); Concluding Observations on the Initial Report of Gabon (n 34) para 44.

41 Concluding Observations on the Initial Report of Uganda (n 34) para 38; Concluding Observations on the Initial Report of South Africa (n 34) para 34; Concluding Observations on the Initial Report of Senegal (n 34) para 33; Concluding Observations on the Initial Report of Morocco (n 34) para 38(c).

42 Concluding Observations on the Initial Report of Sudan (n 34) para 39.

43 Concluding Observations on the Initial Report of Ethiopia (n 34) para 43.

44 Concluding Observations on the Initial Report of Rwanda (n 34) para 35.

supportive families for whatever reason. In the specific context of Gabon, the Committee expressed concern about the lack of measures aimed at persons with disabilities who are abandoned by their families, especially in and around the capital in so-called '*cités*'.⁴⁵ In addition and still related to families, the Committee expressed concern that families who are often the sole base of support for persons and children with disabilities (especially those with psychosocial and intellectual disabilities) receive limited assistance from the state.⁴⁶

The fourth issue of concern garnered from the analysis is the inaccessibility of independent living support services in rural areas and for migrants and refugees with disabilities, and the absence of home and community-based care for children with disabilities, especially in rural areas.⁴⁷ The Committee noted that that inaccessible infrastructure and services make it difficult for persons with disabilities to participate in the activities of daily life independently, in particular in rural or remote areas.⁴⁸

The fifth issue of concern raised by the CRPD Committee to some of the African states examined so far relates to the absence of home and community-based care for children with disabilities, especially in rural areas.⁴⁹ In this regard, the Committee expressed concern that private day-care centres where children with disabilities are placed are neither regulated nor monitored by the state. In the specific context of Mauritius, the Committee expressed concern that children with disabilities continue to be placed in '*centres de sauvegarde*' (*abris des enfants en détresse*).⁵⁰

The sixth issue of concern expressed by the CRPD Committee to a number of the African states examined relates to the limited level of awareness among persons with disabilities of available independent living support services, including personal assistance services, and the inaccessibility of those services for persons affected by leprosy, persons with physical disabilities, persons with disabilities in rural areas and migrant workers with disabilities.⁵¹ In addition to the lack of information on the availability of accessible independent living support services in the community, the Committee expressed concern about the lack of awareness about how to claim such assistance.⁵²

45 Concluding Observations on the Initial Report of Gabon (n 34) para 44.

46 Concluding Observations on the Initial Report of Mauritius (n 34) para 31.

47 Concluding Observations on the Initial Report of Niger (n 34) para 31.

48 Concluding Observations on the Initial Report of Rwanda (n 34) para 35.

49 Concluding Observations on the Initial Report of Senegal (n 34) para 33(c).

50 Concluding Observations on the Initial Report of Mauritius (n 34) para 31.

51 Concluding Observations on the Initial Report of Senegal (n 34) para 33(b).

52 Concluding Observations on the Initial Report of Niger (n 34) para 31.

4 The present and potential role of NHRIs in advancing article 19 of the CRPD: The case study of the Kenyan National Human Rights Institution

4.1 Why NHRIs are well suited to advance article 19 of the CRPD

Many of the issues discussed in the foregoing section reveal system deficits that National Human Rights Institutions (NHRIs) are ideally placed to address and help resolve, given their broad mandate to promote and protect human rights under the Paris Principles.⁵³ NHRIs, especially those that are compliant with the Paris Principles, play a critical and unique role in the promotion and protection of human rights at national level,⁵⁴ while treaty and charter-based mechanisms play a critical role at an international level in assessing state compliance with human rights treaties. In essence, human rights protection and promotion cannot be achieved without effective national human rights systems. In this regard, state parties bear the primary responsibility of respecting, protecting and fulfilling rights obligations, and NHRIs created in compliance with Paris Principles form part of the central elements of a strong national human rights system that contribute to the promotion and protection of human rights at national level.⁵⁵

The recognition of the importance of NHRIs in implementation of the CRPD can be found under article 33(2) of the CRPD. Article 33(2) obligates state parties to designate or establish one or more independent mechanisms to promote, protect and monitor the implementation of the Convention taking into account the Paris Principles. Article 33(2) has been noted as one of its kind in monitoring implementation of treaty obligations at national level. As observed by GD Beco:⁵⁶

Human rights treaties define which rights States should respect, protect and fulfil. However, these treaties do not determine through which means they should do this ... In contrast, Article 33(2) of the CRPD provides that States should designate or establish one or more independent mechanisms to promote, protect and monitor the implementation of Convention taking into account the Paris Principles ... the inclusion of obligation to create independent mechanisms is a recent phenomenon.

53 United Nations General Assembly resolution on national institutions for the promotion and protection of human rights (20 December 1993) UN Doc A/RES/48/134 (1993) at 1.

54 United Nations Office of the United Nations High Commissioner for Human Rights 'National human rights institutions: History, principles, roles and responsibilities' (2010) Professional Training Series No 4 13.

55 As above.

56 Beco (n 1) 1.

This means that article 33(2) requires state parties to maintain, strengthen, designate or establish within the state party one or more independent mechanism or mechanisms to promote, protect and monitor implementation of the Convention. The state party may choose to appoint an existing body or bodies and empower them with the mandate to promote, protect and monitor the implementation of rights contained in the Convention.⁵⁷ The body designated to be an independent mechanism or part of bodies that are so designated must be compliant with the Paris Principles.⁵⁸

4.2 The role of NHRIs in advancing article 19 of the CRPD and potential limitations

This section examines the role of NHRIs in advancing article 19 of the CRPD using the case study of the Kenyan NHRI, the Kenya National Commission on Human Rights (hereinafter KNCHR or the Commission).⁵⁹ The Commission is the designated national monitoring agency under article 33(2) of the Convention on the Rights of Persons with Disabilities.

NHRIs can support the enjoyment of article 19 of the CRPD by persons with disabilities in a variety of ways. First, NHRIs can advocate for the development of a well-defined legislative framework on deinstitutionalisation and independent living community support services to encourage the inclusion of persons with disabilities.⁶⁰ NHRIs can make recommendations on this matter during review of bills and policies for compliance with human rights standards. This is in line with the responsibilities envisaged for NHRIs under the Paris Principles. Under the Paris Principles, NHRIs should advise and provide opinions, recommendations, proposals and reports to the government, parliament or other responsible organ on legislative or administrative provisions.⁶¹

Critical bills and policies that might present significant opportunities for deinstitutionalisation (in law) include mental health laws as well as stand-alone ‘persons with disabilities’ laws. This would be in line with General Comment 5 (2017) on living independently and being included in the community, in which state parties are required to adopt a national strategy on living independently and being included in the community and

57 Beco (n 1) 11.

58 Beco (n 1) 12.

59 The Kenya National Commission on Human Rights (KNCHR) is an Independent National Human Rights Institution with ‘A’ Status Accreditation. It is established under the article 59 of the Constitution and operationalised under the Kenya National Commission on Human Rights Act, 2011 (revised 2012). The Commission carries out functions under its founding Act and the Prevention of Torture Act, 2017.

60 Concluding Observations on the Initial Report of Senegal (n 34) para 33(a); Concluding Observations on the Initial Report of Morocco (n 34) para 39(a).

61 UN Doc A/RES/48/134 (1993) (n 53) para 3 (a)(i).

prevent the isolation or segregation of persons with disabilities.⁶² In this regard, KNCHR has been at the forefront of advocating for amendments to Kenya's Mental Health Act, 1989 to render the Act more in line with the UN Convention on the Rights of Persons with Disabilities. Accordingly, the Commission has advised the National Assembly that the mental health law should:⁶³

Avoid institutionalization and medicalization of children to the greatest extent possible. The law should explicitly recognise that institutionalization is detrimental to the development of the child, and contain a general principle to the effect that every effort shall be made to provide support and treatment of children through community health services. The law should ensure that children and adolescents with mental health conditions are provided with early intervention through evidence-based psychosocial and other non-pharmacological interventions based in the community, avoiding institutionalization and medicalization.

While the advisory role is critical to the effectiveness of NHRIs in advancing human rights,⁶⁴ one disadvantage related to this is that states may disregard the recommendations of NHRIs, which are not binding.⁶⁵ Indeed the implementation of recommendations made by NHRIs depends upon the commitment of other state departments to act on findings made by NHRIs and their capacity to do so.⁶⁶ To militate against this, NHRIs should endeavour to develop and maintain good relationships with relevant government agencies to facilitate dialogue where appropriate. This calls for carefully balancing between the adviser and adversarial roles played by NHRIs.⁶⁷ It is also important for NHRIs to foster strong partnerships with business and civil society actors at national level in order to amplify efforts.

The second role of NHRIs in advancing article 19 of the CRPD relates to their mandate in ensuring compliance with obligations under treaties relating to human rights.⁶⁸ The Paris Principles prescribe that NHRIs

62 Concluding Observations on the Initial Report of Rwanda (n 34) para 36; Concluding Observations on the Initial Report of Algeria (n 34) para 33; Concluding Observations on the Initial Report of Sudan (para 34) para 40.

63 Kenya National Commission on Human Rights 'Advisory on the Mental Health (Amendment) Bill 2018' presented to the National Assembly Departmental Committee on Health (31 October 2019).

64 J Mertus 'Evaluating NHRIs: Considering structure, mandate and impact' in R Goodman & T Pogram (eds) *Human rights, state compliance and social change: Assessing national human rights institutions* (2012) at 77.

65 United Nations Office of the United Nations High Commissioner for Human Rights (n 54) 17.

66 D Meyer 'National human rights institutions, opportunities and activism' in R Goodman & T Pogram (eds) *Human rights, state compliance and social change: Assessing national human rights institutions* (2012) at 328.

67 The Danish Institute for Human Rights 'Challenges in NHRI effectiveness' <https://www.humanrights.dk/learning-hub/challenges-nhri-effectiveness> (accessed 27 July 2020)

68 United Nations Office of the United Nations High Commissioner for Human Rights (n 54).

should bolster ratification and implementation of international human rights instruments.⁶⁹ NHRIs are also required to contribute to national human rights reports to treaty body mechanisms and where necessary express an independent opinion on matters discussed.⁷⁰ This entails the issuing of parallel reports to treaty body mechanisms in relation to treaties that have been ratified by the specific state. In this regard, NHRIs can make recommendations to advance article 19 of the CRPD in their parallel reports or in their engagements with special UN mechanisms (not limited to the UN Convention on the Rights of Persons with Disabilities). Such recommendations may call upon the treaty body/special mechanism to require the state in question to take any of the following steps:

- a) Provide grants and budgetary allocations to persons with disabilities to promote independent living in the community covering support for assistive devices, guides, sign language interpreters, affordable skin-care protection for persons with albinism,⁷¹ and cash transfer schemes for personal assistance services.⁷² (This recommendation may fall under the parallel report on the International Covenant on Economic, Social and Cultural Rights).
- b) Adopt the necessary measures to prevent isolation or segregation of persons with disabilities from the community by being hidden in the family, or in segregated institutions.⁷³ (This recommendation may fall under the parallel report on the Convention Against Torture).
- c) Systematically provide information to all persons with disabilities, including migrant workers with disabilities and their families, on how to access support services and assistance.⁷⁴ (This recommendation may fall under the parallel report on the International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families).
- d) Ensure accessibility to community services and facilities by all persons with disabilities in all areas of life, as well as home and community-based care for children with disabilities, particularly in rural areas.⁷⁵ (This recommendation may fall under the parallel report on the Convention on the Rights of the Child).

69 UN Doc A/RES/48/134 (1993) (n 53) para 3(c).

70 UN Doc A/RES/48/134 (1993) (n 53) para 3(d).

71 Concluding Observations on the Initial Report of Uganda (n 34) para 39; Concluding Observations on the Initial Report of Rwanda (n 34) para 36; Concluding Observations on the Initial Report of Morocco (n 34) para 39(c).

72 Concluding Observations on the Initial Report of Kenya (n 34) para 38(c); Concluding Observations on the Initial Report of Senegal (n 34) para 34(d); Concluding Observations on the Initial Report of South Africa (n 34) para 35(c); Concluding Observations on the Initial Report of Morocco (n 34) para 39(c); Concluding Observations on the Initial Report of Sudan (n 34) para 40.

73 Concluding Observations on the Initial Report of Gabon (n 34) para 45.

74 Concluding Observations on the Initial Report of Senegal (n 34) para 34; Concluding Observations on the Initial Report of Niger (n 34) para 32(a).

75 Concluding Observations on the Initial Report of Niger (n 34) para 32(b); Concluding Observations on the Initial Report of Morocco (n 34) para 39(d).

In relation to the above, the Kenya National Commission on Human Rights' 2019 parallel report on the third cycle of the Universal Periodic Review⁷⁶ noted violations on the right of persons with disabilities to live independently in the community and made the following recommendations:⁷⁷

- (i) Amend Sections 10(3), 14, and 16 of the Mental Health Act which allows for involuntary detention of users of mental health services in consultation with organizations for/of persons with disabilities;
- (ii) Develop action plan to support de-institutionalization and transition to community based mental health service;
- (iii) Provide state funded support services for persons with disabilities at community level, including caregivers, respite services, peer support and personal assistance services.

Parallel reports by NHRIs may influence the Concluding Observations issued by treaty body mechanisms to a specific state. While Concluding Observations are very valuable expert interpretations, they are often not widely disseminated and the public in the given country often remains unaware of them. In many cases, states pay little attention to their implementation.⁷⁸ This illustrates why it is critical for NHRIs to effectively play their role in relation to promoting compliance with obligations under treaties relating to human rights.

The third role that NHRIs may play to advance article 19 of the CRPD relates to monitoring, especially in relation to NHRIs which have already been designated as the monitoring agencies under article 33(2) of the CRPD as discussed in section 4.1 above. In this regard, NHRIs can monitor the extent to which Concluding Observations on article 19 are implemented. They can also monitor non-compliance with progressive national legislation that may advance article 19 of the CRPD.⁷⁹ In addition, NHRIs can, for example, regularly and closely monitor places where children are institutionalised and advocate for the development of family and community-based alternatives for those deprived of a family environment.⁸⁰ Monitoring should also include mental health institutions. In relation to mental health institutions, the World Health Organisation has developed a human rights-based toolkit for monitoring entitled the

76 Kenya National Commission on Human Rights 'Kenya National Commission on Human Rights (KNCHR) Third Cycle UPR report' <https://www.knchr.org/Portals/0/InternationalObligationsReports/KNCHR%203RD%20CYCLE%20UPR%20REPORRT.pdf?ver=2019-07-22-084058-850> (accessed 30 March 2020).

77 As above.

78 J Lhotský 'Human rights treaty body review 2020: Towards an integrated treaty body system' 10 <https://www.geneva-academy.ch/joomlatools-files/docman-files/Jan%20Lhotsky%C3%BD%20-%20Towards%20an%20Integrated%20Treaty%20Body%20System.pdf> (accessed on 26 July 2020).

79 General Comment 5 (n 7) para 38(d).

80 Concluding Observations on the Initial Report of Mauritius (para 34) para 32.

QualityRights Toolkit,⁸¹ which has a specific module on the right of persons with disabilities to live independently in the community. NHRIs should be keen to partner/collaborate with health ministries towards use of the WHO QualityRights Toolkit in monitoring mental health institutions. The Kenya National Commission on Human Rights is already involved in this process.⁸²

NHRIs should ideally monitor the extent to which relevant authorities follow the recommendations set forth in the monitoring reports. This presupposes a good working relationship with government departments,⁸³ as NHRIs may require information from these departments in order to assess progress on implementation of recommendations. The inherent limitation is that governments may take the NHRI's advice on small points, while pressing ahead with actions that breach human rights commitments.⁸⁴ NHRIs can mitigate this by using courts or specialised tribunals as avenues to enforce recommendations in specific instances where their recommendations have been ignored or rejected.⁸⁵ However, the ability of NHRIs to effectively leverage on this mandate must be accompanied by structural baseline commitments such as the ability to intervene in court cases relevant to human rights and the authority to take recommendations to court for enforcement.⁸⁶

The fourth role that NHRIs can play to advance article 19 of the CRPD relates to receiving and investigating complaints about alleged violations of the right of persons with disabilities to live independently and be included in the community. The Paris Principles require that national institutions be vested with specific mandate to protect human rights,⁸⁷ which may entail activities such as receiving, investigating and resolving complaints.⁸⁸ The Paris Principles do not *require* for NHRIs to have the power to receive complaints for alleged human rights violations,⁸⁹ but where an NHRI is provided with this mandate it is expected to handle the complaints fairly and effectively.⁹⁰ Therefore, NHRIs should, on receipt of

81 World Health Organisation 'QualityRights Toolkit' https://www.who.int/mental_health/publications/QualityRights_toolkit/en/ (accessed 27 October 2019).

82 So far, the following mental health facilities have been assessed in the 2019/2020 financial year: Mathari National Teaching and Referral Hospital, Moi Teaching and Referral Hospital, Port Reitz Psychiatric Unit and the Jaramogi Oginga Odinga Teaching and Referral Hospital.

83 United Nations Office of the High Commissioner for Human Rights 'Assessing the effectiveness of National Human Rights Institutions' (2005) 22 <https://www.ohchr.org/Documents/Publications/NHRIen.pdf> (accessed 26 July 2020).

84 As above.

85 United Nations Office of the United Nations High Commissioner for Human Rights (n 54) 17; Mertus (n 64) at 81.

86 Mertus (n 64) at 81.

87 UN Doc A/RES/48/134 (1993) (n 53) at 1.

88 United Nations Office of the United Nations High Commissioner for Human Rights (n 54) 31.

89 General Observations of the Sub-Committee on Accreditation, Global Alliance of National Human Rights Institutions (21 February 2018) at 50.

90 As above.

individual complaints revealing a violation of article 19 of the CRPD, take steps to secure appropriate redress.

In order to effectively handle complaints, NHRIs should be easily accessible to members of the public.⁹¹ Unfortunately, this is not always the case as some NHRIs are not in a position to establish offices within easy reach of the whole population and digital access may also be limited by various factors. In other cases, NHRIs may be inundated with complaints and lack adequate resources and personnel to handle the complaints effectively.⁹² NHRIs can militate against this by advocating for higher budgetary allocations from government, as well as seeking alternative sources of funding where appropriate.

The fifth role that NHRIs can play to advance article 19 relates to their function in advancing economic, social and cultural rights generally, and in particular the right to housing. Notably, there are ongoing projects to upgrade slums in many African countries, including Kenya, and such projects should be inclusive of persons with disabilities. In this regard, the Kenya National Commission on Human Rights was ordered by the High Court in the case of *David Ngige Tharau & 128 others v Principal Secretary Ministry of Lands, Housing and Urban Development & 2 others*⁹³ to oversee the allocation of houses in the Kibera Slum Upgrading Process to ensure that only genuine beneficiaries benefitted from the project.⁹⁴ Where opportunities to advance economic, social and cultural rights are present, NHRIs should ensure that the principle of non-discrimination⁹⁵ is applied in fulfilling these rights so that persons with disabilities are not left behind.

In carrying out the above roles, NHRIs must ensure the active participation of persons with disabilities and their representative organisations⁹⁶ in accordance with articles 4(3) and 33(3) of the CRPD.

4.3 The potential role of NHRIs in advancing article 19 of the CRPD

As was stated in the introduction, the Paris Principles require that national institutions be vested with specific mandate to promote and protect human rights.⁹⁷ The Office of the High Commissioner for Human Rights understands promotion as those functions needed to change attitudes and

91 As above.

92 United Nations Office of the High Commissioner for Human Rights (n 83).

93 Petition Number 304 of 2015 [2016] eKLR.

94 Para 39.

95 Committee on the Rights of Persons with Disabilities General Comment 5 (n 7) para 38(b).

96 Concluding Observations on the Initial Report of Kenya (n 34) para 38; Concluding Observations on the Initial Report of Gabon (n 34) para 45; Concluding Observations on the Initial Report of Algeria (n 34) para 33.

97 UN Doc A/RES/48/134 (1993) (n 53) 1.

behaviour which may include education, outreach, publications, training and capacity building and advising and assisting governments.⁹⁸ NHRIs should therefore take up the mandate to educate and inform state and non-state actors about article 19 of the CRPD. One of the reasons why persons with disabilities fail to fully enjoy the right to live in the community is stigma and negative attitudes that cause families to hide family members who have disabilities.⁹⁹ NHRIs should raise public awareness about the inherent worth of all persons, including those with disabilities, in order to create more inclusive societies.

Many NHRIs have an express or implied mandate to hold public inquiries, either in relation to a single serious incidence or more often in relation to systemic or general human rights issues.¹⁰⁰ The inquiry process enables NHRIs to examine an issue in depth and from a human rights perspective.¹⁰¹ For these purposes, NHRIs have full powers to compel testimony and witnesses.¹⁰² NHRIs may also choose to convene inquiries on issues of interest, but without utilising coercive powers. In this regard, NHRIs may rely on voluntary witnesses and seek the contribution of members of the public and NGOs without the formal powers of a more formal and adversarial process that is based on statute.¹⁰³ Although public inquiries are resource intensive, conducting them can help promote respect for rights and raise public awareness.¹⁰⁴ In relation to article 19 of the CRPD, an inquiry could be held in response to a serious incident, for example, allegations of abuse of institutionalised individuals residing in a mental health facility. This may require an NHRI to compel testimony and witnesses, and is best suited for NHRIs that have investigative powers.¹⁰⁵ NHRIs can also hold a (non-coercive) inquiry to understand the extent to which persons with disabilities are able to access support services, or the extent to which they experience isolation and segregation from the community contrary to article 19(b) of the CRPD.

98 United Nations Office of the United Nations High Commissioner for Human Rights (n 54) 31.

99 United Nations Division for Social Policy Development & Department of Economic and Social Affairs 'Toolkit on disability for Africa: Culture, beliefs and disability' 6 <https://www.un.org/esa/socdev/documents/disability/Toolkit/Cultures-Beliefs-Disability.pdf> (accessed 27 July 2020).

100 Asia Pacific Forum & Raoul Wallenberg Institute 'Manual on conducting a national inquiry into systemic patterns of human rights violations' (2012) 4.

101 United Nations Office of the United Nations High Commissioner for Human Rights (n 54) 97.

102 As above.

103 United Nations Office of the United Nations High Commissioner for Human Rights (n 54) 98.

104 United Nations Department of Economic and Social Affairs 'Disability' <https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-seven-creating-national-institutions-to-implement-and-monitor-the-convention-3.html> (accessed 27 July 2020).

105 As above.

As part of their mandate to protect human rights, many NHRIs can intervene in court proceedings as a 'friend of the court' in cases involving significant human rights issues.¹⁰⁶ Some NHRIs can also initiate cases that are either of broad public interest or that would have a significant impact on advancement of human rights.¹⁰⁷ This includes rights of persons with disabilities, including their right to live independently in the community.

5 Conclusion

The historical development and proliferation of national human rights institutions (NHRIs) as documented in this article demonstrates wide acceptance that NHRIs are a central pillar in the protection and promotion of human rights at national level. The Paris Principles remain central towards assessing the effectiveness of an NHRI and the ability of an NHRI to perform its function of promoting, protecting and monitoring the rights provided under the UN Convention on the Rights of Persons with Disabilities (CRPD).

Globally, it is well documented that persons with disabilities have historically been denied personal and individual choice and control across all areas of their lives.¹⁰⁸ The situation in Africa is no different, as has been demonstrated by the review of Concluding Observations to 13 African countries carried out in section 3 above. To reverse this historical injustice and redress the abandonment, over-dependence on family, institutionalisation, isolation and segregation experienced by persons with disabilities requires concerted efforts from state and non-state actors including NHRIs.

This article has identified critical ways in which NHRIs can advance article 19 of the CRPD. These include advocating for a well-defined legislative framework on deinstitutionalisation and independent living community support services and promoting compliance with obligations under treaties relating to human rights. Other roles that NHRIs can play in this regard include monitoring under article 33(2) of the CRPD, receiving and investigating complaints about alleged violations of article 19 and playing their function in advancing economic, social and cultural rights generally. In addition to these roles, NHRIs should fully utilise their mandate to advance the right of persons with disabilities to live in the community. This may be achieved through educating and informing state and non-state actors about article 19 of the CRPD, holding public inquiries

106 Asia Pacific Forum of National Human Rights Institutions 'Fact sheet 8: Responsibilities and functions of NHRIs: Intervening in court proceedings' <https://www.asiapacificforum.net/support/what-are-nhris/fact-sheet-8-responsibilities-and-functions-nhris-intervening-court-proceedings/> (accessed 27 July 2020).

107 Kenya National Commission on Human Rights 'Legal Services' <https://www.knchr.org/Our-Work/Legal-Services> (accessed 27 July 2020).

108 Committee on the Rights of Persons with Disabilities General Comment 5 (n 7).

on issues related to article 19 and intervening in court proceedings in order to promote this right.

In conclusion, the right of persons with disabilities to live independently in the community should be considered a priority issue, including in resource allocation. Resource allocation should cover all the important elements of this right, including choice of a place of residence on an equal basis with others; the provision of support services to enable inclusion in the community, including for persons who require a high level of support; and responsiveness of community services and communities to the needs of persons with disabilities. Finally, NHRIs that are designated as monitoring agencies under article 33(2) of the CRPD should receive adequate funding to enable them monitor the entire gamut of rights guaranteed under the CRPD.