

CHOICE, SUPPORT AND INCLUSION: IMPLEMENTING ARTICLE 19 OF THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES IN KENYA

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Summary

This article examines article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which comprises the right to live independently and to be included in the community, from an African perspective. The context is one in which persons with disabilities live with their families but without individualised state funded support services, against a cultural backdrop consisting of a largely communal way of life. This article examines the import of article 19, tracing its history and looking at various sources to flesh out the nature and content of the right to live independently in the community. It then gives content to the core of article 19 in the Kenyan setting, providing guidance on what the essential components of a policy that promotes article 19 in Kenya should be. This article makes policy proposals which are geared towards ensuring choice, support and inclusion of PWDs in Kenya.

1 Introduction

In terms of article 19 of the CRPD all PWDs have the right to live in the community, with choices equal to others, and have the right to be included in the community. The reality is that PWDs, particularly those who require more intensive support, are marginalised and relegated to the outskirts of society.

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It has been stated that ‘the CRPD effectuates a paradigm shift in the context of disability’.¹ The Convention does this by taking ‘to a new height the movement from viewing persons with disabilities as “objects” of charity, medical treatment and social protection towards viewing persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society’.² The CRPD interprets and applies traditional human rights in a manner that specifically addresses the particular issues that are faced by PWDs.³

Kenya has ratified the CRPD,⁴ and by virtue of article 2(6) of its Constitution, the CRPD forms part of the law of Kenya.⁵ Hence, Kenya must report on the progress it is making to implement the rights contained in the CRPD, including the right to community living. It is therefore necessary to analyse this right in relation to the circumstances present in the country, to ensure its implementation, and to facilitate its monitoring.

This article examines the significance of article 19, exploring its history and shedding light on the nature and content of the right to live independently in the community. It then gives substance to the core of article 19 in the Kenyan setting, providing guidance on what the essential components of a policy that promotes article 19 in Kenya should be.

This article makes policy proposals which are geared towards ensuring choice, support and inclusion of PWDs in Kenya. Some of the proposals considered are those identified by the state in its report to the Committee on the Rights of Persons with Disabilities as being the steps that the state is taking towards implementing article 19.⁶ These include education for PWDs, community based rehabilitation, and the various funds set up by the government to support PWDs.

- 1 Office of the United Nations High Commissioner for Human Rights, Europe Regional Office ‘Getting a life: Living independently and being included in the community. A legal study of the current use and future potential of the EU structural funds to contribute to the achievement of article 19 of the UN Convention on the Rights of Persons with Disabilities (April 2012) 15 http://www.europe.ohchr.org/Documents/Publications/Getting_a_Life.pdf (accessed 2 August 2012).
- 2 CRPD <http://www.un.org/disabilities/default.asp?navid=14&pid=150> (accessed 5 January 2012).
- 3 P Arajärvi ‘UN CRPD and the human rights of persons with disabilities’ in J Kumpuvuori & M Scheinin (eds) *United Nations Convention on the Rights of Persons with Disabilities - Multidisciplinary perspectives* (2009).
- 4 Ratified on 19 May 2008. Convention and optional protocol signatures and ratifications <http://www.un.org/disabilities/countries.asp?navid=12&pid=166> (accessed 25 February 2012).
- 5 The Constitution of Kenya 2010, art 2(6) provides: ‘Any treaty or convention ratified by Kenya shall form part of the law of Kenya under this Constitution’.
- 6 Committee on the Rights of Persons with Disabilities, Future sessions: Consideration of reports (National report: Kenya’s initial report submitted under art 35(1) of the United Nations Convention on the Rights of Persons with Disabilities – 31 August 2011) <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/futuresessions.aspx> (accessed 22 May 2012).

This article is divided into six sections, including the introductory section. The second section defines the foundational terms that are used extensively in the article – ‘community living/independent living’ and ‘institutionalisation’. The contested or relative nature of these concepts is acknowledged and addressed in this section. An attempt is made at contextualising the terms so that they are relevant to the Kenyan perspective.

The third section illuminates the normative implications of article 19 as well as the African human rights framework on disability. This section also explores the position taken by developing countries on article 19 during the negotiations of the CRPD. The fourth section explores the Kenyan context. It discusses the situation of PWDs in Kenya within the ambit of article 19. It also examines and critically analyses the legal and policy framework under which the right to live independently and to be included in the community in Kenya is anchored. The fifth section which precedes the conclusion gives content to the essence of article 19 in Kenya and makes policy recommendations towards realising this right.

This article draws in part from qualitative research.⁷ Interviews with key persons were undertaken in governmental,⁸ constitutional,⁹ and statutory¹⁰ bodies and in Non-Governmental Organisations (NGOs).¹¹ In one case, a group interview was conducted with people with intellectual disabilities.¹² A professional person with a disability¹³ and two parents of children with disabilities were also interviewed.¹⁴ The interviews were conducted between 1 May and 11 May 2012 in Nairobi, Kenya. A semi-structured interview instrument was used. Interviews were in English, Kiswahili and in Kenyan Sign Language with translation. The article is

7 The Article is adapted from: E Kamundia ‘Choice, support and inclusion: Implementing article 19 of the Convention on the Rights of Persons with Disabilities in Kenya’ unpublished LLM thesis, National University of Ireland, 2012.

8 The Ministry of Gender, Children and Social Development <http://www.gender.go.ke/> (accessed 2 July 2012).

9 Kenya National Commission on Human Rights <http://www.knchr.org/> (accessed 2 July 2012).

10 Kenya Society for the Blind <http://www.ksblind.org/site/> and National Council for Persons with Disabilities, Kenya <http://ncpwd.go.ke/> (accessed 2 July 2012).

11 NGOs involved in the research are: United Disabled Persons of Kenya, Leonard Cheshire Disability – Kenya <http://www.lcint.org/?lid=3162>; Sense International (East Africa) <http://www.senseinternational.org.uk/pages/sense-international-east-africa.html>; Users and Survivors of Psychiatry in Kenya <http://www.usp-kenya.com/>; Kenya Association of the Intellectually Handicapped <http://kaihid.org/>; and Ecumenical Disability Advocates Network <http://www.oikoumene.org/en/pro-grammes/unity-mission-evangelism-and-spirituality/just-and-inclusive-communities/people-with-disabilities-edan.html>.

12 The self-advocates interviewed are from the Kenya Association of the Intellectually Handicapped.

13 Dr RMJ Oduor, Lecturer, University of Nairobi.

14 F Wangare of the Kenya Association of the Intellectually Handicapped and J Shiroko of the Brian Resource Center <http://brc.or.ke/> (accessed 2 July 2012).

also informed by numerous discussions with key actors from various parts of the world.¹⁵

2 Defining foundational terms

2.1 Community living

This sub-section is aimed at elaborating the meaning of 'community living', since living as part of our communities serves as the basis for everything we do in life.¹⁶ This sub-section looks at the various ways in which the term 'community' has been defined. The rationale is that different definitions contain glimpses of the truth, and contribute to a fuller picture of the reality requiring definition. This section also explores related terms such as 'communalism' in an attempt to best capture how life in the community is lived in Kenya. As with most words in social sciences, the word 'community' is contested.¹⁷ In defining community from a sociological perspective, Delanty states that communities have been based on ethnicity, religion, class or politics. He notes that communities may be large or small; 'thin' or 'thick' attachments may underlie them; they may be locally based and globally organised; and affirmative or subversive in their relation to the established order. Further, communities may be traditional, modern, and even postmodern, reactionary and progressive. Delanty makes the point that for sociologists, community has traditionally designated a particular form of social organisation based on small groups such as neighbourhoods, the small town or a spatially bonded locality.¹⁸

Taylor writing in the context of communitarianism stresses the social nature of the individual as one that is quite literally embodied in moral relationships. The individual must be seen as rooted in the collective self.¹⁹ Hence, citizenship is based on a social concept of the individual as a member of a community.

The above discussion provides different elements of what 'community' means. This leads us to an exploration of what a 'communal way of life' entails. In this regard, Oduor in discussing communalism in the context of a traditional African ethical outlook states:

15 These actors are from: Inclusion International, Canada <http://www.inclusion-international.org/>; Canadian Association for Community Living, Human Care Association, Japan, <http://www.humancare1986.jp/english.html>; and Open Society Foundations (Mental Health Initiative) <http://www.opensocietyfoundations.org/mental-health-initiative> (all accessed 2 July 2012).

16 Commissioner for Human Rights 'The right of people with disabilities to live independently and be included in the community' CommDH/IssuePaper (2012) 3. https://wcd.coe.int/ViewDoc.jsp?id=1917847#P188_14524 (accessed 19 March 2012).

17 G Delanty *Community* (2003).

18 As above.

19 C Taylor *Sources of the self* (1990).

Communalism ... denotes that outlook which emphasises the social aspect of man's nature, holding that the individual's life can only find fulfilment when that individual co-operates with other members of the community, and puts the interests of the community before his own interests ... Consequently, these communities (traditional African communities) emphasised the need for every member to do his best to contribute towards the good of the community.²⁰

In this way of life, the common good trumps over individual good, social consensus over personal will, inter-dependence over self-dependence.²¹

Interviews undertaken for this study confirm the above discussion of communalism from an African perspective. They also provide insight into what constitutes a person who is considered a full member of the community in Kenya:

The other element about it (Article 19 of the CRPD) is about participation, participation around the community, and when you are participating in the community, we look at very basic things such as going to church, in Kenya we have over 80% Christians, so being able to go to church, to participate in weddings, in funerals, in circumcisions or rites of passage. That for us would be a person who is really accepted within the community, and can function in the community.²²

An inherent part of the right to live in the community is freedom of choice, including freedom to define what 'community' means.²³

One interviewee expressed various facets of community in the Kenyan context:

Africans are too together. You are still your mother's child, son, daughter to death, and you still belong to Kikuyu, Luo, community to death. Independence is good but within a certain set up, that you are independent, you as a person with disability, yes, you can make your own decisions, but living, we're living as a community ... We are inter-dependent [on] each other.²⁴

These discussions help form a more comprehensive picture of what 'community' means. In the context of Kenya, the definition of community also depends on location – and would be slightly different between rural and urban areas. In rural Kenya where people tend to have the same place

20 RMJ Oduor 'Ethnic minorities in Kenya's emerging democracy: Philosophical foundations of their liberties and limits' PhD thesis, University of Nairobi, 2011.

21 P Erny *The child and his environment in black Africa: An essay on traditional education* trans GJWanjohi (1981).

22 Interview with H Obande, Chief Executive Officer, United Disabled Persons of Kenya (Nairobi, Kenya, 2 May 2012).

23 United Nations Enable 'Proposals to the draft text - Israel, 4th session of the Ad Hoc Committee, 27 August 2004' <http://www.un.org/esa/socdev/enable/rights/ahc4israel.htm> (accessed 2 August 2012).

24 Interview with E Saka, Sense International (East Africa) (Nairobi, Kenya, 4 May 2012).

of abode over long durations of time, community of place is still the most common understanding of the term community. Belonging to the same ethnic group goes hand in hand with this, as well as participating in the rites of passage that are observed by that ethnic group. Within the urban areas in Kenya, communities form along other lines such as neighbourhood, leisure and religion, in terms of attending the same places of worship.²⁵

According to the Kenya census of 2009,²⁶ 67.7 per cent of the people in Kenya live in rural areas while 32.3 per cent live in urban areas. All of the 12 interviewees interviewed for this study, and based in Kenya, felt that to date, to a large extent, Kenya retains a communal way of life. It was also clarified that in the urban areas, this is swiftly changing to more individualised lifestyles. There is increased rural urban migration, largely driven by a desire to find employment in urban areas. The affect of rural urban migration on PWDs is profound – as families move to urban areas, they lose the natural support of extended families and close knit communities. This further marginalises them.²⁷

From the foregoing, the one common denominator that all definitions of community seem to share is that the term community denotes belonging. A sense of belonging is key to the formation of one's identity, and following this, to participation in the community. This is what has been denied to persons with disabilities, and is what article 19 of the CRPD seeks to remedy. Indeed, PWDs are often excluded from community life, and routinely denied full citizenship, with devastating effects. Taylor has examined the consequences of exclusion observing that our identity is partly shaped by recognition or its absence, often by the *mis*recognition of others, and so a person or group of people can suffer real damage if the people or society around them mirrors back a confining, demeaning or contemptible picture of themselves.²⁸

This article uses 'community living' instead of 'independent living'. The two terms have been said to be interchangeable.²⁹ However, in the course of conducting interviews in Kenya, it was pointed out that 'independence' is not a particularly African ideal, and that 'inter-

25 A Tarimo, 'Politicisation of Ethnic Identities and the Common Good in Kenya' (April 2008) http://www.scu.edu/ethics/practicing/focusareas/global_ethics/kenya.htm (accessed 24 April 2013).

26 Kenya National Bureau of Statistics 'Kenya census 2009, Nipo! Natambulika! Counting our people for implementation of Vision 2030' <http://www.knbs.or.ke/> (accessed 25 February 2012).

27 Interview with C Laurin-Bowie, Executive Director of Inclusion International, Canada (28 June 2012).

28 C Taylor 'The politics of recognition' in A Gutmann (ed) *Multiculturalism* (1994).

29 European Coalition for Community Living 'Focus on article 19 of the UN Convention on the Rights of Persons with Disabilities' (Focus Report 2009) <http://www.mh-sme.org/assets/files/ECCL-Focus-Report-2009-final-high-res.pdf> (accessed 9 August 2012).

dependence' was a better-suited term, yet 'inter-dependent living' is not the terminology used in the CRPD. This study is therefore of the opinion that the concept of 'community living' would receive more acceptance in the Kenyan context using the term 'community living' as opposed to 'independent living'.

2.2 Institutionalisation

In Kenya, institutionalisation occurs in the context of mental health care, and to some extent, the provision of education for children with disabilities in separate settings. Institutionalisation has been defined in various ways. According to the European Coalition for Community Living:

An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. It is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.³⁰

Institutionalisation as used in this study refers to placing PWDs in a separate setting without access to the options and choices that are available to non-disabled people and in a way that detaches them from life in the community. It is important to note that many PWDs, particularly persons with psychosocial disabilities are institutionalised against their will.

The result of institutionalisation is that people are deprived of the normal roles that are available in the community and are unable to plan their own lives. Institutionalisation also restricts privacy, self-determination and freedom of action. This in turn makes it that much more difficult to integrate into community life.³¹

Further, institutionalisation increases the risk of exploitation, violence, neglect and abuse because life in institutions is conducted as a closed system, typically far from the public eye.³² A dismaying example of this in Kenya was brought to light in February 2011, when a CNN investigation revealed how people with psychosocial disabilities in Kenya are 'dumped' at Mathari Hospital, where they face serious neglect.³³

30 European Coalition for Community Living (n 29 above) 10.

31 As above.

32 Commissioner for Human Rights (n 16 above).

33 'Kenya's mentally ill locked up and forgotten' *CNN* 25 February 2011 <http://edition.cnn.com/2011/WORLD/africa/02/25/kenya.forgotten.health/index.html> (accessed 14 April 2012).

3 Import of article 19 of the CRPD and the African human rights framework on disability

3.1 Independent living and living in the community – the core right

Prior to the CRPD, no other human rights instrument contained an explicit right for all PWDs to live in the community as equal citizens.³⁴ However, while the right to independent living, thus worded is only contained in the CRPD, it is not a new right but rather, a creative interpretation of existing rights that has been specially tailored to apply to the context of PWDs.³⁵

Article 19 of the CRPD requires states parties to recognise the equal right of PWDs to live in the community with choices equal to others and to facilitate the full inclusion and participation of PWDs in the community. Community living, also known as independent living in some jurisdictions and explained in Section 2.1 above,³⁶ refers to PWDs being able to live in their local communities as equal citizens, with the support that they need to participate in every-day life.³⁷

The core elements of independent living are self-determination, choice, autonomy, equal access, living in community, inclusion and participation. These elements are universal and not context specific.³⁸ Indeed, independent living 'has been regarded as a concept rather than an issue requiring specific legal definition'.³⁹ According to the UK Office for disability issues, independent living does not mean: doing things for yourself, or living on your own. Instead, it means having choice and control over the assistance and/or equipment needed to go about your daily life and having equal access to housing, transport and mobility, health, employment and education and training opportunities.⁴⁰

Hammarberg, the 2006-2012 Council of Europe Commissioner for Human Rights, summarises the core elements of the right as follows:

34 European Coalition for Community Living (n 29 above).

35 CRPD (n 2 above).

36 European Coalition for Community Living (n 29 above).

37 European Coalition for Community Living *Creating successful campaigns for community living: An advocacy manual for disability organisations and service providers* (November 2008) <http://www.community-living.info/documents/ECCL-Manual-final-WEB.pdf> (accessed 25 February 2012).

38 Interview with Dr M Seifu, Independent Disability Consultant (Galway, Ireland, 24 February 2012).

39 C Parker & L Clements 'The UN Convention on the Rights of Persons with Disabilities: A new right to independent living?' (2008) *European Human Rights Law Review* 490.

40 Office for Disability Issues 'Independent living: A cross-government strategy about independent living for disabled people' (February 2008) 28.

Article 19 of the CRPD embodies a positive philosophy, which is about enabling people to live their lives to their fullest, within society. The core of the right, which is not covered by the sum of the other rights, is about neutralising the devastating isolation and loss of control over one's life, wrought on people with disabilities because of their need for support against the background of an inaccessible society.⁴¹

Article 19 is a clear demonstration of how the CRPD blurs the traditional divide in the human rights discourse between the traditional civil and political rights and economic, social and cultural rights.⁴² It is difficult to distinguish the civil and political aspects from the social, economic and cultural aspects of the right to living independently and being included in the community.⁴³

During the CRPD negotiations, states were aware that the article merged civil and political rights that are subject to immediate realisation with economic, social and political rights that are to be progressively realised. During the 7th session of the CRPD negotiations, Serbia and Montenegro pointed out the fact that article 19 merged civil and political rights with economic, social and political rights:

The rights in this article are primarily economic and social, and therefore subject to progressive realisation. This is complicated by the centrality of freedom of choice in the article, which has more immediate implementation implications. Countries in transition may have difficulty guaranteeing the right to freedom of choice in the context of personal assistance. How can personal assistance service be developed so that freedom of choice is more easily guaranteed?⁴⁴

Scholars have also acknowledged the multifaceted nature of article 19. Article 19 has been said to extend the traditional right of liberty. In the words of Kayess and French, article 19 equates the right to liberty with the right of persons with disability to live in and be a part of the community.⁴⁵ It has also been stated that article 19(a) on choice 'implies rights to self-determination in relation to matters affecting where and with whom a disabled person lives and the means by which disabled people are involved in the decisions affecting them.'⁴⁶ Article 19(b), on access to a range of supports and services, 'appears to recognise social and economic rights of

41 Commissioner for Human Rights (n 16 above) chap 1.1.

42 JE Lord & MA Stein 'Ratify the UN Disability Treaty' 9 July 2009 www.fpiif.org/articles/ratify_the_un_disability_treaty (accessed 5 January 2012).

43 G Quinn 'Reflecting Strategically about the UN Convention on the Rights of Persons with Disabilities' (Interights Guest Speaker Series, London, December 2011).

44 Serbia & Montenegro, 7th session, 20 January 2006 <http://www.un.org/esa/socdev/enable/rights/ahc/sum20jan.htm> (accessed 3 August 2012).

45 R Kayess & P French 'Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities' (2008) 8 *Human Rights Law Review* 1.

46 C Parker 'Article 19 – Living Independently and being included in the Community: Realising the Right to Community Living' (4th International Summer School, Galway, Ireland 22 June 2012).

disabled people'⁴⁷ and is therefore subject to progressive realisation. Article 19(c), on equal access to mainstream services 'is more in the nature of a civil and political right to non-discrimination in relation to accessing goods and services, including the duty to make reasonable accommodations, legislative measures for which are required with immediate effect, but which in practice (such as in relation to making premises accessible) may take time to be realised in practice'.⁴⁸

3.2 The contribution of developing countries to article 19 during the negotiations of the CRPD

Article 19 of the CRPD is one of the articles that saw a clear divide between the negotiating standpoints of the developing and the developed countries.⁴⁹ The issue presents itself differently in developed countries and in developing countries.⁵⁰ The critical issue in developed countries is institutionalisation. In this regard Parker and Clements point out that: '[i]n many parts of Europe the predominant provision for disabled people (children as well as adults) continues to be institutionalisation (often for life)'.⁵¹

The critical issue in developing countries is unavailability of the required support services to enable independence and facilitate participation in the society.⁵² Further, in most countries of the south, mutual caring and support in the community is a norm and it is often felt that there is no need for PWDs to live physically and financially apart from their families. The emphasis is on one becoming a contributing member of the family rather than to manage her/his own household alone. Thus, the concept of independent living associated with the developed countries is

47 Joint Committee on Human Rights 'Implementation of the right of disabled people to independent living' (23rd Report of Session 2010-12) 18 <http://www.publications.parliament.uk/pa/jt201012/jtselect/jtrights/257/257.pdf> (accessed 3 August 2012).

48 As above.

49 This study acknowledges but does not go into debates about what 'development' means as expressed by the terms 'developing countries' and 'developed countries' as the same are beyond the scope of the study. For purposes of this study, I needed to read particular countries contributions, and used the classification from the American Mathematical Society <http://www.ams.org/membership/individual/types/mem-develop> (accessed 9 July 2012).

50 UN Enable 'Daily summary of discussions related to article 15: Living independently and being included in the community' volume 4, no 5, 28 May 2004 <http://www.un.org/esa/socdev/enable/rights/ahc3sum15.htm>; and UN Enable 'Daily summary of discussions related to article 15: Living independently and being included in the community' volume 5, no 5, 27 August 2004 <http://www.un.org/esa/socdev/enable/rights/ahc4sumart15.htm> (accessed 17 November 2011).

51 Parker & Clements (n 39 above).

52 I Komardjaja 'Independent living and self-determination of women with physical disabilities in Bandung, Indonesia' (2004) 24 *Disability Studies Quarterly*.

not always relevant in the developing countries.⁵³ As a result, during the negotiations, developing countries placed great emphasis on support to families taking care of PWDs.⁵⁴ This support was envisaged as being both material and moral. It was emphasised that PWDs should be able to choose to live with their families, respecting social and cultural practices of family norms.⁵⁵ Developing countries also emphasised that 'independent living' should be understood to refer to a principle and not the 'independent living movement',⁵⁶ which may only apply to certain places or regions.⁵⁷ Some questioned whether anyone living in the community can be truly independent, given the necessary interdependence between members of the community.⁵⁸

Examining the stance of developing countries on article 19 during the CRPD negotiations is important because it sheds light on what they perceived the right to mean in their contexts and on what their fears with regard to it were.

3.3 The African human rights framework on disability

The 1981 African Charter on Human and Peoples' Rights⁵⁹ (Banjul Charter) recognises the rights of PWDs at the generic and specific levels.⁶⁰ This recognition is also present in Africa's other key human rights instruments such as the African Charter on the Rights and Welfare of the Child,⁶¹ the African Charter on Human and People's Rights on the Rights

- 53 Y Oka 'Self-reliance in interdependent communities: Independent living of disabled persons in the Asia Pacific Region' Presented at the Post Congress Seminar on Social Rehabilitation, Hamamatsu, Japan, 10-11 September 1988 <http://www.independentliving.org/docs4/oka.html> (accessed 14 November 2011).
- 54 For Morocco's position, see UN Enable 'Report of the third session of the Ad Hoc Committee on a comprehensive and integral international convention on the protection and promotion of the rights and dignity of persons with disabilities' <http://www.un.org/esa/socdev/enable/rights/ahc3reporte.htm> (accessed 25 October 2011). For Kenya's position, see 'Daily summary of discussions related to article 15: Living independently and being included in the community' vol 5, no 5 (n 50 above). The focus on families was also supported by Botswana, Qatar, Eritrea, Kenya and Jordan.
- 55 India, 3rd Session, May 28, 2004, 'Daily summary of discussions related to article 15: Living independently and being included in the community' vol 4, no 5 (n 50 above). This position was supported by Costa Rica, Morocco and Sudan in the 7th Session of the Ad Hoc Committee on 20 January 2006 <http://www.un.org/esa/socdev/enable/rights/ahc7sum20jan.htm> (accessed 3 August 2012).
- 56 For Thailand's position, see the 5th Session of the Ad Hoc Committee, 3 February 2005 <http://www.un.org/esa/socdev/enable/rights/ahc5sum3feb.htm> (accessed 3 August 2012). This view was also endorsed by Korea and South Africa, in this respect see the 4th session, 27 August 2004 <http://www.un.org/esa/socdev/enable/rights/ahc4sumart15.htm> (both accessed 3 August 2012).
- 57 Kenya, 4th Session, 27 August 2004 <http://www.un.org/esa/socdev/enable/rights/ahc4sumart15.htm> (accessed 3 August 2012).
- 58 Mali, 4th Session, 27 August 2004 (as above).
- 59 Organisation of African Unity, African Charter on Human and Peoples' Rights ('Banjul Charter') 27 June 1981, CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982) <http://www.unhcr.org/refworld/docid/3ae6b3630.html> (accessed 12 January 2013).
- 60 L Mute 'Concept on the list of issues to guide preparation of a protocol on the rights of persons with disabilities in Africa' (2012) (on file with author).

of Women in Africa⁶² and the African Youth Charter.⁶³ At the generic level, the provisions in Africa's human rights instruments, to the extent that they apply to individuals, do ensure protection of PWDs. Of particular importance, in this regard, are provisions which legislate equality and non-discrimination, including article 2 of the Banjul Charter,⁶⁴ article 2 of the 1990 Children's Charter⁶⁵ and article 2 of the 2006 Youth Charter.⁶⁶

At a more specific level, article 18(4) of the Banjul Charter provides that 'the aged and the disabled have the right to special measures of protection in keeping with their physical or moral needs'.⁶⁷ Article 13 of the Children's Charter provides *inter alia* that 'every child who is mentally or physically disabled shall have the right to special measures of protection in keeping with his physical and moral needs and under conditions which ensure his dignity, promote his self-reliance and active participation in the community'.⁶⁸

Other instruments that have specific articles touching on PWDs include the 2003 Maputo Protocol (article 23),⁶⁹ the Youth Charter (article 24),⁷⁰ the Charter on Democracy, Elections and Governance (Democracy Charter – articles 8, 31, and 43),⁷¹ the 2009 African Union Convention for the Protection and Assistance of Internally Displaced Persons in Africa (Kampala Convention – article 9),⁷² and the Protocol on the Protection and Assistance to Internally Displaced Persons (article 4⁷³ and principles 4 and 19⁷⁴). None of these instruments have a specific provision on people with disabilities living independently in the community.

61 Organisation of African Unity, African Charter on the Rights and Welfare of the Child, 11 July 1990, CAB/LEG/24.9/49 (1990) <http://www.unhcr.org/refworld/docid/3ae6b38c18.html> (accessed 12 January 2013).

62 African Union, Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa, 11 July 2003 <http://www.unhcr.org/refworld/docid/3f4b139d4.html> (accessed 12 March 2012).

63 African Union, African Youth Charter, 2 July 2006 <http://www.unhcr.org/refworld/docid/493fe0b72.html> (accessed 12 March 2012).

64 Organisation of African Unity (n 59 above).

65 Organisation of African Unity (n 61 above).

66 African Union (n 63 above).

67 Organisation of African Unity (n 59 above).

68 Organisation of African Unity (n 61 above).

69 African Union (n 62 above).

70 African Union (n 63 above).

71 African Union, African Charter on Democracy, Elections and Governance, 30 January 2007 <http://www.unhcr.org/refworld/docid/493fe2332.html> (accessed 12 January 2013).

72 African Union, African Union Convention for the Protection and Assistance of Internally Displaced Persons in Africa ('Kampala Convention'), 22 October 2009 <http://www.unhcr.org/refworld/docid/4ae572d82.html> (accessed 12 January 2013). The latter has not yet been entered into force.

73 International Conference on the Great Lakes Region: Protocol on the Protection and Assistance to Internally Displaced Persons [http://www.internaldisplacement.org/8025708F004BE3B1/\(httpInfoFiles\)/29D2872A54561F66C12572FB002BC89A/\\$file/Final%20protocol%20Protection%20IDPs%20-%20En.pdf](http://www.internaldisplacement.org/8025708F004BE3B1/(httpInfoFiles)/29D2872A54561F66C12572FB002BC89A/$file/Final%20protocol%20Protection%20IDPs%20-%20En.pdf) (accessed 12 January 2013).

74 Annexed to the Protocol are Guiding Principles on Internal Displacement.

4 The Kenyan context: Lived realities, data, law and policy related to PWDs in Kenya

4.1 The situation of PWDs in Kenya with regard to article 19

According to the 2009 Population and Housing Census report,⁷⁵ Kenya has a total population of 38 610 097 people, 4.6 per cent of whom are PWDs. The 4.6 per cent disability prevalence figure is disputable on several grounds. Firstly, the World Report on Disability of 2011 estimates that including children, over a billion people, or about 15 per cent of the world's population, live with disability.⁷⁶ Secondly, there is a symbiotic relationship between poverty and disability. Hence, the current high levels of poverty in the country are likely to result in a greater proportion of the population being PWDs. Thirdly, there is a problem with the instruments used to identify PWDs, so that mild to moderate impairments frequently go undetected.⁷⁷ Hence, the actual number of PWDs in Kenya is likely to be over five million people, most of who live with their families but without the necessary support to ensure their participation and inclusion in the community. Consequently, the issue of exclusion is important because it affects a significant sector of the society whose inclusion and participation article 19 seeks to ensure.

Several studies done in Kenya demonstrate that for the majority of PWDs, the objectives of article 19 have not been met.⁷⁸ Interviews undertaken for this study reinforce this position. The interviews sought to shed light on the extent to which PWDs are included and participate in community life in Kenya. These are some of the responses from the interviewees:

They [PWDs] are locked up, or they are inside the houses, one because they don't have mobility devices, and two even if they had mobility devices, the environmental barriers, are too many.⁷⁹

and

75 Kenya National Bureau of Statistics and Population and Housing Census <http://www.knbs.or.ke/censuspopulation.php> (accessed 29 June 2012).

76 World Health Organisation & The World Bank 'World Report on Disability' (2011).

77 University of Nairobi 'A final report of the University Disability Mainstreaming Committee' (2011).

78 Kenya UPR Stakeholders Coalition 'Annual Progress Report - An assessment by stakeholders of government's performance in implementation of UPR recommendations' (September 2011) http://www.upr-info.org/IMG/pdf/follow-up_kenya_stakeholders_annual_progress_report_2011.pdf (accessed 24 May 2012); and B Ingstad & L Grut 'See me but do not forget me: People with disabilities in Kenya' (February 2007) SINTEF Health Research, Oslo, Norway <http://siteresources.worldbank.org/DISABILITY/Resources/Regions/Africa/LCKenya2.pdf> (accessed 2 March 2011).

79 Interview with H Obande (n 22 above).

We need to understand the challenges that face people with disabilities, high levels of poverty, societal stigma, and exclusion, which makes it of course very difficult, first of all for them to live independently within their community, and also to be able to make their own decisions ...⁸⁰

It is important to note that the level of participation and involvement in community life depends on how adequately a person's support needs are answered. The needs of people who require high support are often not met, leading to greater incidence of exclusion from society. This distinction has been expressed in terms of 'double invisibility' of some PWDs.⁸¹

It is also critical to note that the majority of PWDs in Kenya live with their families and the primary responsibility for providing the necessary support is situated within the family.⁸² In a study of people with disabilities in Kenya, conducted by Benedicte and Lisbet in 2007, it is noted:

Individual independence can be a solution when the family is non-supportive, but we have seen that those who manage almost as a rule have a supportive family to rely on.⁸³

In spite of the central role of families, a report published by Equal Rights Trust and Kenya Human Rights Commission in 2012, noted that prejudice, stigma and discriminatory attitudes towards disability prevailed within families with far-reaching consequences for the ability of PWDs to participate equally in other areas of life.⁸⁴

In my interview with six self-advocates with intellectual disabilities,⁸⁵ all of whom were living with their families, only one reported a largely positive life at home.

It is clear that the majority of PWDs in Kenya live with their families. However, as stated in section 2, institutionalisation does occur in the context of mental health care, and to some extent, the provision of education in separate settings for children with disabilities.

80 Interview with M Njenga, Administrator, USP Kenya (Nairobi, Kenya, 10 May 2012).

81 G Quinn & T Degener 'Human rights and disability: The current use and future potential of United Nations human rights instruments in the context of disability' (2002) www.ohchr.org/Documents/Publications/HRDisabilityen.pdf (accessed 1 July 2012) provides: 'Some groups of people with disabilities are more invisible than others ... People with intellectual disabilities find it difficult in many societies to make progress – or at least as much progress as other groups with disabilities'.

82 'The Other Side of "Kenya's Terrible Secret"' *Open Society Foundations* 2 March 2011, states: 'Most [people in need of support services in Kenya] are isolated at home without the support they need'.

83 Ingstad & Grut (n 78 above) 52.

84 Equal Rights Trust in partnership with the Kenya Human Rights Commission 'In the spirit of Harambee: Addressing discrimination and inequality in Kenya' ERT Country Report Series: 1, London, February 2012 http://www.equalrightstrust.org/ertdocumentbank/In_the_Spirit_of_Harambee.pdf (accessed 19 March 2012).

85 Interview with R Wanjiku, E Mbithe, D Ongei, J Akinyi, J Rehema and D Misiko, Self-Advocates, Kenya Association of the Intellectually Handicapped (Nairobi, Kenya 9 May 2012).

In the context of mental health care in Kenya, the only formalised support comes in the form of institutionalisation in psychiatric hospitals. Community based mental health care services in Kenya are limited⁸⁶ and lack adequate funding to reach a wider portion of the population affected. Kenya has little provision for mental health; the government only spends 0.01 per cent of its health budget on mental health.⁸⁷ To a large extent, persons with psychosocial disabilities either live in their homes without support, and without meaningful engagement in the community, or as homeless people particularly in urban areas or are institutionalised in psychiatric hospitals, usually Mathari hospital – the main referral public mental hospital in Kenya.

With regard to education, learners with disabilities largely access education from primary school level onwards in boarding schools away from their families and their communities. This is largely due to a lack of choice of schools within their communities.⁸⁸ As has been described in section 2, living in the community in Kenya is linked with one's ethnic group. Special schools for learners with disabilities tend to be few and far between and are necessarily attended by learners with disabilities from all over the country. This inevitably entails a severance with one's community from an early age and has negative implications on the fulfilment of article 19 for children with disabilities in Kenya.

It is clear from the foregoing that PWDs are not fully included in the community. Further data from the interviews confirms that there have not been many initiatives on community living in Kenya.

4.2 Kenya's legal and policy framework related to article 19 of the CRPD

This section presents Kenya's legal and policy framework as it relates to article 19. Critical analysis of this framework is carried out in section 5.

4.2.1 The Constitution of Kenya

Kenya passed a new constitution in 2010, which for the first time provides explicit protection for vulnerable Kenyans including children, minorities and marginalised groups, and PWDs.

86 Interview with M Njenga (n 80 above).

87 Mind Freedom Kenya 'Report on mental health in Kenya' (October 2008) www.nsue.ie/m/uploads/files/MINDFREEDOM_KENYA_MF-K.pdf (accessed 2 July 2012).

88 Public education in Kenya is based on an 8-4-4 system, with eight years of primary education followed by four years of secondary school and four years of college or university. Kenya – Educational System – Overview <http://education.stateuniversity.com/pages/772/Kenya-EDUCATIONAL-SYSTEM-OVERVIEW.html> (accessed 2 July 2012).

The Constitution protects PWDs against discrimination by providing that the state must not discriminate directly or indirectly against any person on the ground of disability under article 27(4). Similarly, under article 27(5), a person may not discriminate against another person merely on account of that other individual having a disability.⁸⁹

Article 54 of the Constitution affirms the rights of PWDs in certain specific regards. These include the right to be treated with respect and dignity; to access education in an integrated setting, 'to the extent compatible with the interest of the person'; to reasonable access to all places, public transport and information; and to access materials and devices to overcome constraints arising from a person's disability. Article 54(2) requires the state to progressively ensure that at least five per cent of the members of the public in elective and appointive bodies are PWDs. The constitution also makes provisions for ensuring the effective representation of PWDs within elective and appointive bodies.⁹⁰

The right to live independently and be included in the community is not one of the rights that is exclusively identified under the constitution generally, or under the disability specific constitutional article (article 54). However, article 19(c) of the CRPD is covered by the extensive anti-discrimination provisions in the Constitution.

Article 19 comprises both civil and political and socio-economic rights. Article 27 of the Constitution of Kenya on equality and freedom from discrimination is the key civil and political right in the Constitution that to some extent echoes article 19.

Article 43 of the Constitution addresses economic and social rights, the right to health care services accessible and adequate housing, adequate food of an acceptable quality, clean and safe water in adequate quantities, social security and education. Article 21(2) of the Constitution requires the state to take measures to achieve the progressive realisation of the rights guaranteed under article 43. The implementation of the social economic rights provided for under the Constitution would go a long way towards promoting article 19 of the CRPD.

4.2.2 The Persons with Disabilities Act

The aim of the Persons with Disabilities Act 14 of 2003⁹¹ is to provide for the rights and rehabilitation of PWDs, to achieve equalisation of

89 L Mute 'The rights of persons with disabilities in Kenya, initiatives, considerations and priorities' Seminar on Rights of Persons with Disabilities in the Commonwealth, New Delhi, India, 15 January 2011.

90 The Constitution of Kenya, arts 54(2), 81(c), 81(2)(c)(i), 97(1)(c), 98(1)d, 177(1)(c), 232(1)(i)-(iii).

91 http://www.kenyalaw.org/kenyalaw/klr_app/frames.php (accessed 10 January 2011).

opportunities for PWDs, and to establish the National Council for Persons with Disabilities. The National Council for Persons with Disabilities is charged with formulating and developing measures and policies designed to enhance the welfare of PWDs.⁹² The Act also establishes the National Development Fund for Persons with Disabilities to provide monetary assistance to organisations and PWDs.

The rights provided for in the Act include civic rights, equal rights of access to opportunities for suitable employment, to special and non-formal education, appropriate health care, participation in sporting and recreational activities and to a barrier free and disability friendly environment. The government is tasked with the progressive realisation of some of these rights. The principle of non-discrimination runs through all these rights.⁹³

The Act does not contain an express right for PWDs to live in the community. It was enacted in 2003, prior to the coming into force of the CRPD. Examining the Act for compliance with article 19 reveals that one aspect of the article is very weakly covered under the Act. Article 7(1)(b)(i) echoes article 19(c) in providing that one of the functions of the National Council for Persons with Disabilities is to 'achieve equal opportunities for persons with disabilities by ensuring to the maximum extent possible that they ... are afforded full access to community and social services'. It is important to note that the use of the words 'to the maximum extent possible' somewhat waters down the strength of the provision. The Act does not contain any provisions with regard to article 19(a) and (b).

4.2.3 The Mental Health Act

The Mental Health Act, Chapter 248, Laws of Kenya regulates voluntary and involuntary treatment of persons with mental and intellectual disabilities. A person received as a voluntary patient intending to leave the hospital must give the person in charge of the hospital seventy-two hours' notice in writing of his intention to leave and the release shall be at the discretion of the person in charge of the mental hospital.⁹⁴ Further, under the Act, the court is empowered to make certain orders with regard to a person with a mental illness. These are orders for the management of the estate of any person with mental disorder and for the guardianship of any person with a mental disorder by any near relative or by any other suitable person. In cases where there is no known relative or other suitable person,

92 The Persons With Disabilities Act, sec 7(1)b.

93 E Kamundia 'Employment of persons with disabilities: A critical analysis of the Persons with Disabilities Act 2003' unpublished LLM thesis, University of Nairobi, 2010.

94 Mental Health Act, sec 10(3) http://www.kenyalaw.org/kenyalaw/klr_app/frames.php (accessed 16 April 2012).

the court may order that the Public Trustee be appointed manager of the estate and guardian of the mentally ill person.⁹⁵

This Act relates to article 19 in that mental health care is one of the areas under which institutionalisation occurs in Kenya, and this is the Act that regulates institutionalisation in this context.

4.2.4 National Disability Policy of 2006

The key policy with regard to PWDs is the National Disability Policy of 2006. The Policy recognises disability as a 'human rights and a development phenomenon that cuts across all aspects and spheres of society and which requires support from all sectors'.⁹⁶

One of the aims of the policy is to 'eliminate disparities in provision of services and ensure that services are available to all citizens with disabilities'. This substantially echoes article 19(c) of the CRPD. The closest the policy comes to mirroring article 19(a) and (b) is where it provides as its aim the 'inclusion and active participation of persons with disabilities in development and decision-making processes'.

Other policies and legal documents that specifically touch on PWDs include the draft national social protection policy,⁹⁷ the Kenya Vision 2030⁹⁸ and The Presidential Circular 1 of May 2008. None of these policies and legal documents explicitly recognises the right of PWDs to live independently in the community.

4.2.5 Cash Transfer Programmes

Kenya does not have a welfare system to support sectors of the population who are less advantaged such as those who are unemployed, or who are unable to meet their basic needs for whatever reasons.⁹⁹ It does however provide piece meal support to a few specific groups of disadvantaged people including older persons, orphans and vulnerable children.¹⁰⁰ In the

⁹⁵ Sec 26.

⁹⁶ Ministry of Gender, Children and Social Development 'National disability policy' (2006).

⁹⁷ Ministry of Gender, Children and Social Development 'Social protection policy' (2011)? <http://www.gender.go.ke/index.php/About-Us/social-protection-policy.html> (accessed 2 August 2012).

⁹⁸ Kenya Vision 2030 <http://www.vision2030.go.ke/> (accessed 2 August 2012).

⁹⁹ For Kenya's economic situation, see the United Nations Development Programme 'Summary human development report 2009 – Overcoming barriers: Human mobility and movement' http://hdr.undp.org/en/media/HDR_2009_EN_Summary.pdf (accessed 26 February 2012); and Central Intelligence Agency 'The world fact book: Kenya' <https://www.cia.gov/library/publications/the-world-factbook/geos/ke.html> (accessed 26 February 2012).

¹⁰⁰ Ministry of Gender, Children and Social Development <http://www.gender.go.ke/index.php/Table/SP-Programmes/> (n 97 above).

context of disability, there are two key state established funds. These are the Cash Transfer Programme for Persons with Severe Disabilities set up under the Ministry of Gender, Children and Social Development and the National Disability Fund for Persons with Disabilities set up under section 32 of the Persons with Disabilities Act.

From the foregoing, it is clear that article 19 is not covered substantively in Kenya's domestic legal and policy framework. Hence, the key proposal in this section is that a policy on community living in the country is necessary to flesh out the import of article 19 in the Kenyan context.

5 Giving content to the core of article 19 in Kenya and recommendations

At this juncture the objective of article 19 needs to be established. The article takes the view that 'the bundle of rights and obligations in Article 19 are both a means and an end. The end is always of the persons' own choosing. The means focus on the steps that need to be taken to allow for real choice'.¹⁰¹ Article 19 has a general end in mind – ensuring full inclusion and participation of all people with disabilities, in the community. Put another way, the vision of article 19 for PWDs is that they should not be isolated or segregated from the community. PWDs should be able to sing in the local choir, play with kids at the local playground, drink with their peers at the local pub if they so wish. PWDs should attend their local school, work, vote and participate fully in community life.

This then leads us to a series of questions: What does community life entail? Is it not living somewhere while at the same time, being able to move from one place to another at will? Is it not expressing ones opinions and wishes? Is community life not to some extent dependent on age, doing the things people of one's age do? In this regard then, is not going to school participating in community life? Is not working participating in community life? What about playing? Is not having a family, having friends, establishing relationships participating in community life? Is this not almost inextricably related to the state of one's health?

Examining these questions demonstrates the challenge of defining the core to the right to community living in the context of Kenya. On one side of the coin, is the fact that the above matters are all core to community life. A look at these matters reveals that they constitute a stand-alone right in the CRPD. This brings us to the other side of the coin which is that the drafters of the CRPD must have been convinced that there is a place where these rights end and the right to living independently and being included in

101 Office of the United Nations High Commissioner for Human Rights (n 1 above).

the community begins. Otherwise, article 19 would have simply been the sum total of the achievement of these rights, and would not have been worth having as a stand-alone right in the Convention. The core of this right has been described as being ‘about neutralising the devastating isolation and loss of control over one’s life, wrought on people with disabilities because of their need for support against the background of an inaccessible society.’¹⁰² In this sense then, where institutionalisation is prevalent, it is clearer what this right means to some extent, because at the very minimum it must surely mean the dismantling of such institutions.¹⁰³ But what does it mean in the context of a country in which institutions are not prolific and PWDs are still excluded from community life? What is at the core of article 19 in this situation and what should a policy that implements article 19 in the Kenyan context look like?

In an attempt to answer these questions, this article makes several policy proposals in the recommendations below. Inevitably, some aspects of these policy proposals have to do with the implementation of other rights considering, as argued above, that the key elements that constitute community life have found expression in the CRPD as stand-alone rights. Elements of community life that may not have at their core stand-alone CRPD rights touch upon stigmatisation of PWDs in society. One is hard pressed to find a situation of exclusion that does not have at its core, these two aspects – the failure to fulfil a substantive stand-alone right in the CRPD; and a tendency by society to fear, stigmatise, and discriminate against people with disabilities. To this end, article 19(c) requires that states ensure that ‘community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs’. As such, article 19(c) makes the other rights core article 19 issues, in light of the fact that the abovementioned services must surely include education, health, employment, recreation and participation in political and public life. Hence addressing, to some extent the fulfilment of other rights in this article is not a diversion – it is addressing a core article 19 issue. To this extent then, article 19 is a study in the interrelatedness and indivisibility of rights. Article 19 cannot be fully implemented without implementing other rights, indeed, article 19 in itself demands the implementation of other rights – yet, there is more to the core of article 19 that cannot wait for the implementation of other rights. The core of community living is not one thing – it consists of many factors interacting with each other.

¹⁰² Commissioner for Human Rights (n 16 above).

¹⁰³ As above. It is important to note that although governments recognise the inevitability of deinstitutionalisation, there is less clarity with regard to the mechanisms that replace institutions and would constitute a human rights based response.

5.1 State obligations

With regard to article 19, what did Kenya bind itself to, when it implemented the CRPD? The answer lies in looking at the interplay between article 4 and article 19. In ratifying the CRPD, Kenya undertook to take effective and appropriate measures to facilitate the full enjoyment of the right of PWDs to live independently with choices equal to others. It also undertook to take effective and appropriate measures to facilitate PWDs' 'full participation and inclusion in the community'.

Part of the required action under article 19 is the explicit recognition of the right to community living.¹⁰⁴ There is no community living policy in Kenya, and article 4(1)(a) may be said to require it as a first step towards ensuring community living for PWDs.

A look at the state obligations reveals that states have bound themselves up to a high ideal; and that is why it is important to keep in mind the principle of progressive realisation.¹⁰⁵ Retrogressive measures are not permissible, unless a state can demonstrate that it has made every effort to use all resources at its disposal to meet its obligation.¹⁰⁶

5.2 Recommendations

In the first place, article 19 read together with article 4 on state obligations requires Kenya to put in place a policy on community living for PWDs. The policy should be designed in such a way as to include persons with high support needs. The following are some of the issues that the policy on community living must address. Though presented as falling under the various sub-articles of article 19, in reality the recommendations cut across the entire article.

To promote choice among PWDs (article 19(a)) the community living policy should:

- Place an obligation on the state to make PWDs aware of their rights;
- Require that PWDs are consulted and actively involved in issues concerning them;
- Require the state to build awareness of the rights of PWDs among families, aiming at changing their attitudes towards their family member with disabilities;

¹⁰⁴ Parker (n 46 above).

¹⁰⁵ Economic and Social Council 'An evaluation of the obligation to take steps to the 'maximum of available resources' under an Optional Protocol to the Covenant' <http://www2.ohchr.org/english/bodies/cescr/docs/statements/Obligationtotakesteps-2007.pdf> (accessed 3 August 2012).

¹⁰⁶ Office of the High Commissioner for Human Rights <http://www.ohchr.org/Documents/Publications/Factsheet31.pdf> (accessed 23 July 2012).

- Provide financial support to families in recognition of their role as carers, and the effect this has on their earning capacity;
- Create flexible working hours for carers of PWDs who are in employment;
- Give clear guidelines on disability assessments, requiring that the applicant's needs occupy a position of prime importance in the assessment;
- Embody a paradigm shift in the CRPD, towards a switch from institutionalisation and towards a community based mental health care system;
- Take into account the interplay between article 19, and the social economic rights provided for under article 43 of the Constitution of Kenya;
- Take into account the link between article 12 on legal capacity and article 19 and hence provide broad principles around the exercise of legal capacity for all persons addressing varying levels of support needs around decision-making;
- In consultation with all the relevant actors address situations where even after all the interventions to prevent severe mental breakdown from happening, the same occurs;
- Give advance directives in mental health care legal standing; and
- Provide for state funding for DPOs upon application.

To promote the provision of individualised support services (article 19(b)) the community living policy should:

- Make it clear that the efforts undertaken under Community Based Rehabilitation (CBR) are tied in directly with participation and inclusion in the community;
- Provide for state funded centres for community living, traditionally known as Centres for Independent Living; and
- Hold a vision for the future that foresees family members receiving direct payments for their caring work, beyond the support currently being provided that is linked to poverty eradication.

To promote equality of access to mainstream services and inclusion (article 19(c)) the community living policy should:

- Give concrete disability mainstreaming guidelines; and
- Provide for inclusive education within the community with the appropriate support to ensure that learners with disabilities access quality education.

Underlying the above recommendations is the need to:

- Address training for government workers on disability issues, and establish a sustainable way of raising awareness;
- Address access, in the broadest sense of the word including access to buildings, public transport and information; and
- Endorse universal design for all upcoming facilities.

6 Conclusion

This article has examined community living for PWDs in the Kenyan context where PWDs live with their families but without state funded individualised support services. The article has confirmed that the majority of PWDs lead isolated lives, despite being physically located within the community. It has also confirmed that institutionalisation does occur in Kenya in the context of mental health care and the provision of education for children with disabilities in separate settings. This article took an in depth look at article 19 of the CRPD to establish what the state obligations are with regard to ensuring that PWDs live independently within their communities. The study then made several recommendations that, if implemented, would go a long way towards ensuring that PWDs participate and are fully included in the community in Kenya.

At this point, it is necessary to make general conclusions. Firstly, in implementing article 19(c), it is important to ensure efforts are not duplicated across government departments. Hence, there is need for coordination among government ministries, via the NCPWD, the coordinating agency under article 33(1) of the CRPD.

Secondly, the monitoring body under article 33(2) of the CRPD needs to be strengthened. Article 19 is primarily about people being allowed to have lives of their own choosing. This makes it extremely difficult to measure. In the context of Kenya, it involves questions like do PWDs attend religious services? Do they undergo rites of passage like their non-disabled peers? Section 5 proposed a community living policy but without a strong monitoring body even if the policy was passed it may not be implemented.

Thirdly, this study did not focus much on what were identified as individual article 19(c) rights. But it suffices here to emphasise that in Kenya, public transport is still inaccessible, public buildings are still, largely, inaccessible and assistive devices are not available to all who need them. Employment of PWDs is still low, and their access to education is far from 'on an equal basis with others'. These issues are not novel but they are certainly not implemented in Kenya and this gap really impacts negatively on the ability of PWDs to live independently in the community.

It is clear that article 19 and the CRPD as a whole, to a large extent, place the obligation for implementation on the state. Hence, the policy recommendations in this study concentrated on what the state should do to meet its obligations under article 19. However, it is important to note that the initiatives of other actors matter. Families of PWDs, DPOs and monitoring bodies must all play their part in ensuring that PWDs live independently in the community.

