

THE RIGHT TO INDEPENDENT LIVING AND BEING INCLUDED IN THE COMMUNITY: LESSONS FROM THE UNITED NATIONS

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ABSTRACT

This review will consider recent United Nations activity on article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) concerning the right to live independently and be included in the community. The Committee on the Rights of Persons with Disabilities adopted its 'General Comment' No. 5 in August 2017, which offers guidance to governments on art 19 implementation. This review critically examines content relevant to mental health and capacity law, policy and practice. It considers the strengths and potential limitations of the General Comment with reference to key issues in the field. Gaps include commentary on the rising marketisation of disability services globally and a focus on low and middle-income countries. Yet overall, the General Comment offers useful guidance on implementing this unusual right, including concepts that may help resolve controversies about the role of coercion in mental health and capacity law.

Key words: CRPD; Convention on the Rights of Persons with Disability; disability; independent living; human rights

I. INTRODUCTION

The institutionalisation and exclusion of persons with disabilities has caused – and continues to cause – immense harm to individuals, families and communities. Resistance to this harm in international human rights law led to the development of a 'right of all persons with disabilities to live in the community, with choices equal to others' in art 19 of the Convention on the Rights of Persons with Disabilities ('CRPD').¹

The unusual provision is highly relevant to mental health and capacity law.² On one hand, mental health and capacity laws can serve to deprive people of liberty in hospitals and other places, including locked wards, hospitals and residential facilities.³ On the

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¹ United Nations [UN] 2515 UNTS 3, UN Doc A/Res/61/106, Annex, GAOR 61st Session Supp 49, 65. (Adopted) 13 Dec 2006, (Opened for Signature) 30 May 2007, (Entered Into Force) 3 May 2008.

² I am using 'mental health and capacity law' in this paper to refer to mental health legislation and other laws related to mental capacity and legal capacity, including those that authorise substituted and/or supported decision-making, E.g. – The Mental Capacity Act 2005 (England and Wales) c 9; Assisted Decision-Making (Capacity) Act 2015 (Ireland) No 64 of 2015; Representation Agreement Act 1996 (Revised Statutes of British Columbia R.S.B.C.) c 405.

³ Agnes Turnpenny and colleagues, for example, note in their survey of mental health policy in 35 European countries, how mental health law can serve as a 'pathway into residential institutions'. A Turnpenny, G Petri, A Finn, J Beadle-Brown and M Nyman, *Mapping and Understanding Exclusion: Institutional, coercive and community-based services and practices across Europe* (Mental Health Europe, 2018) [24] <<https://doi.org/10.22024/UniKent/01.02/64970>> (accessed 12/02/2018).

other hand, 'rights-based mental health legislation'⁴ and late 20th Century guardianship/mental capacity laws in middle and high-income countries were partly introduced to help move people *away* from large, standalone institutions and to promote 'community care'. While the success of 'deinstitutionalisation' may be disputed, it is true that liberal law reformers sought to limit interventions to the 'least restrictive means available' and facilitate access to non-institutional, community-based services.⁵ A third dimension in the relevance of independent living is that the absence of community-based support for independent living can contribute to the types of crises that 'warrant' intervention under the terms of mental health and capacity laws. Civil commitment laws may be invoked after a person's mental health crisis is exacerbated by unstable housing or institutional-like community services. Mental capacity and guardianship law may be invoked when a person with cognitive disability faces a major life decision and is in a situation of extreme risk because of their sheer social isolation.

Mental health and capacity law has provoked considerable controversy since the CRPD came into effect, yet Art 19 seems to draw an unusual consensus. Commentators across the spectrum – from those who see a role for coercion and substituted decision-making, to those who think they should be eliminated – appear to agree on the need for more resources for people with intellectual, cognitive and psychosocial disabilities so as to enable them to exercise their right to live independently and participate in the community. As such, the 2017 release by the 'Committee on the Rights of Persons with Disabilities' (hereafter 'the Committee') of its *General Comment no. 5 on art 19*, will be welcomed by many.⁶

The Committee is established by Article 34 of the CRPD and is comprised of a panel of experts that monitors implementation, including by reviewing the compliance of governments that have signed and ratified the CRPD. A 'General Comment' is a quasi-legal document published by United Nations committees, which provides a detailed interpretation of an article or issue relating to their respective human rights treaties. Helen Keller and Leena Grover have described General Comments as 'non-binding norms that interpret and add detail to the rights and obligations contained in the respective human rights treaties'.⁷

⁴ B McSherry and P Weller (eds), *Rethinking Rights-Based Mental Health Laws* (Hart 2010).

⁵ According to Larry Gostin, statutory duties introduced under rights-based mental health law included those designed to secure individual rights, including rights to access services and refuse medical treatment. L Gostin, 'The Ideology of Entitlement: The Application of Contemporary Legal Approaches to Psychiatry' in P Bean (ed), *Mental Illness: Changes and Trends* (Wiley, 1983) [50].

⁶ Committee on the Rights of Persons with Disabilities, *General Comment No 5: Article 19 (2017) on living independently and being included in the community*, 18th sess, UN Doc CRPD/C/GC/5 (27 October 2017). The Committee is authorised under article 34 of the CRPD to monitor implementation of the CRPD; including reviewing the compliance reports of 'States Parties' (states that have ratified, or have otherwise become party to the CRPD) and offering interpretive guidance on key elements of the CRPD. CRPD Art 34. 'General Comments' allow the relevant UN treaty body, in this case the CRPD Committee, to publicly interpret provisions from their respective human rights treaty. For more information on the legal status of General Comments, see — Michalowski, S, and W Martin, 'MoJ/EAP UNCRPD Project Research Note: The Legal Status of General Comments' (The Essex Autonomy Project, 23 May 2014) <www.autonomy.essex.ac.uk> (accessed 12/02/2018).

⁷ H Keller and L Grover, 'General Comments of the Human Rights Committee and their Legitimacy' in H Keller and G Ulfstein (eds), *UN Human Rights Treaty Bodies: Law and Legitimacy* (Cambridge University Press, 2012) [116], [129].

In this paper I will distil content relevant to mental health and capacity law from the CRPD Committees General Comment no. 5 (hereafter 'the General Comment'). Throughout, I will reflect on, among other issues, the inter-related matters of housing and economic policy, hospital practices, the privatisation and personalisation of welfare services, the issues facing low- and middle-income countries (including countries without mental health legislation).

II. BACKGROUND

The full text of Art 19 is as follows:

Living independently and being included in the community—

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

There is a small but significant body of literature on article 19.⁸ This material builds on a vast literature on disability and 'independent living', which variously refers to: a philosophy of equal opportunities, self-determination and respect,⁹ a global social movement¹⁰ and a framework for developing law, policy and practice.¹¹

Art 19 exemplifies efforts to blend so-called first-and second-generation rights. In other words, the civil and political rights of the provision (particularly, the right to liberty of movement and freedom to choose one's residence) requires the provision of economic, cultural and social rights (for example, the right to an adequate standard of living, including adequate clothing, food and housing). Additional resources are needed to

⁸ E.g. – G Quinn and S Doyle, 'Taking the United Nations Convention on the Rights of Persons with Disabilities Seriously: The Past and Future of the EU Structural Funds as a Tool to Achieve Community Living' (2012) 9 *The Equal Rights Review* [69]; Fundamental Rights Association, *Human Rights Indicators on Article 19 of the CRPD* (2014); Council of Europe Commissioner for Human Rights, "The Right of People with Disabilities to Live Independently and Be Included in the Community", Comm DH/Issue Paper (2012) [3], Strasbourg, 13 March 2012.

⁹ C Barnes, 'Independent Living, Politics and Policy in the United Kingdom: A Social Model Account' (2014) 1(4) *Review of Disability Studies: An International Journal*.

¹⁰ E.g. – P Deegan, 'The Independent Living Movement and People with Psychiatric Disabilities: Taking Back Control over Our Own Lives' (1992) 15 *Psychosocial Rehabilitation Journal* [3].

¹¹ G DeJong, 'Independent Living: From Social Movement to Analytic Paradigm' (1979) 60(10) *Archives of physical medicine and rehabilitation* [435]; Barnes, above n 9.

make civil and political rights real to many disabled people, whereas many non-disabled people take such rights for granted.

The European Commissioner for Human Rights, Thomas Hammarberg, argued that the indivisibility of rights in Art 19 is the key to addressing the devastation caused by institutionalisation and exclusion:

[t]he 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. 'Neutralising' is understood as both removing the barriers to community access in housing and other domains, and providing access to individualised disability-related supports on which enjoyment of this right depends for many individuals.¹²

The Commissioner suggests that new regulatory measures and funding priorities are needed to meet this objective. To this end, the European Fundamental Rights Association developed policy indicators to assess Art 19 compliance.¹³ The indicators were drawn upon by the European Parliament, in order to withdraw 'European Structural and Investment Funds' from the funding of disability institutions.¹⁴

However, closing institutions is but one requirement of Art 19. Hammarberg highlighted 'worrying trends' of standalone institutions being replaced by group-based homes and residential facilities; 'targeted exclusively to persons with disabilities'.¹⁵ These facilities, he writes: 'compromise the individual's ability to choose or to interact with and be included in the community'.¹⁶ Gerard Quinn and Suzanne Doyle elaborate on the Art 19 obligations that spread beyond institutional closures and extend to establishing 'a web of personalised supports to meet the personal circumstances of the person'.¹⁷

This is not so much about needs and services – it is more about the silent revolution in traditional understandings of welfare which is to get away from gross proxies of need (with equally gross services) and to focus instead on the life plans and ambitions of the person.¹⁸

From this view, Art 19 operates to both prohibit institutional models of supported accommodation and paternalistic domination, while also requiring national investment in community-based living options.

Statute and case law have been influenced by Art 19 in some jurisdictions. For example, courts have referred to Art 19 in several decisions in the United Kingdom;¹⁹ New

¹² T Hammarberg, 'The Right of People with Disabilities to Live Independently and be Included in the Community' (Issue Paper, Council of Europe Commissioner for Human Rights, June 2012) [8].

¹³ Fundamental Rights Association, *Human Rights Indicators on Article 19 of the CRPD* (2014).

¹⁴ Community Living for Europe, Structural Funds Watch, *Building on the Promise of European Structural and Investment Funds into the Future, Report on roundtable discussions in the European Parliament - 1st December 2016* (2016) <www.communitylivingforeurope.org/2016/12/15/report-on-roundtable-discussions-in-the-european-parliament-on-1st-december-2016-outcomes-and-video-recording/> (accessed 20/5/2017).

¹⁵ Council of Europe Commissioner for Human Rights, above n 8, [9].

¹⁶ *Ibid.*

¹⁷ Quinn and Doyle, above n 8, [73].

¹⁸ *Ibid.*

¹⁹ *Burnip v Birmingham City Council & Anor* [2012] EWCA Civ 629.

Zealand;²⁰ and Australia²¹ – generally to limit interference by health and social services on the living arrangements of disabled people. Some legislation may even incorporate features of Art 19.²² The Department of Health in England, for example, reported that the ‘wellbeing principle’ of the *Care Act 2014*, which guides service delivery by local authorities; ‘is intended to cover the key components of independent living as expressed in the [CRPD and] in particular, Article 19’.²³ It is not clear whether *The Care Act 2014* actually incorporates Art 19 in practice,²⁴ and the CRPD Committee has expressed concern that the United Kingdom has reduced social protection schemes for housing; household income and budgets for independent living, including the ‘Independent Living Fund’.²⁵ Nevertheless, these examples, including European parliamentary steps to divest from institutions, suggest Art 19 is having some impact on law, policy and practice internationally.

Art 19 raises several questions for governments. To what extent must states respect a person’s right to choose where to live, even in the face of grave risks? What level of supports and adjustments need to be guaranteed to meet positive obligations and avoid a charge of neglect and abuse? At what point, if at all, can intervention take place that might violate the right to independent living – for example, in short-term accommodation or hospitalisation? Is Art 19 violated by small group homes and clustered living arrangements, which appear to be fixtures of many disability housing policies affecting persons who fall under mental health and capacity laws? What are good practices for upholding Art 19 for people with mental health, cognitive and intellectual disabilities?

Just prior to the release of the General Comment, the Office of the United Nations High Commissioner for Human Rights (hereafter ‘OHCHR’) published a background paper.²⁶ The publication includes contributions from Member States, regional organisations, disabled peoples’ organisations, broader civil society organisations, the Special Rapporteur on Disability, national human rights institutions and others.²⁷ A day of general discussion in April 2017 also preceded the General Comment, for which written submissions are publicly available.²⁸ Taken together, these materials form a rich

²⁰ *Ministry of Health v Atkinson* [2012] NZCA 184; [2012] 3 NZLR 456 (14 May 2012) [42]; *Bracking v Secretary of State for Work and Pensions* [2013] EWCA Civ 1345.

²¹ *P J B v Melbourne Health & Anor (Patrick’s case)* [2011] VSC 327 (19 July 2011) [210].

²² Department of Health (United Kingdom), *Guidance: Care and support statutory guidance* (Updated 24 February 2017) <www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance> (accessed 5/05/2017); *Care Act (England) 2014* Ch 23 Pt 1 s 1; see also — *Social Services and Well-being (Wales) Act 2014* anaw 4.

²³ Department of Health (United Kingdom), above n 22, (para) 1.19; *Care Act 2014* Ch 23 Pt 1 s 1.

²⁴ L Series, ‘The elusive Article 19’ on L Series, *The Small Places* (24 Nov 2016) <<https://thesmallplaces.wordpress.com>> (accessed 12/02/18).

²⁵ CRPD/C/GBR/CO/1, (para) 44(b).

²⁶ *Thematic study on the right of persons with disabilities to live independently and be included in the community Report of the Office of the United Nations High Commissioner for Human Rights*, 28th sess, UN Doc, A/HRC/28/37, 12 December 2014.

²⁷ For the full text of submissions, see:

<www.ohchr.org/EN/Issues/Disability/Pages/LiveIndependently.aspx> (accessed 5/05/2017).

²⁸ See: <www.ohchr.org/EN/HRBodies/CRPD/Pages/CallDGDtoliveindependently.aspx>

resource in global efforts to reduce exclusion, and promote independent living and inclusive communities.

III. A SUMMARY OF THE GENERAL COMMENT

The General Comment is grouped into four major sections, related to: (1) the normative content of Art 19, (2) the obligations of States Parties, (3) the relationship of Art 19 to other parts of the CRPD, and (4) national implementation. I will summarise these sections here, though readers familiar with the General Comment may wish to jump straight to Part IV.

(a) Normative Content

The General Comment immediately positions Art 19 as a response to the historical denial of the individual choice and control of disabled person across all areas of their lives.²⁹ As the Committee notes:

[i]ndependent living and inclusive life in the community are ideas that historically stemmed from persons with disabilities asserting control over the way they want to live by creating empowering forms of support'.³⁰

For most people with disability: '[s]upport is either unavailable or tied to particular living arrangements'³¹, and the result for many has been 'abandonment, dependence on family, institutionalization, isolation and segregation'.³² The Committee characterise most law, policy and practice as tending to portray individuals with the disability as the problem. Traditionally, efforts have been directed to altering the behaviour of the individual and forcing her or him to fit into social structures that are unaccommodating and even hostile to people with disability. Hence, the Committee emphasise two dimensions of Art 19: the personal (particularly, creating a sphere of protection around the person's home, lifestyle choices, and so on) and the social (particularly, improving the accessibility and inclusivity of communities).

The Committee highlight that Art 19:

[i]s an example of the interrelation, interdependence and indivisibility of all human rights', describing it as 'one of the widest ranging and most intersectional articles of the Convention [which] has to be considered as integral to [its] full implementation'.³³

The Committee also restates from the CRPD Preamble that most persons with disabilities live in poverty, emphasising the material conditions in which independent living can occur. At the same time, the Committee highlight that the 'cost of social exclusion is high as it perpetuates dependency'.³⁴

(accessed 5/05/2017).

²⁹ CRPD Committee, above n 6, [4].

³⁰ Ibid [4].

³¹ Ibid [1].

³² Ibid [1].

³³ Ibid [6].

³⁴ Ibid [5].

Furthermore:

[p]olicies and concrete plans of action for social inclusion of persons with disabilities... represent a cost-effective mechanism to ensure the enjoyment of rights, sustainable development and a reduction in poverty.³⁵

The Committee links Art 19 to previous human rights treaties.³⁶ The Universal Declaration of Human Rights (hereafter “UDHR”), for example, recognises the interdependence of an individual’s personal development and his or her social and community life. Art 29(1) of the UDHR states:

Everyone has duties to the community in which alone the free and full development of his personality is possible.³⁷

For those who have seen—or themselves experienced—the way peoples identities are spoiled in institutional environments, the relevance of free and full development of personality will be immediately obvious. The restatement in Art 19 of the right to choose one’s place of residence also stands as an integral part of several human rights instruments.³⁸

(b) The Obligations of State Parties

The Committee discuss the obligations on States Parties to ‘respect’, ‘protect’ and ‘fulfil’. The first of these obligations, the obligation to *respect* refers to governments refraining from interference in a person’s autonomy and his or her choices about where and with whom to live.³⁹ This obligation includes:

Releas[ing] all individuals who are confined against their will in mental health services or other disability-specific forms of deprivation of liberty. It further includes the prohibition of all forms of guardianship and the obligation to replace substituted decision-making regimes with supported decision-making alternatives.⁴⁰

The second obligation, to *protect*, relates to states preventing ‘third parties from directly or indirectly interfering with the enjoyment of the right to live independently within the community’, which includes ‘family members and third parties, service providers, landowners or providers of general services’.⁴¹ Positive obligations include improving ‘accessibility for persons with disabilities within the community and [raising]

³⁵ Ibid.

³⁶ The Convention on the Elimination of Discrimination against Women UN Doc A/RES/34/180, Annex (CEDAW) is discussed, as is the Convention on the Rights of the Child (United Nations [UN]) 1577 UNTS 3, CTS 1992/3, UN Doc A/RES/44/25, UN Reg No I-27531 (CRC). See — CRPD Committee, above n 6, [10-11].

³⁷ Universal Declaration of Human Rights (United Nations [UN]) UN Doc A/810, 71, UN Doc A/RES/217(III) A, GAOR 3rd Session Part I, 71 (Signed) 10 Dec 1948,[art 29 (1)].

³⁸ E.g. – UDHR, article 13; ICCPR, articles 12, 25.

³⁹ CRPD Committee, above n 6, [47-49].

⁴⁰ Ibid [48].

⁴¹ Ibid [50].

awareness among all persons in society about inclusion of persons with disabilities within the community'.⁴²

The third obligation, to *fulfil*, refers to the creation of 'appropriate legislative, administrative, budgetary, judicial, promotional and other measures' to meet Art 19 requirements, including: 'deinstitutionalising', consulting with disabled peoples organisations in crafting alternatives, ensuring affordable housing, moving away from deficit-focused assessments of impairment as a pre-requisite for services and instead looking to a person's support needs, and personalising services accordingly.⁴³ The Committee also promotes access to justice, including through 'reasonable accommodation' (article 2)⁴⁴ and 'procedural accommodation' (article 13)⁴⁵ so that persons with disabilities can assert their right to independent and community living and have it enforced.⁴⁶

(c) Relationship to other Articles

The General Comment contains a reasonably comprehensive section on the relationship between article 19 and other parts of the CRPD. Particular attention is paid to Art 4(3) (in which consultation with disabled people is required),⁴⁷ Art 5 (equality and non-discrimination),⁴⁸ Art 6 (intersectional barriers facing women and girls),⁴⁹ and so on.⁵⁰ I will discuss in the next Section the Committees view on interactions between Art 19 and key operative articles affecting mental health and capacity law, particularly articles: 12 (equal recognition before the law); 14 (liberty and security of the person), 16 (freedom from exploitation, violence and abuse), 23 (the right to family for children and parents with disabilities), and 25 (health care).⁵¹ The connections between Art 19 and other parts of the CRPD helps to connect the concept of independent living across different points of a person's typical life-course; as a child, a student, a worker, a voter, a family member, senior citizen, and so on.⁵²

⁴² Ibid [57]. See also — Concluding Observations by the CRPD Committee on Kenya (CRPD/C/KEN/CO/1 [23]), Uganda (CRPD/C/UGA/CO/1 [22]).

⁴³ CRPD Committee, above n 6, [54-65].

⁴⁴ 'Reasonable accommodation' is defined in the CRPD as 'necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms'. CRPD, Article 2.

⁴⁵ 'Procedural accommodation' is defined in the CRPD as measures that facilitate a person's 'effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages'. CRPD Article 13.

⁴⁶ Ibid [66] and [81].

⁴⁷ Ibid [70].

⁴⁸ Ibid [71].

⁴⁹ Ibid [72].

⁵⁰ Ibid [73-77].

⁵¹ Ibid [78-91].

⁵² On this point, the Mental Disability Advocacy Centre (now 'Validity') submission is informative. Mental Disability Advocacy Centre, 'The Right to Live Independently and be Included in the Community - Written Comments to the UN Committee on the Rights of Persons with Disabilities in response to its Call for Submissions to the Day of General Discussion on 19 April 2016 <<http://www.ohchr.org>> (accessed 6 February 2018).

(d) Implementation at the National Level

The Committee identify key elements needed for States Parties to realise a 'standardized minimum support level sufficient to allow the exercise of the right to live independently and be included in the community'.⁵³ These elements include: ensuring the right to legal capacity; ensuring non-discrimination in accessing housing ('including the elements of both income and accessibility'); developing action plans for independent living for persons with disabilities within the community; monitoring and sanctioning non-compliance with legislation; developing plans and guidance on accessibility requirements for basic mainstream services; taking steps towards developing and implementing 'basic, personalized, non-shared and rights-based disability-specific support services'; and collecting 'consistent quantitative and qualitative data on persons with disabilities, including those still living in institutions'.⁵⁴ Failure to ensure any of these elements to persons with disabilities counts as a failure to fulfill States Parties' Art 19 obligations, according to the Committee.⁵⁵

The Committee distinguishes between parts of Art 19 subject to 'immediate and progressive realisation'. The Committee note that: '[a]s a civil right, article 19(a), the right to choose one's residence and where, how and with whom to live, is immediately applicable'.⁵⁶ In contrast, both 19(b) and (c) are 'subject to progressive realization',⁵⁷ given that Art 19(b) 'is a classic social right', and Art 19(c) 'is a social and a cultural right, given that many community services, such as cinemas, public parks, theatres and sports facilities, serve cultural purposes'. Nevertheless, States Parties must:

[t]ake steps to the maximum of their available resources .. taken immediately or within a reasonably short period of time .. (and in a way that is) .. deliberate, concrete, targeted and .. (pursued by) .. all appropriate means.⁵⁸

The Committee acknowledge 'advancements in implementing article 19 in the past decade' yet frame the Comment by listing major barriers to this implementation. These barriers are worth citing in full:

- (a) Denial of legal capacity, either through formal laws and practices or de facto by substitute decision-making about living arrangements;
- (b) Inadequacy of social support and protection schemes for ensuring living independently within the community;
- (c) Inadequacy of legal frameworks and budget allocations aimed at providing personal assistance and individualized support;
- (d) Physical and regulatory institutionalization, including of children and forced treatment in all its forms;
- (e) Lack of deinstitutionalization strategies and plans and continued investments in institutional care settings;

⁵³ CRPD Committee, above n 6 [38].

⁵⁴ Ibid [38][a-h].

⁵⁵ Ibid [43], See -- International Covenant on Civil and Political Rights (United Nations [UN]) 999 UNTS 171, UN Doc A/6316, UN Doc A/RES/2200(XXI), Annex, UN Reg No I-14668 [Signed] 19 Dec 1966 [Entered into Force] 23 Mar 1976, [Article 2].

⁵⁶ CRPD Committee, above n 6, [39].

⁵⁷ Ibid. *International Covenant on Civil and Political Rights*, [Article 2(1)].

⁵⁸ CRPD Committee, above n 6, [41].

- (f) Negative attitudes, stigma and stereotypes preventing persons with disabilities from being included in the community and accessing available assistance;
- (g) Misconceptions about the right to living independently within the community;
- (h) Lack of available, acceptable, affordable, accessible and adaptable services and facilities, such as transport, health care, schools, public spaces, housing, theatres, cinemas, goods and services and public buildings;
- (i) Lack of adequate monitoring mechanisms for ensuring the appropriate implementation of article 19, including the participation of representative organizations of persons with disabilities;
- (j) Insufficient mainstreaming of disability in general budget allocations;
- (k) Inappropriate decentralization, resulting in disparities between local authorities and unequal chances of living independently within the community in a State party.⁵⁹

Each of these barriers can be seen to operate in the mental health and capacity law context in some way. Many of these barriers more closely concern policy, including budgets; awareness-raising, and closing institutions and institutional environments. Explicit legal matters are raised at paragraph 15 subsections (a) and (d), regarding legal capacity restrictions and forced treatment.

IV. DISCUSSION

Several features of the General Comment stand out as being immediately relevant to this review.

(a) Definitions

The Committee usefully define terms such as 'independent living', 'community living', and 'personal assistance'.⁶⁰ Independent living is premised upon *interdependence* as the natural state of human being:

Independent living/living independently means that individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives... Independent living is an essential part of the individual's autonomy and freedom and does not necessarily mean living alone. It should also not be interpreted solely as the ability to carry out daily activities by oneself. Rather, it should be regarded as the freedom to choose and control, in line with the respect for inherent dignity and individual autonomy as enshrined in article 3 (a) of the Convention.⁶¹

The Committee was almost certainly influenced in its understanding of interdependence by Jenny Morris and the conceptual inroads of other ethics of care scholars.⁶² The 2017 report of Catalina Devandas, the United Nations Special Rapporteur on the Rights of Persons with Disabilities, on rights-based support also elaborates on interdependence, offering a useful supplement to the General Comment (and an informative report in its own right).⁶³

⁵⁹ CRPD Committee, above n 6, [15].

⁶⁰ Ibid [16](a-d).

⁶¹ Ibid [16](a).

⁶² E.g. – J Morris, 'Impairment and disability: constructing an ethics of care that promotes human rights', (2001) 16(1) *Hypatia* [1].

⁶³ Human Rights Council, 'Report of the Special Rapporteur on the rights of persons with disabilities' UN Doc, 34th sess, A/HRC/34/58 (20 December 2016).

The Committee define the inverse concept of 'institutionalisation' quite broadly:

[i]t is not "just" about living in a particular building or setting; it is, first and foremost, about not losing personal choice and autonomy as a result of the imposition of certain life and living arrangements... [N]either large scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, *nor even individual homes* can be called independent living arrangements if they have other defining elements of institutions or institutionalization.⁶⁴

Defining elements of institutionalisation include:

[o]bligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment. Institutional settings may offer persons with disabilities a certain degree of choice and control; however, these choices are limited to specific areas of life and do not change the segregating character of institutions.⁶⁵

This definition expands on Erving Goffman's concept of 'total institution',⁶⁶ and is likely to challenge all governments, whether concerning large-standalone institutions and other largescale sites of congregation, residential facilities, group homes or even family homes with a segregating character.

The definitions in the General Comment are surely valuable. Terminology in this area is often technical, and sector or discipline-specific. 'Person-centred', 'social inclusion', 'empowerment' and 'peer-support', for example, are commonly used in policy, scholarship, advocacy, programming and elsewhere, often without a clear sense of what precisely is meant. Tribunals, courts, policymakers, service providers, may not acknowledge the intended meaning, cloaking the underlying purposes of their use, which remain at best only vaguely stated. Participants in debates risk misunderstanding one another. Even the term 'community' may be misused or used vaguely in ways that describe practices that would fall squarely within the Committees definition of 'institutional'.⁶⁷

⁶⁴ CRPD Committee, above n 6, [15](c) (emphasis added).

⁶⁵ Ibid.

⁶⁶ See — E Goffman, 'On the characteristics of total institutions' in *Symposium on preventive and social psychiatry*, Walter Reed Army Medical Centre, 1961, [312].

⁶⁷ This point is made by the WNUSP in its submission: [t]he use of the term community in [Art 19] must be distinguished from that which may be artificially created within settings that amount to deprivations of liberty. Communities should be identified to be neighbourhoods, integrated schools, free labour market workplaces.' The World Network of Users and Survivors of Psychiatry, in its submission to the Committee, produced a useful annexure on this point. World Network of Users and Survivors of Psychiatry (WNUSP) 'Submission of the World Network of Users and Survivors of Psychiatry (WNUSP) for the Day of General Discussion (DGD) on the right of persons with disabilities to live independently and be included in the community, to be held on 19 April 2016 in Geneva', fn 5 <<http://www.ohchr.org>> (accessed 6 February 2018).

Interestingly, the Committee expressed concerns over terminology misuse more explicitly in the *draft* General Comment. ‘Independent and community living’ and ‘personal assistance’ were described as ‘frequently used by organizations providing residential or institutional support services [in ways that] that mislead assumptions by the public’.⁶⁸ The paragraph was removed in the final General Comment, but similar sentiments remained elsewhere in the final text.⁶⁹

(b) Mental Health and other Substituted Decision-Making Legislation

The Committee re-states its explicit rejection of mental health legislation and all forms of substituted decision-making.⁷⁰ States must:

[r]epeal all laws that prevent any person with disabilities, regardless of the type of impairment, to choose where and with whom and how to live, including the right not to be confined on the basis of any kind of disability.⁷¹

For the Committee:

[n]either the full or partial deprivation of any “degree” of legal capacity nor the level of support required may be invoked to deny or limit the right to independence and independent living in the community to persons with disabilities.⁷²

The Committee reject ‘forced treatment in all its forms’ as one of the barriers to independent living and community participation,⁷³ making clear that interventions under mental health or mental capacity laws cannot be construed as somehow ‘facilitating’ the right to live independently and be included in the community. This position will frustrate those who see involuntary treatment or deputyship /guardianship as a ‘tincture of coercion’ that can restore a person’s agency and ability to take part in community. An example might be a person in sheer psychosis living on the street who refuses all help but after a short period of forced treatment, willingly seeks support and moves to ‘safer’ living conditions.⁷⁴ Another example might be a temporary intervention under mental capacity law to remove a person with a cognitive disability who faces daily substituted decisions, and even abuse, by an overbearing parent, yet who wishes to remain in the house.⁷⁵

From the Committees view, even if substituted decision-making can serve these functions in *some* circumstances, intervention against the will and preference of a

⁶⁸ CRPD Committee, above n 6, [16].

⁶⁹ Ibid [51].

⁷⁰ See — Committee on the Rights of Persons with Disabilities, *General Comment No 1: Article 12: Equal Recognition Before the Law*, 11th sess, UN Doc CRPD/C/GC/1 (19 May 2014); Guidelines on the right to liberty and security of persons with disabilities (A/72/55, annex).

⁷¹ CRPD Committee, above n 6, [97][a].

⁷² Ibid [20].

⁷³ CRPD Committee, above n 6, [15](d).

⁷⁴ L Rosenbaum, ‘Liberty versus Need — Our Struggle to Care for People with Serious Mental Illness’ (2016) 375(15) *New England Journal of Medicine* [1490].

⁷⁵ For an incisive CRPD-oriented examination of precisely this scenario, see — A Arstein-Kerslake, ‘An Empowering Dependency: Exploring Support for the Exercise of Legal Capacity’ (2016) 18(1) *Scandinavian Journal of Disability Research* [77].

person or removal of the person to an institutional environment is an unacceptable cost. Instead, pathways to independent living and community participation must be created for people in various degrees of crisis and disablement. In addition, states are obligated under articles 4(e) and 5.2 to prohibit discrimination by private actors who refuse to respect the autonomy and legal capacity of persons with disabilities and must find ways to do so that do not intrude on the rights of the victims/survivors.

Locked mental health wards clearly activate Art 19 – even as they may more directly concern Art 14 (right to liberty) – and are a logical site for CRPD-based change. Locked wards have been criticised by several commentators in recent years,⁷⁶ including by some empirical quantitative researchers. Christian Huber and colleagues, for example, published the findings from their 2016 analysis of 349,574 admissions to 21 German psychiatric inpatient hospitals, monitored over a 15-year period. They reported that suicide, suicide attempts, and absconding with return and without return (all major justifications for locking wards) were *not* increased in hospitals with an ‘open door policy’; in contrast, treatment on open wards was associated with a decreased probability of suicide attempts, absconding with return, and absconding without return, but not completed suicide (to which the difference was considered insignificant).⁷⁷ Drawing on the same dataset, the researchers later reported that rates of aggression by service users and others subject to mental health law were lower in wards with an open door policy.⁷⁸ Huber and colleagues concluded by recommending; ‘policies targeted at empowering treatment approaches, respecting the patient’s autonomy and promoting reductions of institutional coercion’.⁷⁹ Their research was not without critics,⁸⁰ but the findings offer some empirical and pragmatic support for rights-based claims against locked wards.

In addition to requiring compliance in mental healthcare settings, Art 19 also seems to require non-hospital alternatives for people who may need support, including support for people in acute crises who may wish to stay in their home. The rather arbitrary dichotomy between ‘hospital’ and ‘community’, which took hold in policy discourse in the post-asylum era (at least in high-income countries), surely reflects a lack of political imagination in conceiving a wide range of supports required for people with psychosocial disability across the population. According to the WNUSP, the broader policy framework required should include reasonable accommodation for people with disabilities to use mainstream community services like legal services, hospitals, shelters (and not just disability-specific services), as well as home-based supports for people in

⁷⁶ See — B McSherry, ‘Locked Mental Health Wards: The Answer to Absconding?’ (2014) 22(1) *Journal of Law and Medicine* [17].

⁷⁷ CG Huber, et al. ‘Suicide Risk and Absconding in Psychiatric Hospitals with and without Open Door Policies: A 15 Year, Observational Study’ (2016) 3(9) *The Lancet Psychiatry* [842].

⁷⁸ AR Schneeberger, et al. ‘Aggression and Violence in Psychiatric Hospitals with and without Open Door Policies: A 15-Year Naturalistic Observational Study’ (2017) 95 *Journal of Psychiatric Research* [189].

⁷⁹ *Ibid.*

⁸⁰ T Pollmächer and T Steinert, ‘Arbitrary Classification of Hospital Policy Regarding Open and Locked Doors.’ (2016) 3(12) *The Lancet Psychiatry* 1103. There is also some evidence produced by Nijman and colleagues that door locking is associated with reduced absconding. H Nijman et al. ‘Door locking and exit security measures on acute psychiatric admission wards’ (2011) 18 *Journal of Psychiatric and Mental Health Nursing* [614].

crisis, recognition of support systems for decision making, the linking of hospitals and registered disabled people's organisations, and prohibiting any sort of linkage between eligibility for accessing services and a person's decision to discontinue or modify treatment directives.⁸¹ Arguably this challenge to the hospital/community binary, particularly in the mental health context, calls for a re-casting of current responses to acute crisis resolution, including the provision of respite services, peer-run respite houses, intensive home-based support, and so on.

The Committee draw out links between Art 12 and 19, which may help uncover common ground among those disputing the value of forced interventions and substituted decision-making:

To fully realize the transition to supported decision-making and implement the rights enshrined in article 12, it is imperative that persons with disabilities have the opportunity to develop and express their wishes and preferences in order to exercise their legal capacity on an equal basis with others. To achieve this, they have to be a part of the community. Furthermore, support in the exercise of legal capacity should be provided using a community-based approach which respects the wishes and preferences of individuals with disabilities.⁸²

In other words, independent living and participation in the community can offer 'building blocks' for a person to exercise his or her standing as a person before the law.⁸³ Having a safe home, a valued social role, and a variety of relationships can help create opportunities to exercise one's autonomy. As an example, consider a person who does not even consider the abuse and violence she experienced in an institution or a group home to constitute a crime. In addition, she may have felt so devalued that she did not raise concerns with authorities for fear of being dismissed. After being supported to move into a home of her own, and establishing friends, neighbours and colleagues, she may come to understand her experience as assault and pursue legal redress.⁸⁴

Housing is another area in which 'building blocks' can be laid for achieving equal recognition before the law (bringing together articles 12, 19, 23 and 28). Housing in the mental health context could include housing that is both aligned and non-aligned to mental health services. Some may refuse any housing attached to mental health services, others may embrace it. 'Housing First' policies and programs are an example of how such support can be provided. Under some iterations of the scheme, people with actual or perceived psychosocial disability who are homeless are supported through intensive case management to move into regular housing, with no requirement that they adhere to treatment plans (even as it is offered).⁸⁵

⁸¹ WNUSP, above n 67, [12].

⁸² CRPD Committee, above n 6, [26].

⁸³ G Quinn, 'Rethinking Personhood: New Directions in Legal Capacity Law and Policy' (Paper, New Foundations for Personhood and Legal Capacity in the 21st Century Conference, University of British Columbia, 29 April 2011) 17 <www.nuigalway.ie>.

⁸⁴ For an example of this dynamic for a person with intellectual disability, see e.g. – Jane Rosengrave, 'You Only Live Once', in *19 Stories of Social Inclusion* (website), Belonging Matters & University of Melbourne <<https://www.19stories.org/copy-of-story-14-2>> (accessed 09/03/2018).

⁸⁵ E.g. – Micah Projects, *Housing First: a foundation for recovery Breaking the cycle of Brisbane's housing, homelessness and mental health challenges* (2016) <www.micahprojects.org.au> (accessed 3/4/2018).

The often-cited 'personligt ombud' (PO) scheme in Sweden (PO Skåne) is another example. Under the scheme, a legal mentor or personal ombudsperson is appointed to assist a person to make legal decisions.⁸⁶ Consider the following case described by the Swedish National Board of Health and Welfare:

After a stay in hospital, a client wanted to live in a flat of his own. Since this was the client's wish, he was supported by the personal ombudsperson while many other professionals involved with the client advised against it, saying that it would not work out. This in fact turned out to be the case: the client eventually moved into housing with special support and was very happy there. Professionals in the social services and psychiatric services thought that this was an unnecessary failure, while the PO's view was that the reason why the client was so happy in the special housing was that he had been given the chance to live in his own flat.⁸⁷

The emphasis of the personal ombudsperson on respecting the will and preference of the client in this case, rather than prioritising risk-aversion and expert-based paternalism, demonstrates how articles 12 and 19 (and other articles, such as 28 on adequate standard of living and social protection) can work in practice. The example also highlights the importance of having a floor of social protection that allows for multiple choices from among 'good' options about how to live.

One challenging issue for governments and civil society is the type of mistakes and consequences which must be tolerated under a CRPD-based framework, for example; where a person takes a risk and ends up coming to great harm, including suicide or violence against others. In deliberating on any such concerns in domestic law and policy reform, it should be immediately acknowledged that current schemes entail consequences that are effectively seen as an acceptable cost—even if such costs are seen as regrettable with steps taken to try to ameliorate them (for example, traumatic experiences and side-effects from forced psychiatric interventions, increasing rates of hospital-based detention in some countries,⁸⁸ high rates of sexual harassment and assault of women involuntarily placed in psychiatric wards, and so on).

Just as improving social conditions can improve one's chances of exercising legal capacity, the converse is also true. Restoring formal legal capacity under domestic laws can clearly improve one's chances for independent living and participation in the community. The 2011 case of *P J B v Melbourne Health & Anor* (known as "Patrick's Case") in Victoria, Australia, is illustrative. "Patrick" was a 58 year-old man with psychosocial disability who appealed an order by the Victorian Civil and Administrative Tribunal appointing a financial administrator under the *Guardianship and Administration Act 1986* (Vic) (Austl). The appointed administrator made clear his intention to sell

⁸⁶ UN Office of the High Commissioner for Human Rights, 'Chapter Six: From provisions to practice: implementing the Convention, Legal Capacity and Supported Decision-Making', *United Nations Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities* (Geneva, 2007) [89] <www.un.org>.

⁸⁷ Swedish National Board of Health and Welfare, 'A New Profession is Born – Personligt ombud, PO' (Västra Aros, Västerås, November 2008) [10] <www.personligtombud.se>.

⁸⁸ Community and Mental Health Team, NHS Digital, *Inpatients formally detained in hospitals under the Mental Health Act 1983, and patients subject to supervised community treatment Uses of the Mental Health Act: Annual Statistics, 2015/16* (30 November 2016) <www.content.digital.nhs.uk>.

Patrick's home against Patrick's wishes. Patrick was detained under the *Mental Health Act 1986* (Vic) (Austl) at the time. His treating psychiatrist had sought the appointment to prevent Patrick from repeatedly seeking to leave hospital and return to his own home. The presiding judge referred to Patrick 'using his home as a medical refuge' in the eyes of the psychiatrist.⁸⁹ The Court held that the order of Tribunal appointing an administrator unjustifiably interfered with Patrick's human rights under the *Victorian Human Rights Charter* and ordered that the appointment of an administrator be set aside. The Judge referred explicitly to articles 12, 19 and 23 (the right to respect for home and family) of the CRPD in framing the decision.⁹⁰

There have been some efforts to integrate the push for positive rights with Art 19 into mental health law. Argentina's *National Mental Health Law 2010* ('*NMHL*'),⁹¹ for example, contains a mechanism in which people in apparent mental health crises are subject to interdisciplinary evaluations which seek to identify the availability of support in a person's life. Where gaps appear, the evaluations can lead to a court ordering that voluntary services are made available to the individual (though the voluntary nature of this support is clearly distorted to some degree by the prospect of forced intervention by the same evaluation team/court).⁹² The evaluation team reportedly use the CRPD as a guide when communicating and reporting to judges, including highlighting a person's communication needs, seeking to discover the person's views on past experiences of involuntary treatment, and possible gaps in informal or formal services that could be remedied with voluntary services marshalled by the court.⁹³

The *NMHL* clearly does not accord with the CRPD and the high standards of the CRPD Committee; it neither questions the legitimacy of forced psychiatric intervention nor removes a rebuttable presumption of mental capacity. Yet, the *NMHL* does show how government agencies working under current laws can to some degree promote Art 19 obligations by placing an order, as it were, on services to assist a person to live independently and participate in community.

As noted, one stated purpose of 'rights-based' mental health and capacity law was to facilitate access to the supports people need in the wake of 'deinstitutionalisation'.⁹⁴ However, this stated goal is generally agreed to be the least successful of the 'new

⁸⁹ E.g. – *P J B v Melbourne Health & Anor (Patrick's case)* [2011] VSC 327 (19 July 2011).

⁹⁰ *P J B v Melbourne Health & Anor (Patrick's case)* [2011] VSC 327 (19 July 2011) [134-137], [337].

⁹¹ Law No 26657, 3 December 2010 [32041] BO 1; 'Mental Health Regime', House of Representatives Res D-276/07 (7 March 2007) Art 1.

⁹² Law No 26657, 3 December 2010 [32041] BO 1; 'Mental Health Regime', House of Representatives Res D-276/07 (7 March 2007) Art 42.

⁹³ FJ Bariffi and MS Smith, 'Same Old Game but with Some New Players Assessing Argentina's National Mental Health Law in Light of the Rights to Liberty and Legal Capacity under the United Nations Convention on the Rights of the Persons with Disabilities' (2013) 31(3) *Nordic Journal of Human Rights* 325, at [339-40].

⁹⁴ Statutory duties introduced under mental health law include those designed to secure individual rights, including rights to accessing services, refusing medical treatment, and having a review process for decisions concerning detention and imposed treatment decisions. L Gostin, 'The Ideology of Entitlement: The Application of Contemporary Legal Approaches to Psychiatry' in P Bean (ed), *Mental Illness: Changes and Trends* (Wiley, 1983) [50].

legalism' framework. Gerard Quinn has argued that this shortcoming draws mental health debates into an imprisoning logic:

Some civil libertarians would hesitate to use an argument for a legal right to treatment (no matter how meritorious) lest the need for treatment might be used to justify an undue encroachment on liberty. Contrariwise, some professionals in the field who have the responsibility to deliver services, would hesitate to embrace liberty-enhancing arguments lest it interfere too much with their capacity to deliver a substantive right to treatment—with their professional prerogatives.⁹⁵

A common critique of 'new legalism' is its struggle to secure substantive rights to persons with mental impairments in the form of facilitating access to voluntary healthcare and support.⁹⁶ The normative content of Art 19 provides an alternative framework for garnering appropriate social provisions and altering the powers of expertise over subjects of mental health law.

Looking beyond mental health and capacity law, examples from domestic violence, drug and alcohol, and homelessness services are worth considering. The previous hypothetical about housing support did not include a situation where someone refuses housing services and government-run shelters *altogether*. The Committee is not explicit about an appropriate response in such cases. Imaginably, good support would include blankets, a tent, food, advocacy, periodic reiteration that housing options are available, and other basic guarantees aimed at harm minimisation.

Similarly, in drug and alcohol services, strategies for basic guarantees and harm minimisation might include needle exchange and safe injecting houses, and the offer for a range of voluntary rehabilitation services — these are all existing practices. In domestic violence service and policies, there are well established harm minimisation strategies in situations where victims/survivors of abuse prefer to live with perpetrators, in which *parens patriae* or police powers are not marshalled against the victim/survivor. Art 19 and the CRPD more broadly, invite a comparison of the liberty rights and social protection promoted in these other service contexts compared to the public policy imperatives of mental health or mental capacity laws. The equality demands of the CRPD counter the view that there is something about mental health conditions that warrants special exceptions to normative rights.

(c) Group Homes, Clustered Living and Involuntary Community Intervention

The Committee call for states to 'ensure that public or private funds are not spent on maintaining, renovating, establishing, building existing and new institutions in any form of institutionalization' including 'private institutions... established in the guise of "community living".⁹⁷ This characterisation would include numerous sites affecting people subject to mental health and capacity laws. Group homes, aged-care settings,

⁹⁵ G Quinn, 'The United Nations Convention on the Rights of Persons with [sic] Disabilities – Towards a Unified Field Theory of Disability' (presentation paper) Indian Law Society, G.V. Pandit Memorial Oration, Pune, India, 10 October 2009, 11 <www.nuigalway.ie/cdlp>.

⁹⁶ See — P Weller, 'Lost in Translation: Human Rights and Mental Health Law' in B McSherry and P Weller (eds), *Rethinking Rights-Based Mental Health Law* (Hart, 2010) [51]; J Peay (ed), *Seminal Issues in Mental Health Law* (Ashgate, 2005) [xvii].

⁹⁷ CRPD Committee, above n 6, [51].

long-stay psychiatric wards, secure facilities, community-based clustered homes will fall under the expansive definition of 'institutional'. Certain forms of compulsory interventions outside of hospitals (e.g. 'community treatment orders' and 'assertive outpatient treatment') may also offend Art 19. '[E]ven individual homes' are implicated where other defining elements of institutionalisation are present, including 'no or limited influence over whom one has to accept assistance from ... a paternalistic approach in service provision [and] supervision of living arrangements'.

Congregate and cluster housing models are used by numerous governments as a "step-down" from institutionalisation or as stable feature of so-called deinstitutionalised systems. Middle and high-income countries often develop such arrangements as cornerstones of 'deinstitutionalisation'. Many congregate and cluster housing models have been criticised in the past for being at odds with the policy aims of 'community care' and 'normalisation'.⁹⁸ However, the Committee do not rule out group-based housing and nor is there anything in Art 19 that prohibits it. Instead, the Committee suggests congregation is typically a defining element of institutional environments. Indeed, a particularly oppressive family home, in which one person with disability lives among many without disability, could contain 'institutional' and exclusionary elements that offend Art 19. The OHCHR's thematic study here provides tests to identify living situations that are not compliant with the CRPD, which include the following:

Living arrangements should be assessed taking into account issues such as the choice of housemates, who decides when residents can enter or exit, who is allowed to enter a person's home, who decides the schedule of daily activities, who decides what food is eaten and what is bought and who pays the expenses.⁹⁹

It is noteworthy that the term 'group homes', which were referred to pejoratively in the Draft version of the General Comment, were removed for the final draft. It is possible that this amendment occurred in response to the submission of the Centre for Disability Studies and Disability Law Hub, University of Leeds, which stated that outright rejection of group settings risked:

(a) overlooking the *de facto* institutionalization that can take place when a disabled person lives alone or isolated in the community and is dependent upon support and services over which they have no choice or control; and (b) overlooking the potential of collective living options in which disabled people (and others) may choose to live and in which they will have full choice and control.¹⁰⁰

WNUSP take up this point and, like the University of Leeds submission, emphasises the importance of deliberative design in compliant group settings. WNUSP made a specific request for the involvement of 'our representative organizations [in the] designing of a range of residential, in-home and community services to ensure inclusion and full participation in the community, and encourage innovation in... research'.¹⁰¹

⁹⁸ I Wiesel and C Bigby, 'Movement on Shifting Sands: Deinstitutionalisation and People with Intellectual Disability in Australia, 1974–2014' (2015) 33(2) *Urban Policy and Research*, [178].

⁹⁹ Office of the United Nations High Commissioner for Human Rights, above n 26, [20-22].

¹⁰⁰ Centre for Disability Studies and Disability Law Hub, University of Leeds, 'Response to Draft General Comment on Article 19', [1] <<http://www.ohchr.org>> (accessed 6 February 2018).

¹⁰¹ WNUSP, above n 67, 12.

(d) Cost

The Committee point to recent global financial crises and warn against the disproportionate impact of fiscal downturns on people with disabilities. So-called austerity measures – whether real or contrived – would require specific safeguards, according to the Committee, to prevent disproportionate effect on persons with disabilities.¹⁰² This directive is timely. Case law is emerging in which austerity measures appear to influence the imposed limits on the provision of state resources for independent living.¹⁰³

Cost will inevitably pose a barrier to achieving Art 19 in policy and practice. It is true that care homes and other sites of congregated living might be a more expensive option. Many group homes, for example, are expensive in both the short and long-term.¹⁰⁴

On the other hand, there will be instances in which congregate care options are ‘cheaper’, at least in financial terms, even as human costs may be great.

The Committee acknowledge financial cost and the implementation challenges but argue that ‘the level of support required’ may not be invoked to deny the right to independent living and community participation.¹⁰⁵ This will be particularly challenging for States Parties and civil society actors wishing to keep services from ‘reading down’ their obligations under Art 19, and it will be important to shine a light on any sectoral interests that may run contrary to Art 19 (for example, private group home providers and some public sector unions that seek to retain institutional environments).

(e) Low and Middle-Income Countries

The General Comment has a strong focus on middle and high-income jurisdictions in Europe, and the broader ‘Anglosphere’.¹⁰⁶ Deinstitutionalisation emerges as a major concern of the General Comment, and understandably so. Yet, there may well be more parts of the world in which institutionalisation has not been, at least historically, the major barrier to independence and community participation; for example, in many parts of Asia, Africa¹⁰⁷ and the Pacific.

¹⁰² CRPD Committee, above n 6, [38],[43],[62].

¹⁰³ See — *Davey v Oxfordshire County Council* (The Equality & Human Rights Commission and Inclusion London intervening) [2017] EWCA Civ 1308, 1 September 2017.

¹⁰⁴ E.g. – C Purcal et al. *Supported Accommodation Evaluation Framework Summary Report (SPRC Report 31/2014) for the NSW Department of Family & Community Services, Ageing Disability and Home Care* (Sydney: Social Policy Research Centre, UNSW Australia, 2014), [37].

¹⁰⁵ CRPD Committee, above n 6, [20].

¹⁰⁶ This point was made quite strongly in a webinar by Inclusion International on preparing a response to the draft General Comment. See — Inclusion International, ‘Video: Preparing Feedback to the CRPD Committee on the Draft General Comment on Article 19’ <<http://inclusion-international.org/video-preparing-feedback-to-the-crpd-committee-on-the-draft-general-comment-on-article-19/>> (accessed 26/03/18).

¹⁰⁷ Elizabeth Kamundia has elaborated on this point with regards to Africa, and a specific focus on Kenya. See — E Kamundia, ‘Choice, Support and Inclusion: Implementing Article 19 of the Convention on the

There are clear exceptions to the above generalisation, as the Users and Survivors of Psychiatry Kenya and the Japan National Assembly of Disabled Peoples' International point out in their submissions to the Committee.¹⁰⁸ Notably, these are two submissions among only four from Asia and Africa, the other two coming from the Government of Mongolia and the India-based organisation, Transforming Communities for Inclusion-Asia (TCI-Asia).¹⁰⁹ TCI-Asia report a troubling development in the recent growth of institutions in Asia, noting that:

[e]ven though mental health legislations do not exist in many [Asian] countries, and some have [only] recently adopted new coercive mental health laws, mental institutions are coming up quite fast, resulting in the escalation of barriers to inclusion.¹¹⁰

Bhargavi Davar (who leads TCI-Asia) has argued elsewhere that CRPD and legal capacity debates are often presented by Anglosphere commentators in universal terms.¹¹¹ The General Comment may leave the Committee open to a similar charge.

The Committee does state that:

Article 19 reflects the diversity of cultural approaches to human living and ensures that its content is not biased towards certain cultural norms and values.¹¹²

Perhaps this point could have been elaborated upon, and may be a fruitful area for future research. Davar again has argued that non-Western, low and middle income countries tend to be more concerned with developing inclusive and community-based support,¹¹³ rather than curtailing coercive state-based interventions.¹¹⁴ Advocates in these countries may be more concerned with family-led or localised forms of segregation, such as 'Pasung' in Indonesia,¹¹⁵ more so than state-based incursions.

Rights of Persons with Disabilities in Kenya' in *African Yearbook on Disability Rights* (Pretoria Law Press, 2013)

<http://www1.chr.up.ac.za/images/files/publications/adry/adry_volume1_2013.pdf>.

¹⁰⁸ Users and Survivors of Psychiatry – Kenya, 'Day of General Discussion on Article 19 of the UN Convention on the Rights of Persons with Disabilities' (2017), paras (5-7). <<http://www.ohchr.org>> (accessed 6 February 2018); Japan National Assembly of Disabled Peoples' International, 'Submission to the Committee on the Rights of Persons with Disabilities on the Day of General Discussion on Article 19, CRPD' (2017), (para) 1. <<http://www.ohchr.org>> (accessed 6 February 2018).

¹⁰⁹ Transforming Communities for Inclusion – Asia, 'Submission to the UNCRPD Monitoring Committee, Day of General Discussion, Article 19' <<http://www.ohchr.org>> (accessed 6 February 2018).

¹¹⁰ Ibid.

¹¹¹ B Davar, 'Legal Capacity and Civil Political Rights for People with Psychosocial Disabilities' in A Hans (ed), *Disability, Gender and the Trajectories of Power* (Sage, 2015) [ch 11].

¹¹² CRPD Committee, above n 6, [8].

¹¹³ Davar, above n 111.

¹¹⁴ Ibid. See e.g. – Transforming communities for Inclusion, Asia, *Summary Report on Transforming Communities for Inclusion - Asia: Working Towards TCI - Asia Strategy Development* (Asia-Pacific Development Centre on Disability, June 2015)

<www.apcdfoundation.org/?q=system/files/TCI%20Asia%20Report_Readable%20PDF.pdf> (accessed 5 May 2016).

¹¹⁵ 'Pasung' refers to the chaining and caging of individuals with psychosocial disability. See; H Minas and H Diatri, 'Pasung: Physical Restraint and Confinement of the Mentally Ill in the Community' (2008) 2 *International Journal of Mental Health Systems* [8].

Consider Davar's comment on recent debates in India around mental health law reform and institutionalisation:

[e]ven these intense debates... are relevant only to the middle and upper classes in urban areas, especially non-resident Indians looking for the ideal mental institutions for ageing parents, sisters or other siblings and dependents. This may constitute around 7% of the Indian population. For the remaining 93% population in rural areas, inner city slums, mountainous terrains, and other far-flung regions of the country, where the social fabric is still intact, and where there is no doctor or asylum, this will have no relevance.¹¹⁶

Elizabeth Kamundia has written from the African context about persons with disabilities typically living with their families against a cultural backdrop of largely communal ways of life without individualised state-funded support services.¹¹⁷ Approaches to securing the right to independent living and participation in the community in these contexts will differ enormously along social, cultural, economic and political lines.

Problem-solving and sharing of solutions between disabled people's organisations between and within low and middle income countries has been taking place for many decades, and show no sign of slowing down. There is scope to foster further collaboration. Some well-known research suggests low income countries tend to enjoy better long-term outcomes for people with severe mental health issues precisely because of higher levels of collectivism and social cohesion.¹¹⁸ This exceptionalism may even apply to socio-economically marginalised groups *within* high income countries. Among Aboriginal and Torres Strait Islander people with disabilities in Australia, for example, some data indicates their participation in cultural activities in their own communities is *on par* with other Aboriginal and Torres Strait Islander people (which is quite unlike non-Indigenous people with disabilities).¹¹⁹

Such solutions and positive trends are relevant to all countries, and their cross-fertilisation surely warrants further research and support. Researchers could also consider how countries without mental health legislation are faring, and how CRPD-based development in those jurisdictions might occur. The World Health Organisation 'QualityRights Framework' may be useful for addressing these intersections,¹²⁰ as are

¹¹⁶ B Davar, 'Legal Frameworks for and against People with Psychosocial Disabilities' (2012) 47(52) *Economic and Political Weekly* [123].

¹¹⁷ Kamundia, above n 107.

¹¹⁸ M Savill, C Banks, H Khanom, and S Priebe, 'Do Negative Symptoms of Schizophrenia Change over Time? A Meta-Analysis of Longitudinal Data' (2015) 45(8) *Psychological Medicine* [1613]. See also – Transforming communities for Inclusion, above n 114.

¹¹⁹ Australian Bureau of Statistics, *Social and Economic Wellbeing of Aboriginal and Torres Strait Islander people with disability. National Aboriginal and Torres Strait Islander Social Survey 2014-2015*. (Feature article) Rel. 4714.0 (2017); S Avery, 'Disability in Aboriginal and Torres Strait Islander communities: The numbers and the narratives' Presentation at the NHMRC-Lowitja Institute Knowledge Translation Conference, Brisbane, Australia (2017).

¹²⁰ See — World Health Organisation, 'WHO QualityRights initiative - improving quality, promoting human rights'—website<http://www.who.int/mental_health/policy/quality_rights/en/>(accessed 27/02/2018). Bernadette McSherry and Yvette Maker have considered the benefits and challenges for mental health practitioners of integrating a human rights perspective into mental health treatment and care. B McSherry and Y Maker, 'International Human Rights and Mental Health: Challenges for law and practice.

the existing regional collaborations between communities in low- and middle-income countries.

(f) Privatisation and Marketisation

To some extent, the Committee brings attention to the increasing privatisation and marketisation of disability and other social services in some countries. The final draft of the General Comment included increased emphasis on 'ensur[ing] that no rights enshrined in article 19 are violated' by '*private entities*' in addition to the state – a point that did not appear in the Draft.¹²¹ However, the scale of social policy change generated by marketisation and privatisation of health and social services in recent decades, particularly in high and middle income countries, may have warranted further attention. Marketisation is linked to efforts to personalise disability supports.¹²² My point is not to query the intrinsic value of 'personalisation' (which involves complex and often context-specific questions about service delivery that have been well-investigated by others)¹²³ but rather to point out that marketisation and personalisation contain potential downsides, such as detracting from social justice agendas and meaningful choices for citizens.¹²⁴ These pitfalls warrant attention by States Parties, civil society organisations and others who are enthusiastically embracing policies of personalisation, often in the name of rights. The General Comment will likely contribute to such enthusiasm, though perhaps without the caution, which (at least I would argue) is required.

The previously noted report of the Special Rapporteur on the Rights of Persons with Disabilities, provides useful insights in on matters of privatised and market-driven services.¹²⁵ In many countries, Art 19 will require effective regulation of market-driven systems aimed at improving choice and control for people with intellectual, cognitive and psychosocial disabilities, and ensuring sufficient feedback loops to guarantee social protection and respond to problems as they arise.

V. CONCLUSION

This review could not cover all issues warranting attention. The Committee does not specifically mention the experience of people with autism, for example. However, the Committee does not focus over-much on any one disability type (the term 'mental health', for example, only appears once, and 'psychosocial' three times). Yet, the absence of specific consideration of autism is noteworthy, including among the submissions.

¹²¹ CRPD Committee, above n 6, [40]. See also – paras (51) and (97(j)).

¹²² See — A Roulstone and H Morgan, 'Neo-liberal Individualism or Self-directed Support: Are We All Speaking the Same Language on Modernising Adult Social Care?' (2009) 8(3) *Social Policy and Society* [333].

¹²³ Ibid. See also – K Rummery, 'A comparative analysis of personalisation: balancing an ethic of care with user empowerment' (2011) 5(2) *Ethics and Social Welfare* 138; J Owens, T Mladenov and A Cribb, 'What Justice, What Autonomy? The Ethical Constraints upon Personalisation' (2017) 11(1) *Ethics & Social Welfare* [3].

¹²⁴ Owens, Mladenov and Cribb, above n 123.

¹²⁵ Human Rights Council, above n 63, [60-62].

Another concern, only touched upon here, is the expansion in some countries of *parens patriae* and police powers beyond mental health law into other policy areas, including drug and alcohol services (for example, forced drug and alcohol ‘rehabilitation’) and homelessness (for example, services using civil commitment laws to detain homeless people who refuse shelter).¹²⁶

Finally, ‘special defences’ in criminal law such as unfit to plead rules and the insanity defence are clearly relevant. People subject to such rules are often detained indefinitely. In many cases, increased community-based support will offer alternatives to custodial detention (notwithstanding the major legal challenge of the CRPD to this area of criminal law).¹²⁷

A key next step for those wishing to animate Art 19 is the deliberative development of basic guarantees, a satisfactory floor of social protection, harm minimisation strategies that respect non-interference, and the prioritising of structural changes required to achieve the transformative equality promoted by the CRPD.¹²⁸ Overall, the General Comment brings together both the views of the Committee and a wide range of submission respondents, providing a welcome concentration of global knowledge on this most *sui generis* of CRPD rights. The material highlights points of overlapping consensus among diverse commentators and clear goals for concerted legal change and political action.

¹²⁶ E.g. – K Holland, ‘Services ‘sectioning’ homeless people who refuse shelter’ *Irish Times* (3 March 2018).

¹²⁷ E.g. – A Arstein-Kerslake, P Gooding, L Andrews, B McSherry, ‘Human Rights and Unfitness to Plead: The Demands of the Convention on the Rights of Persons with Disabilities’ (2017) 17(3) *Human Rights Law Review* [399]; T Minkowitz, ‘Rethinking Criminal Responsibility from a Critical Disability Perspective: The Abolition of Insanity/Incapacity Acquittals and Unfitness to Plead, and Beyond’ (2014) 23 *Griffith Law Review* [434].

¹²⁸ See — T Minkowitz, ‘CRPD and Transformative Equality’ (2017) 13(1) *International Journal of Law in Context* [77]; T Degener, ‘Disability in a Human Rights Context’ (2016) 5(3) *Laws* [35].