Centre for Disability Studies and Disability Law Hub, University of Leeds

response to

Draft General Comment on Article 19

**We welcome this opportunity to contribute to the Committee’s work on this important topic. Our contribution is divided into five sections - in the first four, substantive points are tackled and, in the fifth, minor typographical and other issues are set out.**

## 1. Institutions and Institutionalized Living

We welcome the recognition in the draft General Comment of the ways in which institutionalization occurs outside of certain living arrangements.

For example, in paragraph 14(d) there is recognition of ‘physical and regulatory institutionalization’ as a barrier to implementation of Article 19. Again, at paragraph 15(c) it is rightly stated that, “Institutionalization is not about living in a particular setting, it is, first and foremost, about losing control as a result of the imposition of a certain living arrangement.”

However, we are concerned that there are places in which all group settings appear to be problematized – where the focus shifts from the lack of choice and control (which is central to institutionalization) to the number of people living in the setting. Paragraph 15(c) states that:

“Both concepts, i.e. independent and community living, refer to **life settings outside of institutions**, including large or smaller group homes.” And,

“neither large scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals can be called independent living or community living arrangements.”

Statements such as these risk (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.

There does appear to be recognition at paragraph 47 that people may choose to live in a particular setting which could fall within the Committees definition of an institution. However, it is then stated that the “right to choose a residential, institutional setting does not correspond with a state party’s duty to maintain institutions or to ensure the availability of residential support services”. This is potentially confusing and problematic. It is important to acknowledge that collective living arrangements (which allow meaningful choice and control over support and services) might be places in which people with disabilities choose to live and which enable meaningful inclusion in the community (e.g. housing collectives, communes, centres for independent living, retirement communities). If the General Comment were to expresses its concern with institutionalized living, rather than with particular settings, then this problem disappears. We would therefore urge the Committee to ensure that throughout the Comment, the problem is framed in terms of institutional or institutionalized living rather than in terms of group settings. This would remove the need to define an institution and focus instead on identifying features of institutionalized living.

This concept was summarized very effectively in the UN OHCHR study on Article 19 in 2014,[[1]](#footnote-1) as follows:

‘While institutionalization can differ from one context to another, certain common elements define it: isolation and segregation from community life; lack of control over day-to-day decisions; rigidity of routine, irrespective of personal preferences or needs; identical activities in the same place for a group of persons under a central authority; a paternalistic approach in the provision of services; supervision of living arrangements without consent; and disproportion in the number of persons with disabilities living in the same environment. Institutionalization is therefore not just about living in a particular setting; it is, above all, about losing control as a result of the imposition of a certain living arrangement. In that sense, small environments, including group homes, are not necessarily better than large institutions if overall control remains with supervisors.’ (para. 21 of that report)

We would encourage the Committee to refer to that report in finalizing its General Comment.

## 2. Community Living and Being Included in the Community

We congratulate the Committee for including definitions of key terms associated with Article 19. However, we are concerned that including a definition of “community living” in para 15(b) creates unnecessary confusion and complexity. This is not a term used in Article 19 – but is one that has a history and context. We would strongly urge the Committee to focus instead on defining “being included in the community” – the term actually used in Article 19.

## 3. Economic Social and Cultural Rights and Civil and Political Rights

We welcome the recognition that Article 19 “entails civil and political as well as social and cultural rights” and that “modern human rights theory recognizes that in order to be realized, all human rights require resources. Systematic realization also requires structural changes which have to be taken step by step, no matter whether civil and political or social, economic and cultural rights are at stake” (paragraph 7). We are concerned, however, by the categorisation (in paragraph 41) of Article 19(a) as a civil right, Article 19(b) as a social right, and Article 19(c) as a social and cultural right. We worry that this categorisation fails to recognise that a blend of different types of right runs through the entire article and that it might give rise to overly-simplistic approaches to implementation. Thus, in relation to Article 19(a), the meaningfulness of choice will be affected by the range of support and accessible accommodation available. In relation to Article 19(c) there is such a strong emphasis on making services and facilities available to people with disabilities on an equal basis with others that categorising it as a social and cultural right seems to attach insufficient weight to the prohibition of discrimination which it entails. Further, the services and facilities covered will include those associated with the full range of living activities (including shopping, banking, transport, health care, political meetings, voting etc.). Paragraph 41 notes public community facilities and services associated with participation in cultural activities but it is important to acknowledge that these also concern participation in economic, political and social activities. See, for example, Paragraph 43 of the OHCHR Thematic Study on Article 19

“Persons with disabilities must be allowed access to mainstream community services and facilities to fully enjoy their right to live independently and be included in the community. Article 19 (c) requires States parties to 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. This is to be interpreted broadly to cover all services and facilities provided for in society, and can include, by way of illustration, the rights to attend a community school, to use the general transport system and to have access to work in the open job market depending on individual aspirations and qualifications. In combination with specific support services, the availability of community services and facilities is also essential for successful deinstitutionalization.”[[2]](#footnote-2)

## 4. Data and monitoring

We welcome the Committee’s acknowledgement of Article 31, including its call for systematic data and independent monitoring information, but we believe this should go further than the focus suggested in paragraphs 92 and 94k. The framework adopted by the UN OHCHR affirms that human rights indicators should address structure, process and outcomes. The draft GC focuses on monitoring existing service ‘structures’ and de-institutionalization ‘processes’ but it overlooks the importance of developing ‘outcome’ indicators in relation to Article 19.

We agree with the need for data concerning ‘housing, living arrangements, social protection schemes’ identified in paragraph 92. We also concur with the Committee’s requests for information in dialogue with individual states, focusing on the type, size and number of institutions. It is essential that all forms of monitoring and data collection include populations living in residential service settings (i.e. census, surveys, administrative data, and research studies). Nevertheless, there is an opportunity also to signal the importance of outcome indicators that measure fulfilment of Article 19 rights more directly.

Outcome indicators for Article 19 should seek to establish the extent to which persons with disabilities have ‘choices equal to others’ to live independently and the extent to which they are ‘included’ in the community and not ‘isolated’ from it. Progressive realization of the right must be judged, ultimately, on these things rather than on developments in service design alone. This means monitoring not only the availability of a range of support options but also measuring actual independent living outcomes for persons with disabilities who live in the community. Both subjective and objective measures are useful in this respect. Research and development work currently undertaken by the EU Agency for Fundamental Rights (FRA) offers some examples of how this can be achieved.

**5. Other Issues**

In relation to families and informal carers, the draft General Comment could emphasise more strongly the need to support families and informal carers to enable this independence, choice and control that is central to Art 19. There is reference at paragraph 53 for example to the need to ensure that autonomy and self-determination of persons with disabilities are protected in family contexts. Whilst this is important, there is a danger that this paragraph may reinforce a view that family/informal carers may be antagonistic to independence, and may reify an individualistic concept of independence and autonomy which is contested culturally and politically. It might usefully be reworded to also, alongside this, emphasise the need for services and support to be available to carers to enable them to support and facilitate meaningful choice and control and inclusion in the community for persons with disabilities.

Para 33: it would be helpful if after the word ‘inclusive’ (in the first sentence) the word ‘accessible’ is inserted. All too often inadequate access (for example the unavailability of school transport) is a major barrier to adequate education.

Para 35: It would be helpful if before the word ‘housing’ (in the first sentence) the words ‘safe and adequate’ are inserted. Housing needs not only to be accessible it also needs to be safe and adequate to meet the needs of persons with disabilities.

Para 15(b): The final couple of sentences seem convoluted. The final one in particular “Hence, persons with disabilities must be entitled to be independent in community everywhere, and for all type of activities”.

Para 45: Final sentence here could usefully be reworded for clarity ‘…should ensure that persons with disabilities are protected against social cutbacks because they tend to impact more heavily on them than the general population’.

Para 58: It is not clear what the final sentence of this paragraph is doing here? Potentially contentious and unnecessary.

1. [http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Documents/A\_HRC\_28\_37\_ENG.doc](https://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Documents/A_HRC_28_37_ENG.doc) [↑](#footnote-ref-1)
2. http://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session28/Documents/A\_HRC\_28\_37\_ENG.doc [↑](#footnote-ref-2)