

**Comments on the
Committee on the Rights of Persons with Disabilities
Draft General Comment No. 5 (2017) Article 19 CRPD:
Living Independently and being Included in the Community
Centre for Health and Social Care Law (CHSCL)
Cardiff School of Law and Politics, Cardiff University**

Preface

This response has been prepared by academics at the Centre for Health and Social Care Law ('the Centre'),¹ at the School of Law and Politics, Cardiff University, UK. The Centre exists to promote research and its dissemination in the field of Health and Social Care Law. The response to this consultation has been led by Dr Emily Kakoullis (Lecturer in Law)² with contributions from Dr Lucy Series (Research Fellow) and Alison Tarrant (Doctoral Researcher). We welcome the opportunity to comment on this important Draft General Comment on Article 19: Living independently and being included in the community. Our contribution is based on our research carried out in the States of Cyprus and the United Kingdom (UK), however we recognise that the challenges of implementing Article 19 CRPD vary globally.

Our research indicates that one of the key problems with implementing Article 19, including in a State like the UK that has many past and present policies that indicate support for the concept of independent living,³ is a lack of understanding of the Article's character. Research by Dr Emily Kakoullis on the ratification process for the CRPD in Cyprus found that the Greek conceptual language with which to discuss the content of the English language CRPD's provisions was not always available, and was a factor in shaping the final content of the translated Greek language CRPD text in Cyprus.⁴ Research on guardianship laws by Dr Lucy Series indicates that

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³ See, for example: Prime Minister's Strategy Unit, *Improving the Life Chances of Disabled People* (2005); Office for Disability Issues and others, *Independent Living: A Cross-Government Strategy about Independent Living for Disabled People* (2008); Department for Work and Pensions, *Fulfilling Potential: Next Steps* (2012) para 1.10; Welsh Government, *A Framework for Action on Independent Living* (2013).

⁴ Emily Kakoullis, 'A Shift from Welfare to Rights: A Case Study of the Ratification Process for the Convention on the Rights of Persons with Disabilities in Cyprus' (PhD Thesis, University of Bristol, 2015).

promoting ‘independence’ or ‘independent living’ is sometimes used by the domestic courts and health and social care services as a basis for coercive interventions that use detention and substitute decision making powers to require a person to live in an ‘independent living’ service against their will,⁵ or to undergo coercive treatments (including psychiatric detention,⁶ and even sterilisation⁷), on the basis that these will foster independence or independent living skills. Doctoral research by Alison Tarrant indicates that in the national policy and legislative contexts the concepts of ‘independence’ and ‘independent living’ are often conflated, causing confusion in what is meant by these terms and potentially merging ideas of autonomy with self-reliance.⁸

Comments and suggestions

When proposing amendments to the Draft General Comment, we use *italics* to suggest an insertion into the text and ~~striketthrough~~ to suggest a deletion.

1. Language and Terminology employed Throughout the draft General Comment

We consider that the phrase ‘independent living’ (preferred option), or alternatively the phrase ‘living independently’, should be used throughout the draft General Comment in preference to the terms ‘independent’ or ‘independence’. This is because our empirical research on the use of language of independence and independent living in legal and policy documents in England and Wales suggests that ‘independence’ often carries connotations of self-reliance and managing without support, or being separated from close caregiving relationships with family members, rather than the understandings developed by the disabled people’s movement that are connected with having choice and control over one’s living arrangements and life.

2. Paragraph 7 (page 2):

We suggest the insertion of the term ‘economic’ in the first sentence of paragraph 7, so that the sentence would read:

‘Article 19 entails civil and political as well as *economic*, social and cultural rights’

⁵ *A Primary Care Trust v AH* [2008] EWHC 1403 (Fam); *A Local Authority v WMA & Ors* [2013] EWHC 2580 (COP).

⁶ *Northamptonshire Healthcare NHS Foundation Trust v ML (Rev 1)* [2014] EWCOP 2.

⁷ *A NHS Trust v DE* [2013] EWHC 2562 (Fam).

⁸ Ongoing doctoral research.

We also suggest the insertion of the term ‘economic’ in the second sentence of paragraph 7, so that the sentence would read:

The right to independent living ... *economic*, social and cultural rights enshrined in this norm are fulfilled’

This is because Article 19 contains both civil and political, and **economic**, social and cultural rights, which needs to be reflected in the General Comment. Putting in place the supports, adjustments and services required to implement the right to independent living will sometimes incur economic costs, which the General Comment should acknowledge and reflect.

3. Paragraph 15(a) (page 4)

We suggest the insertion of the term ‘choice’ in the first sentence in paragraph 15(a), so that the sentence would read:

‘... are enabled to exercise *choice and control* over their lives and make all decisions that concern their lives’

This is because ‘control’ is not enough, ‘choice’ is also needed. Further, ‘choice’ is to be understood as ‘choices equal to others’. In the UK, ‘choice and control’ are seen as definitional elements of independent living.⁹

We also suggest the replacement of the word ‘what’ with ‘who’ to emphasise that this is about the identity of *persons* not objects:

‘These actions and decisions constitute ~~what~~ *who* we are’

4. Paragraph 15(c) (page 4)

We suggest the insertion of the term ‘choice’ in the first sentence in paragraph 15(c), so that the sentence would read:

‘... it is first and foremost, about losing *choice and control* as a result of the imposition of a certain living arrangement’

This is for the same reasons as for paragraph 15(a), above.

We also suggest the following amendment:

‘neither 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 or community living arrangements *if the living arrangements have other defining elements of institutions*’

This is because our experience in the UK is that some individuals may be moved into so-called independent living accommodation against their will, and although they may live alone or with one or two others, their care arrangements may have many

⁹ Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation 2011) p 5.

hallmarks of institutionalisation. For example, they may have little real choice over who provides their support, or the terms upon which that support is provided, they may be required to live according to rules imposed and enforced by care providers, or subject to other restrictions or forms of surveillance that would not ordinarily be imposed on non-disabled adults living in their own homes. There is a growing tendency of 'supported living' providers to purchase or build blocks of flats intended for individual inhabitation, which are marketed as for independent living, but because they are *only* for disabled users of care services they still have a segregative character.

5. Paragraphs 15(a) – 15(c) (pages 4-5)

We agree with the definition and explanation of the concept of 'independent living' as set out in paragraphs 15(a)-15(c). Nevertheless, we are of the view that greater emphasis should be placed on the important point that independent living does not relate to the ability of people to carry out activities of daily living (sometimes referred to in the UK as "independent living skills") or to live without support.

In the UK, disabled people have been alert for decades to the risks of the appropriation of their language of choice.¹⁰ Experience demonstrates that ideas and language of the Disabled People's Movement in the UK, including that of independent living, have been 'colonised and corrupted'.¹¹ Research carried out at Cardiff University School of Law and Politics has found that there is evidence for these concerns.

While independent living has been strongly referenced and developed within policy documents in the UK, drawing on definitions provided by disabled people,¹² the meanings ascribed to 'independence' in these documents slide between different ideas including self-determination and self-reliance.¹³ While the term 'independence' may be used synonymously in these documents with the phrase 'independent living', it is also used in the same documents to refer to self-reliance in daily activities. This creates a dual risk, first that the construction of independent living as it is established in Article 19 is open to misinterpretation and secondly that the ideas of independent living and self-reliance may be deliberately or unintentionally merged. We would like

¹⁰ As long ago as 1998, Philip Mason argued: "Suddenly the term 'independent living' became a catch phrase for social welfare professionals, for the orthodox charities and for anybody else... We have lost control of the very creature we created. Each interest group has defined the term to its own advantage. The original concept and the aspirations of disabled people have been lost in the scramble". Philip Mason, 'Back to Basics' (Facing Our Future: Experts Seminar on Independent Living and Direct Payments, Hampshire Centre for Independent Living, July 1998).

¹¹ Jenny Morris, *Rethinking Disability Policy* (Joseph Rowntree Foundation 2011), p 3.

¹² See, for example: Prime Minister's Strategy Unit, *Improving the Life Chances of Disabled People* (2005) 70; HM Government, *The Case for Change – Why England Needs a New Care and Support System* (May 2008) 35.

¹³ Alison Tarrant, 'Disabled People and Independence: A Study of the Language of Adult Social Care Policy', (Unpublished MSc dissertation, Cardiff University 2013).

to draw attention to the possibility that where the term 'independence' is not clearly defined within the context of 'independent living', there is a real risk that the use and deployment of this language and terminology in policy and legislation may *appear* to be reproducing the ideas of the Disabled People's Movement while having the effect of referring to ideas of self-reliance in daily life.¹⁴ We argue that employing the phrase 'independent living' (or 'living independently') reduces this risk.

6. Paragraphs 5 and 59

We suggest that where resources and eligibility are discussed, the General Comment should provide a reminder that independent living is not connected to the requirement to live without (or with reduced) support. Paragraph 5 notes that independent living 'represent[s] a cost-effective mechanism to ensure sustainable development and eradicate poverty',¹⁵ and paragraph 59 discusses eligibility criteria. At times when States' resources may be highly restricted and/or governments seek to reduce reliance on public sector provision, there is a risk that 'independence' (and even 'independent living') may be interpreted as the ability to be (more) self-sufficient in daily activities.

For example, in the UK this has been vividly illustrated by the recent case *R (Davey) v Oxfordshire CC*.¹⁶ This was the first case to test the 'wellbeing principle' in the English Care Act 2014, which is stated in the guidance to the Act to be 'intended to cover the key components of independent living, as expressed in the UN Convention on the Rights of People with Disabilities (in particular, Article 19 of the Convention)'.¹⁷ The care plan stated that Mr Davey wished to gain more independence. While Mr Davey understood this term to mean self-determination, an occupational therapist and the Local Authority considered that it meant being alone without support, which Mr Davey did not want.¹⁸ Despite fully exploring the terms of Article 19, Mr Justice Morris relied on the interpretation of the Local Authority.¹⁹

While the statements in paragraphs 5 and 59 are accurate, we are of the view that it would be helpful to strengthen the references to self-determination in paragraph 59. We thus suggest the following insertions to paragraph 5, so that it would read:

'In the Preamble to the Convention, States parties recognized that the majority of persons with disabilities live in conditions of poverty and stressed the need to

¹⁴ Alison Tarrant, 'Disabled People and Independence: A Study of the Language of Adult Social Care Policy', (Unpublished MSc dissertation, Cardiff University 2013); Alison Tarrant, ongoing doctoral research.

¹⁵ p 1.

¹⁶ [2017] EWHC 354 (Admin)

¹⁷ Department of Health, 'Care Act Statutory guidance' (Updated version published 26 September 2016) <<https://www.gov.uk/government/publications/care-act-statutory-guidance>> paragraph 1.19.

¹⁸ *Davey v Oxfordshire CC*, paragraphs 75-76; 103; 107.

¹⁹ *Davey v Oxfordshire CC*, paragraphs 122; 128-129; 131.

address the negative impact of poverty. The cost of social exclusion is high and strategies to tackle poverty often require significant extra budgetary resources. However, policies for achieving social inclusion of persons with disabilities, including through the promotion of their right to independent living *as it is articulated in article 19*, represent a cost-effective mechanism to ensure sustainable development and eradicate poverty'

We also suggest the following insertions to paragraph 59:

'States parties should ensure that eligibility criteria for access to support incorporates the following elements: The assessment should be based on a human rights approach to disability, focus on the requirements of the person because of barriers within society rather than the impairment, *take into account, and wherever possible, follow a person's will and preferences* and ensure *the full involvement of persons with disabilities in the decision-making process*. It is important to adopt an open concept of disability compliant with article 1 of the Convention'

7. Paragraph 33

The choice of the phrase 'sine-qua-non' in paragraph 33 on accessibility, is not phraseology that is accessible, particularly to non-lawyers. We thus suggest the sentence is amended to read:

'... as well as inclusive education and health are *an essential condition* for inclusion and participation of persons with disabilities ...'

8. Paragraph 41

We suggest the following amendment and insertions to the second sentence of paragraph 41:

'~~As a civil right~~, article 19 (a), the right to choose one's residence and where, how and with whom to live, is immediately applicable, *as it is a civil and political right*'

9. Paragraph 42

We suggest the following amendment and insertions to the first and second sentences of paragraph 42:

'In order to achieve the *progressive* realization of *economic*, social and cultural rights, States parties must take steps to the maximum of their available resources (art. 2 (1) ICESCR). ~~While full realization of the goals may be achieved progressively,~~ *these steps towards it must be taken immediately or within a reasonably short period of time*'

10. Paragraph 44

We suggest the following amendment to paragraph 44, as the last sentence in the paragraph is unnecessary in view of paragraph 45 which is articulated more clearly:

~~'The duty of progressive realization also entails a presumption against retrogressive measures in the enjoyment of economic, social and cultural rights. Retrogressive measures only should be adopted after careful consideration of all alternatives, if they are duly justified by references to the totality of the rights provided for in the Convention, in the context of the use of the maximum available resources of the State party'.~~

References

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- HM Government, 'The Case for Change – Why England Needs a New Care and Support System' (Department of Health 2008).
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List of Cases

- A Local Authority v WMA & Ors* [2013] EWHC 2580 (COP).
- A NHS Trust v DE* [2013] EWHC 2562 (Fam).
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