

advocacy for **inclusion**

**Submission to the Draft General
Comment No. 5 (2017) Article 19: Living
independently and being included in
the community**

Advocacy for Inclusion

June 2017

About Advocacy for Inclusion

Home of the Disability Rights Law Centre

Advocacy for Inclusion acknowledges the Ngunnawal people as the traditional owners of the land on which we work.

Advocacy for Inclusion is a non-for-profit Disabled People's Organisation (DPO) community organisation in the Australian Capital Territory (ACT), Australia. We provide individual and systemic advocacy services to people with disabilities to promote their human rights and inclusion in the community. We act with and on behalf of individuals in a supportive manner, or assist individuals to act on their own behalf, to obtain a fair and just outcome for the individual concerned.

Advocacy for Inclusion works within a human rights framework and acknowledges the *United Nations Convention on the Rights of Persons with Disabilities*, and is signed onto the *ACT Human Rights Act*.

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We agree to this submission being posted on the website of the Office of the High Commissioner for Human Rights.

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1. Executive Summary

Advocacy for inclusion is a not-for-profit non-government Disabled People's Organisation (DPO) in the Australian Capital Territory (ACT). We provide individual, self and systemic advocacy to people with disabilities to promote their human rights and inclusion in the community. We work directly with people with disabilities who experience the denial of their human rights on a daily basis, including the right to live indendently, to be a parent, to be free from violence and abuse and within the justice system.

Advocacy for Inclusion routinely see many people with disabilities living in forced co-tenancy arrangements, staying with their families throughout their adult life, or living alone without basic personal care or equipment needs. Additionally, many people with disabilities live their lives isolated or segregated from the community around them.

Advocacy for Inclusion notes that Article 19 of the Convention recognise the equal rights of people with disabilities to live in the community, with choices equal to others, and to have full enjoyment of full inclusion and participation in the community, including:

- 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 needs¹.

The Draft General Comment provides clarity to Article 19 and is a platform for challenging the practices and instruments that deny people with disability to live independently in the ACT.

2. Comments supported by Advocacy for Inclusion

Advocacy for Inclusion supports the recommendations and interpretations made in the Draft General Comment. In particular, Advocacy for Inclusion approves the following initiatives:

1. Parties to the Convention are required to ensure that people with disabilities are able to live in the community with accommodation options equal to others. People with disabilities must be able to choose with whom they live on an equal basis with others.
2. State Parties under obligation to take effective and appropriate measures to facilitate the full enjoyment of the right and the full inclusion and participations of persons with disabilities in the community.

¹ Office of the High Commissioner, CRPD *Article 19 – Living independently and being included in the Community*, <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx#19>

3. Legal capacity and equal recognition before the law are the basis of the realisation of independent and community living for people with disabilities.
4. People with disabilities have the right to choose services and service providers according to their individual requirements and personal preferences.
5. Accessible housing, providing accommodations to persons with disabilities, who live independently, in a group or as part of a family unit, must be available in sufficient number, within all areas of the community to provide the right and possibility for persons with disabilities to choose from.
6. Housing must be affordable to persons with disabilities, often individually subsidised, as people with disabilities have less income and are highly marginalised in the community in comparison to their non-disabled counterparts.
7. Monitoring mechanisms to protect people with disabilities being institutionalised based on their disability and establish appropriate mechanisms to detect violence and abuse faced by people with disabilities.

3. Summary of Recommendations

- 1. Suggest the term ‘live independently’ be replaced with the concept of ‘choice on equal basis of others’ to choose where and with whom they live to reflect the choice of community.**
- 2. Suggest State Parties develop transitional plans in consultation directly with people with disabilities and their representative organisations in order to effect the full inclusion of people with disabilities in the communities.**
- 3. State Parties to better analyse measures and outcomes to reduce marginalisation and inequality under Article 19 of the CRPD.**
- 4. In the conditions for compliance with Article 19 the General Comment should clarify that:**
 - The endurance of autonomy and self-determination involving living arrangements should not be solely protected in family contexts, where *family* could possibly be negligent or violent towards the person with disability and thus preventing a decision to leave.**
- 5. The reference to ‘family violence’ should be removed and redefined to emphasise the broad definition of ‘domestic violence’ involving people with disabilities in the community.**

4. Certainty of Article 19 – Paragraph 6 and Paragraph 42

Advocacy for Inclusion propose that Article 19 should be interpreted as a certain and absolute right to end desegregation in the community.

Paragraph 6 of the Draft General Comment states:

The present General Comment is aimed at assisting States Parties in their implantation of article 19 and fulfilling their obligations under the Convention. It primarily concerns the States parties' obligations to ensure every individual's enjoyment of the right to live independently and be included in the community, but is also related to other provisions. Article 19 plays a distinct role as one of the wide ranging and most intersectional articles of the Convention and has to be considered as a precondition for the implementation of the Convention across all articles.²

Although the Convention does not include an exemption or relaxation of a rule or law of Article 19, the term 'living independently'³ could be problematic as the ability to live 'independently' could become an eligibility criterion for independency in the community.

People with disability in the Australian Capital Territory are restricted in their right to 'live independently' and to be included in the community, including the right to choose freely where and with whom they live with. The current inaccessible design of social and private housing options and the lack of appropriate support are key barriers to the right to 'live independently'. The predominant 'supported accommodated' framework used in Australia within the disability service system plays a key role in the restriction to live independently.

Advocacy for Inclusion suggest the term 'live independently' be replaced with the conception of 'choice on equal basis of others' to choose where and with whom they live. The ICCPR already recognises the right to choose one's residence and the reason to include within Article 19 of the CRPD is critical.

Recommendation: Suggest the term 'live independently' be replaced with the concept of 'choice on equal basis of others' to choose where and with whom they live to reflect the choice of community.

Article 19 addresses the need for support for people with disabilities transitioning to the community from institutional settings. Proposals to limit applications of human rights principles by cultural norms may have untended consequences of protecting and even perpetrating discriminatory cultural norms of social care.

A strong focus of Advocacy for Inclusion's recent work^{4 5} has been on the human rights of people with disabilities in the context of social care, particularly within congregated living arrangements in the Australian Capital Territory. The severe impact on people with disabilities and a breach of their human rights is to be argued a factor of congregated and group living arrangements where choice and control is non-existent.⁶ Examples included individuals receiving inadequate support; instances of intention physical abuse; lack of choice and control in their living situation and those they live with; chemical restraint and

² Committee on the Rights of Persons with Disabilities (2017) *Draft General Comment No. 5 (2017)*, Article 19: Living independently and being included in the community.

³ *Ibid*, Para. 4

⁴ Advocacy for Inclusion (2013), *Ask Me: I make my own decisions*.

http://www.advocacyforinclusion.org/Control_and_Choice_Study_Report_FINAL.pdf

⁵ Advocacy for Inclusion (2015), *Submission to the Senate Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings*.

http://www.advocacyforinclusion.org/Site%20Data/Publications/Submissions/2015/Submission_to_Senate_Inquiry_into_institutional_violence_against_FINAL.pdf

⁶ Advocacy for Inclusion (2013), *Ask Me: I make my own decisions*.

restrictive practices as a control measure by support staff and severe lack of personal privacy and freedom.

As outlined in Paragraph 42, it is necessary to recognise that the right to living in the community without restriction of freedom is more than the right not to live in an institution. The right to live in the community includes full access to health care, employment, education and access to justice.

Throughout Australia, many areas of the community, including public infrastructure (i.e. transport, building access), housing and equal access to health care, are inaccessible to people with disabilities. Advocacy for Inclusion has documented cases where the situation effectively keeps people with disabilities confined to their homes, particularly institutional living arrangements where control is extensive and the pervasive use of a 'supported accommodation' framework to address housing and support needs of people with disability continue to perpetrate the view that people with disabilities require care facilities and arrangements, rather than genuine community living arrangements.

In Australia, the focus on funding and providing 'innovative supported accommodation models, has led to 'contemporary' institutions, where group living arrangements in form of a single house, neighbourhood or multi-complex care health model eliminate the benefit of engaging in mainstream community living.⁷ Advocacy for Inclusion has seen examples of forced co-tenancy where a person with disability must live in a group home with another person or several with disability in order to receive supports and where a person must 'agree' to another person moving into their home so support can be shared⁸.

Forced co-tenancy means Article 19 is not met as an individual human right as the quality of support is diminished and the tenant loses the right to make important lifestyle choices, including who they share their home with and to what capacity.

Recommendation: Suggest State Parties develop transitional plans in consultation directly with people with disabilities and their representative organisations in order to effect the full inclusion of people with disabilities in the communities.

5. Meeting core obligations – Paragraph 43

The objective of Article 19 is to ensure the ability of all persons with disability are to live within the community without institutionalisation and to ensure their full inclusion within society through access of social care and supports on a non-discriminatory basis.

Obligations placed on State Parties to exempt from progressive realisation regarding Article 19 (b) and (c) by ensuring that the "the minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights" had not been failed.⁹ Australia recognises its obligation to review domestic laws to determine extent to which they comply actively with the CRPD and its progress. Although Australia's national standards do comply and reflect the Universal Declaration of Human Rights (UDHR) and the Convention

⁷ Council of Australian Governments, *National Disability Strategy 2010-2020*, p. 84.

⁸ Advocacy for Inclusion (2015), *Submission to the Senate Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings*.

⁹ Committee on the Rights of Persons with Disabilities, *Draft General Comment No. 5*, Para. 43

on the Rights of Persons with Disabilities (CRPD), the implementation and interpretation has seen Australia's obligations to meet Article 19 can be argued to be exploited and human rights breached.

The National Disability Strategy (NDS) 2010-2020¹⁰ also includes an action focused on developing supported accommodation models for people with high complex needs as per obligations under Article 19. The obligations are contained in sections addressing specialist disability care and supports rather than in sections addressing rights to housing, and many disability representative, advocacy and human rights organisations are sceptical that they can or will comply with Article 19.

As part of its obligations in which are welcomed, Australia has committed to introducing a National Disability Insurance Scheme (NDIS), key initiatives to enable persons with disabilities with significant support needs to emphasised to obtain, choose, control and manage supports they need to live independently in the community, including choosing and living independently in supported or solo accommodation. This is currently being debated in Australia as part of the roll out of the scheme across Australia.

6. Establish monitoring mechanisms to support people with disabilities facing abuse and violence – Paragraph 51

Advocacy for Inclusion is pleased to see that paragraph 51 outlines a necessary need for the establishment of monitoring mechanisms of service providers, adopt measures which will protect and detect people with disabilities from violence and abuse.

There has been very little data and research to establish monitoring mechanisms of where people with disabilities facing abuse and violence turn to when escaping violent situations. For women, shelters are the most common option; however it is the least used. Security requirements, reasonable accommodations and the shared environment are often inaccessible for women with high support needs¹¹. People with disabilities living in institutional settings where abuse and violence is consistent¹² are not provided with the option to leave at all.

Article 31 of the CRPD features Statistics and Data Collection; yet, it is evident that the lack of data to support the implementation of the Convention is universal.¹³ It is difficult for Australia to report on CRPD implementation without benchmarking critical data, despite the UN making it clear that Australia must develop nationally consistent measures for data collection and public reporting of disaggregated data across the full range of obligations contained in the CRPD.

¹⁰ Commonwealth of Australia (2011) *National Disability Strategy 2010-2020*, p. 32
<https://www.humanrights.gov.au/sites/default/files/NDS%20PDF.pdf>

¹¹ Advocacy for Inclusion (2017), *The Right to Escape without Restriction for Women with Disabilities: Reply to call for Submissions on Protection Orders & Shelters as Two Ways of Prevention & Protection of Violence Against Women*,
http://www.advocacyforinclusion.org/Site%20Data/Publications/Submissions/2017/Protection_Orders__Shelters_-_for_Special_Rapporteur_FINAL_copy.pdf

¹² Advocacy for Inclusion (2015), *Submission to the Senate Inquiry into violence, abuse and neglect against people with disability in institutional and residential settings*.

¹³ Committee on the Rights of Persons with Disabilities (2013) Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 September 2013); see UNDoc: CRPD/C/AUS/CO/1

The Australian Bureau of Statistics (ABS) is the major national data collector on the status of people with disabilities in Australia; however, it does not collect data on experiences of violence or abuse. There has been no systematic data collection by the Australian Government or by state and territory governments unless referred to academic data conducted in research analysis and this is not enough to develop a clear, national picture of violence and abuse.

Recommendation: State Parties to better analyse measures and outcomes to reduce marginalisation and inequality under Article 19 of the CRPD.

7. Ensure autonomy and self-determination – Paragraph 53

Advocacy for Inclusion also supports the recommendation that States Parties should ensure autonomy and self-determination of the person with disabilities concerning their living arrangements prevail, including persons with disability under guardianship arrangements.

There is one critical element to be reconsidered in this section: a clear statement that not all people with disabilities can or are protected in a family context. It is recognised that *supportive* families contribute to the realisation of independent living, but this can be disputed when the person with disability is restricted when in a domestic violence circumstance living with a spouse, immediate and/or extended family member.¹⁴ This is important in distinguishing living arrangements where people with disabilities have or have not provided choice and control in who they live with and the circumstances involved.

Recommendation: In the conditions for compliance with Article 19 the General Comment should clarify that:

- **The endurance of autonomy and self-determination involving living arrangements should not be solely protected in family contexts, where *family* could possibly be negligent or violent towards the person with disability and thus preventing a decision to leave.**

There should be no reference to family contexts in the General Comment. Not all relationships in which people with disabilities experience violence can be defined within a family-like context. Any definition of ‘domestic violence’ needs to be sufficiently broad to cover spousal relationships, intimate personal relationships (including dating relationships and same sex relationships), housemate shared arrangements, family relationships (with a broad definition of relative), and formal and informal care relationships.

In particular, people with disability live in a diverse range of domestic settings including, a community based group home or residential institution, a boarding house, hospital, psychiatric ward, or nursing home. It is highly common that people with disability who have only experienced living in supported accommodation have no knowledge about alternatives and no readily accessible means to acquire that knowledge. It is under these living arrangements that many people with disability are particularly isolated, with limited ability to have relationships and confidants outside the ‘family’ where the abuse is taking place.

¹⁴ See Advocacy for Inclusion submission *The Right to Escape without Restriction for Women with Disabilities: Reply to call for Submissions on Protection Orders & Shelters as Two Ways of Prevention & Protection of Violence Against Women*, March 2017

People with disability face different forms of violence than their counterparts without a disability that are interrelationship of Article 19 with other provisions of the Convention. For example, forced sterilisation and abortion, chemical restraint, withholding of aids and equipment, having services or activities withheld, continual belittling and demeaning treatment based on the disability, and threats to remove children.

Recommendation: The reference to ‘family violence’ should be removed and redefined to emphasise the broad definition of ‘domestic violence’ involving people with disabilities in the community.

8. Conclusion

Advocacy for Inclusion notes that Article 19 of the Convention recognise the equal rights of people with disabilities to live in the community, with choices equal to others, and to have full enjoyment of full inclusion and participation in the community. If people with disabilities are to justly participate in all aspects of community life, barriers to community living outside of institutionalised setting need to be removed.

To ensure that Article 19 is realised support services, including in home support, residential and community support services, and personal care must be readily available – without the heavy reliance on ‘supported accommodation’ and co-tenancy arrangements. There will be many different ways that people with disabilities choose to live, but the realisation of Article 19 of the UN CRPD must be considered when developing any options or undertaking any planning with individuals.

People with disabilities must have the freedom to live in and be a part of the community, and they must not be obliged to live, work, or learn in any particular arrangement particularly those that are separate to the broader community. Most importantly the choice must be theirs. Advocacy for Inclusion recognises the right to live independently and to be included in the community is a right that every person, without exception, should enjoy and have respected.