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an Duine agus Comhionannas
Irish Human Rights and Equality Commission

CRPD Article 19: Living independently and being included in the community

Issue Paper

Disability Advisory Committee

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Introduction

This session will give the DAC the opportunity to discuss independent living and the measures the State has taken/is taking to facilitate the full enjoyment of disabled people of the right to independent living and to ensure their full inclusion and participation in the community.

Article 19 of the Convention on the Rights of Persons with Disabilities (CRPD) recognises the equal right of all disabled people to live in the community, with choices equal to others. It requires State Parties to take effective and appropriate measures to facilitate full enjoyment by disabled people of this right and their full inclusion and participation in the community.¹ This includes ensuring that disabled people -

- 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;
- 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; and
- that community services and facilities for the general population must be available on an equal basis to disabled people and be responsive to their needs.²

CRPD Article 19 emphasises that disabled people are rights holders and recognises the importance of individual autonomy and independence, including the freedom to make one's own choices.³ The Special Rapporteur on the rights of persons with disabilities has described Article 19 as being intimately connected to the mission of the CRPD as a whole.⁴ The Committee on the Rights of Persons with Disabilities (the Committee) has described it as one of the widest ranging and most intersectional articles of the Convention and that it must be considered as integral to the full implementation of the Convention.

IHREC is seeking DAC's advice regarding the measures the State has taken/is taking to facilitate the full enjoyment by disabled people of CRPD Article 19 and their full inclusion and participation in the community.

¹ [Article 19 – Living independently and being included in the community.](#)

² *Ibid.*

³ [General comment No. 5 \(2017\) on living independently and being included in the community.](#)

⁴ Report of the Special Rapporteur on the rights of persons with disabilities, [Transformation of services for persons with disabilities](#) (2022), para 23.

IHREC Strategy Statement 2022-2024

Two of the Commission's strategic priority areas relevant to this topic are 'Economic Equality' and 'Respect and Recognition'.

- Economic Equality: Economic inequality affects all marginalised groups and prevents the realisation of many fundamental rights. Under this strategic priority, the Commission will seek greater economic equality in housing, employment, income and for carers.⁵
- Respect and Recognition: A society cannot be inclusive or fair without addressing: the structural and institutional arrangements, practices, policies and cultural norms, which have the effect of excluding or discriminating against individuals or groups based on their identities. Under this strategic priority, the Commission will promote the eradication of racism, ableism, ageism and sexism through public understanding and State action.

Article 19 - Living independently and being included in the community

General Comment No. 5 (2017) on living independently and being included in the Community

The Committee issued General Comment No. 5 to provide guidance to State parties on the implementation of Article 19.⁶ It includes definitions of 'independent living', 'being included in the community', 'independent living arrangements', and 'personal assistance'.⁷

The Committee states that the following core elements of Article 19 should always be respected, particularly in times of financial or economic crisis. The core elements are as follows.

- To ensure the right to legal capacity, in line with the Committee's general comment No. 1, to decide where, with whom and how to live for all persons with disabilities, irrespective of impairment;

⁵ [IHREC Strategy Statement 2022-2024](#), p.11.

⁶ [General comment No. 5 \(2017\) on living independently and being included in the community](#).

⁷ *Ibid*, para 16.



- To ensure non-discrimination in accessing housing, including the elements of both income and accessibility, and adopting mandatory building regulations that permit new and renovated housing to become accessible;
- To develop a concrete action plan for independent living for persons with disabilities within the community, including taking steps towards facilitating formal supports for independent living within the community so that informal support by, for example, families is not the only option;
- To develop, implement, monitor and sanction non-compliance with legislation, plans and guidance on accessibility requirements for basic mainstream services to achieve societal equality, including participation by persons with disabilities within social media, and secure adequate competence in information and communications technologies to ensure that such technologies are developed, including on the basis of universal design, and protected;
- To develop a concrete action plan and take steps towards developing and implementing basic, personalized, non-shared and rights-based disability-specific support services and other forms of services;
- To ensure non-retrogression in achieving the content of article 19 unless any such measures have been duly justified and are in accordance with international law;
- To collect consistent quantitative and qualitative data on people with disabilities, including those still living in institutions;
- To use any available funding, including regional funding and funding for development cooperation, to develop inclusive and accessible independent living services.⁸

Interdependence of Article 19 with other Convention Rights

In 2019, IHREC funded a 'Research Report on Article 19 of the UN Convention on the Rights of Persons with Disabilities' (the Report). The Report was prepared by Prof. Eilíonóir Flynn, Dr. Áine Sperrin and Dr. Janos Fiala-Butora at the Centre for Disability Law and Policy, NUI Galway. It set

⁸ National Disability Authority, [Overview of UNCRPD Article 19 in Ireland - Living independently and being included in the community](#) (August 2022), p. 9.



out contemporary legislation and policy provisions, as well as practical initiatives, which purport to realise the right to live independently and participate in the community as prescribed by CRPD Article 19. Further, it outlines the interconnectedness between Article 19 and other CRPD Articles. While all CRPD rights are interconnected, interdependent and indivisible, the research team focussed on the following:

- Articles 12 (Equal recognition before the law) and 14 (Liberty and security of the person);
- Articles 6 (Women with disabilities), 7 (Children with disabilities), and 23 (Respect for the home and family life); and
- Articles 8 (Awareness raising) and 9 (Accessibility).⁹

The following passages are taken from the Report.

Article 12 (Equal recognition before the law) and Article 14 (Liberty and security of the person)

Article 12 expresses the fundamental right of persons with disabilities to exercise their legal capacity on an equal basis with others. Article 19(a), as well as Article 3(a), addressing individual autonomy¹⁰, is closely linked to the right to legal capacity primarily because the person's need to be recognized before the law is crucial for making decisions about place of residence and where and with whom one will live. As explained in the Committee on the Rights of Persons with Disabilities' General Comment No. 1 on legal capacity, to fully realize the rights contained in Article 12, persons with disabilities must have the opportunity to live independently and to have control over their everyday lives.¹¹ A community-based support network is key to both exercising legal capacity and living independently.¹² Therefore, institutionalisation violates both articles 19 and 12 of the UNCRPD.

As set out in General Comment 1, "States parties must recognize that communities are assets and partners in the process of learning what types of support are needed in the exercise of legal

⁹ Articles 12 and 14 complement the respect for decision making and exercise of choice. Articles 6, 7 and 23 relate to women and children with disabilities and respect for the family, which are central components of independent living. Articles 8 and 9 focus on important factors to be addressed within society – awareness raising among the public about the rights of persons with disabilities and accessibility – which are everyday barriers to independent living.

¹⁰ Article 3(a) states: "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons."

¹¹ [General Comment No. 1 – Article 12: Equal recognition before the law \(April 2014\)](#), para. 44

¹² *Ibid*, para. 45.



capacity, including raising awareness about different support options. States parties must recognize the social networks and naturally occurring community support (including friends, family and schools) of persons with disabilities as key to supported decision-making. This is consistent with the Convention's emphasis on the full inclusion and participation of persons with disabilities in the community.¹³

The lack of disability specific support services often cause or increase involuntary institutionalisation on the basis of impairment or associated circumstances such as presumed "dangerousness" and other factors as elaborated in the Committee's guidelines on Article 14.¹⁴ Implementing Article 19 thus will ultimately prevent violations of Article 14 as well.

As the Committee notes in its Guidelines on Article 14, "Enjoyment of the right to liberty and security of the person is central to the implementation of article 19 on the right to live independently and be included in the community ... it has recommended implementing support services and effective deinstitutionalisation strategies in consultation with organizations of persons with disabilities. In addition, it has called for the allocation of more financial resources to ensure sufficient community-based services".¹⁵

Article 6 (Women with disabilities), Article 7 (Children with disabilities) and Article 23 (Respect for home and the family)

Article 6

The Committee on the Rights of Persons with Disabilities' General Comment No. 3 on women and girls with disabilities highlights the gender-specific aspects of institutionalisation (Article 6 of the UNCRPD). Cultural norms and patriarchal family values might affect the right of women with disabilities to choose their places of residence, leading to multiple discrimination and institutionalisation.¹⁶ At the same time, women with disabilities are particularly exposed to violence and abuse in institutions.¹⁷

¹³ *Ibid*, para. 45.

¹⁴ *Ibid*, para. 83.

¹⁵ CRPD Committee's Guidelines on Article 14 of the Convention on the Rights of Persons with Disabilities, Adopted During the Committee's 14th session, held in September 2015, para. 9

¹⁶ [General Comment No. 3 on women and girls with disabilities \(25 November 2016\)](#), para. 55.

¹⁷ *Ibid*.



When implementing the right to independent living, particular attention should be paid to gender equality, because women with disabilities who face domestic violence are frequently more economically, physically, or emotionally dependent on their abusers, which prevents women with disabilities from leaving abusive relationships and leads to further social isolation.¹⁸

States parties should ensure equal access to social services and support by addressing gender-based inequalities in accessing them¹⁹, including measures supporting women in re-entering the open labour market.²⁰ State parties should also ensure that shelters for victims of gender-based violence are fully accessible to women and girls with disabilities.²¹

Articles 7 and 23

For children with disabilities adequate and age-sensitive support (Article 7) is crucial to prevent institutionalisation.²² It is critical to respect the evolving capacities of children with disabilities so that they can express their choice with regard to their living conditions.²³ Children may prefer personal assistance to informal support and might require support to practice sports and take part in leisure activities with their age peers.²⁴

The right to independent living also requires services that facilitate the transition into adulthood, such as assistance with moving out of the family home, starting employment and continuing into higher education.²⁵

Family support services under Article 23 are essential not only to prevent children with disabilities from being taken away from their families and placed in institutions, but also to ensure that children are not placed in alternative care arrangements due to their parents' disability.²⁶ Community-based support is necessary to prevent financial pressures and constraints for the family of persons with disabilities. It must also be recognised that being a parent is equally a pathway to participate in

¹⁸ [General comment No. 5 \(2017\) on living independently and being included in the community](#), para. 73.

¹⁹ *Ibid*, para. 74.

²⁰ *Id.*

²¹ *Id.*, para. 75.

²² *Id.*, para. 76.

²³ *Id.*

²⁴ *Id.*

²⁵ *Id.*, para. 77.

²⁶ *Id.*, para. 88.



community activities for parents with disabilities as it is for non-disabled parents, and this should be facilitated.

Article 8 (Awareness raising) and Article 9 (Accessibility)

Article 8

Article 19 is linked to the fulfilment of the obligation under Article 8 of the UNCRPD. Human flourishing can only exist when there is awareness and receptiveness to the rights of people with disabilities. As Article 19 is ultimately about transforming communities, awareness-raising is essential to eradicate stereotypes, ableism and misconceptions that prevent persons with disabilities from living independently.²⁷ Any deinstitutionalisation policy must be based on societal receptiveness and attitudinal change toward inclusion. This is highly unlikely to happen when people with disabilities are institutionalised or living in congregate care remotely from society. As Article 19 is increasingly realised, it will contribute to the expectations of children with disabilities changing for themselves as well as by society. Awareness-raising should be provided for authorities, civil servants, professionals, the media, the general public and persons with disabilities and their families to create open, enabling and inclusive communities.²⁸

Article 9

Accessibility (Article 9) in a broad sense is a precondition to inclusion. The Convention innovates by crafting accessibility and participation rights in a variety of spheres including the economic, social, cultural, and the political. Accessible environment, transportation, information and communication, and services are a precondition for inclusive communities and for fulfilling the right to independent living.²⁹ Article 9 requires the identification and elimination of barriers in buildings open to the public, such as the revision of building control acts and urban planning codes, the inclusion of standards of universal design in a variety of sectors, and the establishment of accessibility standards for housing.³⁰

²⁷ *Id.*, para. 78.

²⁸ *Id.*

²⁹ CRPD General Comment No. 2 – Article 9: Accessibility, UN Doc CRPD/C/GC/2 (22 May 2014) para 37

³⁰ [General comment No. 5 \(2017\) on living independently and being included in the community](#), para. 79.

The Irish Context

The below sets out a brief overview of the Irish context and is intended as a snap shot and not the Irish context in its entirety.

Independent Living

Deinstitutionalisation

In 2011, the Irish Government published the *Time to Move on from Congregated Settings* Report³¹, in which a policy to decongregate disabled people from institutional settings was set out.

At the time the policy was published, there were approximately 4,099 individuals living in congregated settings of 10 or more people. A commitment was made to transition all these individuals to the community by 2021. By end 2019, the most recent year for which figures are available, there were approximately 1,950 individuals remaining in congregated settings.³²

Although the CRPD does not specifically mention deinstitutionalisation or address the transition process from institutional to community-based support, the Committee has underlined that it is an essential component of fulfilling Article 19.³³

The implementation of deinstitutionalisation measures requires effective and regular monitoring³⁴ through the use of concrete benchmarks³⁵ and measurable human rights-based indicators³⁶. It must also be accompanied by sufficient resources³⁷ in the form of specific budgetary allocations for the development of community services³⁸. In a number of cases, the Committee found that despite their commitments, states parties continue to invest their available resources in building,³⁹

³¹ HSE, [Time to Move on from Congregated Settings: A Strategy for Community Inclusion](#) (2011).

³² National Disability Authority, [Overview of UNCRPD Article 19 in Ireland - Living independently and being included in the community](#) (August 2022), p. 16.

³³ Grene H., O'Hare S. and Flynn E, (2019) [From institutions to community living: drivers and barriers of deinstitutionalisation Case study report: Ireland 2018](#). European Union Agency for Fundamental Rights.

³⁴ CRPD Committee, Concluding Observations: Czech Republic, UN Doc CRPD/C/CZE/CO/1 (15 May 2015) para 40

³⁵ CRPD Committee, Concluding Observations: Paraguay, UN Doc CRPD/C/PRY/CO/1 (15 May 2013) para 48

³⁶ CRPD Committee, Concluding Observations: Kenya, UN Doc CRPD/C/KEN/CO/1 (30 September 2015) para 38

³⁷ CRPD Committee, Concluding Observations: Ukraine, UN Doc CRPD/C/UKR/CO/1 (2 October 2015) para 37

³⁸ CRPD Committee, Concluding Observations: Kenya, UN Doc CRPD/C/KEN/CO/1 (30 September 2015) para 38

³⁹ CRPD Committee, Concluding Observations: Belgium, UN Doc CRPD/C/BEL/CO/1 (28 October 2014) para 33



renovating⁴⁰ and expanding institutions,⁴¹ sometimes with the support of the European Union's Structural Investment Funds⁴².

National Housing Strategy for Disabled People

The National Housing Strategy for Disabled People 2022 – 2027⁴³ sets out the Government's vision for delivering housing and related supports for disabled people. The Strategy echoes the vision of the first Strategy with a particular emphasis on disabled people living independently and being included in their communities, and having choice and control over their living arrangements.⁴⁴ It outlines that no one Government department or organisation can deliver on the vision of the Strategy; rather, delivery must be carried out in a coordinated and collaborative way with disabled people at the centre.

Access to Specialist Support Services

Specialist disability services in Ireland have been predominantly delivered by the voluntary sector. As the landscape has evolved, some services are now delivered directly by the Health Service Executive (HSE), while the majority are still delivered by the voluntary sector, with funding provided and administered by the State through the HSE.⁴⁵ This funding has traditionally been delivered through block grants, which has made it challenging to move to individualised funding while continuing to deliver services within existing budgets.⁴⁶

⁴⁰ CRPD Committee, Concluding Observations: Lithuania, UN Doc CRPD/C/LTU/CO/1 (11 May 2016) para 41

⁴¹ CRPD Committee, Concluding Observations: European Unions, UN Doc CRPD/C/EU/CO/1 (2 October 2015) para 51

⁴² CRPD Committee, Concluding Observations: Lithuania, UN Doc CRPD/C/LTU/CO/1 (11 May 2016) para 41

⁴³ The Strategy was developed by the Department of Housing, Local Government and Heritage, Department of Health, and the Department of Children, Equality, Disability, Integration and Youth. [National Housing Strategy for Disabled People 2022 - 2027](#)

⁴⁴ Department of Housing, Local Government and Heritage; Department of Health; Department of Children, Equality, Disability, Integration and Youth, [National Housing Strategy for Disabled People 2022 – 2027: Publication](#) (January 2022).

⁴⁵ National Disability Authority, [Overview of UNCRPD Article 19 in Ireland - Living independently and being included in the community](#) (August 2022), p. 28.

⁴⁶ In this context 'block grants' are an amount of funding to an organisations to provide services to all those to whom the provider provides services. 'Individualised funding' is an amount of money provided to an organisation to meet the needs of an individual based on an assessment of that individual's needs. See National Disability Authority, [Overview of UNCRPD Article 19 in Ireland - Living independently and being included in the community](#) (August 2022), p. 28.

Personal Assistance

Personal assistance has long been acknowledged in Ireland as important to support disabled people both in their personal care needs and in participating in their communities on an equal basis with others. However, the provision of personal assistance has never met need and the Irish Wheelchair Association estimates that there is a deficit of over 520,000 PA hours for persons with physical and sensory disabilities alone⁴⁷. There is a need for a joined up approach to the delivery of personal assistance services. This would recognise that people need flexibility in their personal assistance across their entire lives – from in home support, engaging in education and employment, attending social and cultural events and accessing transport and health facilities⁴⁸. When a comprehensive personal assistance scheme is implemented, it will be important to collect data on the impact of these services on the quality of life of service users, the frequency of use, geographic trends and how the service is being used.

Disability Capacity Review – a Review of Disability Social Care Demand and Capacity Requirements up to 2032

The ‘Disability Capacity Review – a Review of Disability Social Care Demand and Capacity Requirements up to 2032’ was published by the Department of Health in July 2021. It sets out the estimates of the levels of unmet need for specialist disability support services delivered or funded by the HSE, and of future needs arising from change in the size or age-structure of the population.⁴⁹

The Joint Oireachtas Committee on Disability Matters raised concern with the significant levels of unmet need identified in this review for disability services and changes in size and age profile of the disability service population, which will add to the demand for services over the coming decade. The Joint Oireachtas Committee on Disability Matters expressed concern that the current level of unmet need is not sustainable and as set out in the Review, there may be a significant human cost for the individuals concerned and their families.⁵⁰

⁴⁷ Irish Wheelchair Association, [Personal Assistance Services](#).

⁴⁸ ILMI, [Submission to the Committee on Housing, Planning and Local Government](#) (June 2019)

⁴⁹ Department of Health, [Disability Capacity Review – a Review of Disability Social Care Demand and Capacity Requirements up to 2032](#) (2021)

⁵⁰ Joint Committee on Disability Matters, [Ensuring Independent Living and the United Nations Convention on the Rights of Persons with Disabilities](#) (March 2022), p. 79.

Ireland's first report to the United Nations Committee on the Rights of Persons with Disabilities

On 10 November 2021, Minister of State with Special Responsibility for Disability, Anne Rabbitte TD, published Ireland's first report to the United Nations Committee on the Rights of Persons with Disabilities. In the summary of submissions received by the Department of Children, Equality, Disability, Integration and Youth on the Draft Initial State Report to the Committee on the Rights of Persons with Disabilities, the following comments were made on Article 19:

- It is essential that Article 19 goes beyond "living in the community" and refers to "being included in the community". Inclusive communities need to be pursued and achieved, ensuring that events, activities, and facilities are accessible and inclusive.
- The State Report should include information on cross-governmental policies and programmes to combat social exclusion and segregation of people with disabilities.
- The Draft Report does not prioritise the development of a Housing and Disability Strategy. Local authorities should have an allocation of social housing for persons with disabilities. There must be statutory effect to the National Guidelines for the Assessment and Allocation Process for Housing Provision for People with Disabilities.
- Many people with disabilities have little or no choice in terms of their living accommodation. There is a need for a range of accommodation options to ensure that people can live independently in their communities and a path to independent living for people with disabilities who are currently living with family.
- There is no mention of the disproportionate amount of people with disabilities who are homeless, or analysis of the accessibility of homelessness supports.
- The application process for housing adaptation grants is bureaucratic. There is no analysis of the difficulties persons with disabilities experience trying to access the grant, or recognition that the level of the grant falls below current building costs.
- Local authorities must take into consideration the specific needs of persons who are blind or vision impaired when allocating social housing, for example, public transport links, access to community health facilities, secure garden area for a guide dog. These requirements should be part of housing allocation policies.
- Further detail should be provided on the allocation of finance and resources for personal assistance and the demand for personal assistance services. This service is resource led and



not demand led, which leaves people with disabilities in a very vulnerable situation and at the mercy of department budgets.

- The Draft Report references the Task Force on Personalised Budgets. The Report does not highlight the low numbers of people currently in receipt of a Personalised Budget or propose a wider implementation to ensure access for as many people as possible. Further data should be provided on numbers included in the pilot project, criteria for participation, the timeline, and operation to date. Clarity is required on the resource allocation model used to determine the funding of personalised budgets, and the involvement of the representative organisations of persons with disabilities in its development.

Questions for DAC discussion

When you think about Article 19

- What are your main issues and concerns?
- Do you have any examples that illustrate these issues or concerns? These can be individual, at community level or institutional level.
- What are your views on the Irish State's realisation of Article 19 to date?
- What are your views on how the Irish State's can further realise Article 19?
- Where do you feel the biggest gaps are with regards to legislation, policy, research and data?