SEGREGATION OF PEOPLE WITH DISABILITY IS DISCRIMINATION AND MUST END



















People with disability and our representative and advocacy organisations remain extremely concerned by existing law, policy and practice frameworks that maintain the segregation of people with disability from community life.

The everyday reality for many people with disability is one of inequality and discrimination that separates us from community life by preventing us from undertaking everyday activities, such as catching public transport, getting a job, going grocery shopping, eating out with friends and family, living in appropriate, accessible housing, accessing news and public information and participating in sport and recreation.

Many people with disability are separated from the rest of the community by law, policy and practice frameworks that directly and explicitly enable 'special', segregated arrangements, such as 'special' schools, institutional living environments and segregated workplaces. Very often, people with disability are unable to choose any other options but 'special', segregated arrangements as there are no other choices, the choices are limited, or the choice is made for us by others. This is particularly the case for people with intellectual disability, cognitive disability, psychosocial disability, as well as neurodiverse peoples, people with multiple impairments, and others who are warehoused in segregated settings and environments due to a lack of adequate services and supports.

It is imperative that the segregation of people with disability is recognised and conceptualised as discrimination and as not adhering to the United Nations Convention on the Rights of Persons with Disabilities (CRPD)¹ and other international human rights conventions to which Australia is a party.² The CRPD underpins the law, policy and practice frameworks for the development of the next ten-year National Disability Strategy (NDS),³ the ongoing implementation of the National Disability insurance Scheme (NDIS),⁴ the implementation of the NDIS Quality and Safeguards Commission (NDIS Commission)⁵ and the work of the Royal Commission into Violence, Abuse, Neglect and Exploitation (Disability Royal Commission).⁶ It is essential that, consistent with Australia's international human rights obligations, concerted action to end the segregation of people with disability is incorporated within these critical disability reform processes.



Segregation is discrimination

The CRPD does not establish new human rights for people with disability but translates existing human rights to the specific situation of people with disability. The principles of equality and non-discrimination are foundational human rights contained in all the core international human rights conventions. In the CRPD, these principles affirm that people with disability are of equal worth and value in their humanness, and are entitled to the human rights and fundamental freedoms due to <u>all</u> human beings without discrimination on an equal basis with others.

Equality and non-discrimination in international human rights law incorporates the principle that segregation is inherently unequal and discriminatory. The Universal Declaration of Human Rights (1948) (UDHR) stipulates that everyone is entitled to all human rights and fundamental freedoms without distinction of any kind, such as distinctions based on "race, colour, sex, language, religion, political or other opinion national or social origin, property, birth or other status". This is specifically elaborated in the context of race in the International Convention on the Elimination of All Forms of Racial Discrimination (1965) (ICERD), which prohibits racial discrimination, including racial segregation and apartheid, and requires its prevention and eradication. ICERD rejects the 'separate but equal' standard that was the longstanding justification for segregated education on the basis of race, and which was found discriminatory by the US Supreme Court in 1954.

The prohibition of 'separate' standards for 'separate' groups is reinforced in the International Covenant on Economic, Social and Cultural Rights (1966) (ICESCR). In its general comments, or guidance papers on interpretation and implementation of ICESCR, the Committee on Economic, Social and Cultural Rights (CESCR Committee) outlines that disability-based discrimination includes segregation, isolation and separation based on impairment.¹⁰

In the context of education, the CESCR Committee stipulates that segregated educational systems breach the ICESCR.¹¹ Although ICESCR recognises that parents have a right to choose the schools that their children attend, this right is limited to a choice between public and private education where the objective of the choice is to ensure religious and moral education that conforms with parental convictions.¹² This limited right does not extend to disability-based segregation, as this would be inconsistent with the international human rights standard of equality and non-discrimination.¹³

In the context of the right to live independently in the community, a well-known 1999 decision by the US Supreme Court found that the institutionalisation of people with disability constituted discrimination under the Americans with Disabilities Act (ADA).¹⁴ Along with international human rights law and other authoritative court decisions from other jurisdictions, this decision was influential during the drafting of the CRPD, reflecting the legal norm that segregation is a form of discrimination.¹⁵

Article 5 of the CRPD Equality and non-discrimination affirms the established principle in international human rights law that segregation is inherently unequal and discriminatory. Legitimising segregated systems for people with disability is a direct contravention of the CRPD and the human rights normative standard of equality and non-discrimination. This normative standard means that a key purpose and objective of the CRPD is to undo the legacy of inequality and discrimination, including the segregation of people with disability. This requires reviewing existing practices of segregation and eliminating them.¹⁶

The Committee on the Rights of Persons with Disabilities (CRPD Committee) has provided guidance on the interpretation and implementation of article 5 through its General comment No. 6 (2018) on equality and non-discrimination.¹⁷ It makes clear that the segregation of people with disability is discrimination and that measures must be taken to end this discrimination.¹⁸ This is reinforced by the CRPD Committee in its general comments specifically relating to the right to inclusive education,¹⁹ which includes a definition of segregation,²⁰ and the right to live independently and be included in the community.²¹

While the CRPD allows for specific measures to achieve equality for people with disability, these measures must be positive and affirmative measures that must not result in the maintenance of segregation, isolation and stigmatisation.²² Segregation and segregated facilities cannot be justified as a specific measure to meet higher support, complex, 'challenging behaviour' needs or any other needs of people with disability. The ongoing investment in segregated facilities, such as special schools, units or classrooms, group homes and other institutional living settings and segregated workplaces, including Australian Disability Enterprises (ADEs), cannot be justified as transitionary measures to achieve equality. Investment in segregation and segregated facilities is discrimination under the CRPD.²³



Ableism, segregation and disability reform

The long history of the segregation of people with disability in residential institutions, special schools, sheltered workshops (now known as ADEs), psychiatric facilities & forensic disability units, aged care facilities and other settings is underpinned by ableism - the harmful social norms and beliefs that devalue people with disability as 'less than', as 'deficient', as 'other'. Ableism underpins the inequality and discrimination experienced by people with disability and ableism is an enabler of violence, abuse, neglect and exploitation. Ableism appears neutral, benign and natural,²⁴ and the ableist response to disability appears self-evident - the establishment of 'special' laws, policies and programs to provide care, treatment, medical interventions and protection for people with disability.

The legacy of this history is embedded in existing systems that segregate us from others in the community, deny our autonomy and prevent our full participation and inclusion in society. Many people with disability remain indirectly segregated from community life by pervasive environmental, communication, attitudinal and systemic barriers that law, policy and practice frameworks have failed to remove – such as inaccessible housing, transport, information and communication systems, voting; non-inclusive violence prevention and response services; barriers in accessing justice and legal systems; and employment and health discrimination. Many people with disability remain directly segregated by law, policy and practice frameworks that continue to establish, maintain and fund segregated settings - such as special schools, units and classrooms; institutional accommodation settings; and segregated employment - as well as through substitute decision-making arrangements that limit our autonomy, such as guardianship, financial management and involuntary mental health systems.

The ableism that is inherent to the segregation of people with disability is further compounded and has multiple effects when it intersects with sexism, ageism, racism and other forms of inequality. This intersectional discrimination means that segregation is underpinned by and results in multiple and unique forms of disadvantage for different groups of people with disability, including children with disability, older people with disability, women and girls with disability, First Nations people with disability, culturally and linguistically diverse (CALD) people with disability, and people with disability from the LGBTIQA+ communities.

For over sixty years, people with disability have challenged the ableist approaches to disability that have legitimised our segregation. Not only does this segregation expose the "social apartheid"²⁵ experienced by people with disability, it also significantly increases the experience of violence, abuse, neglect and exploitation in our daily lives.²⁶

In response to these challenges, Australia has gradually shifted to a rights-based approach to disability, including through the establishment of disability rights advocacy programs,²⁷ the closure of many large residential institutions²⁸ and the introduction of the Disability Discrimination Act 1992 (DDA).²⁹ Over the last decade, Australia has ratified the CRPD, implemented the National Disability Strategy 2010-2020 (NDS),³⁰ introduced the NDIS, established the NDIS Commission and established the Disability Royal Commission.

Despite these important disability reforms, ableism remains entrenched in existing Australian law, policy and practice frameworks. These frameworks often reference the CRPD and aim to implement human rights obligations to ensure the inclusion of people with disability in all aspects of community life. However, this has not always translated into action to achieve genuine human rights for people with disability. In many cases, it has only resulted in action to enhance existing systems, rather than challenging the ableism at the core of these systems. The reform of existing systems only serves to normalise, legitimise and reinforce the continuation of segregation of people with disability.

Support for segregated systems is too often justified by ableist assertions and cloaked by the language of 'benevolent paternalism', such as being 'in our best interests', for 'our safety and protection', to address 'high support and complex needs', to respond to 'severe and profound impairment', to manage 'challenging behaviours', to prevent 'risk of harm to self and others' and to address the lack of alternative options and resources. Segregated systems are often supported by well-established funding and vested interests in disability, education, mental health, aged care and other service systems, with the purpose, existing financial arrangements and status of these systems privileged over the rights of people with disability.



Ending segregation

The CRPD provides the principles and standards to undertake the social transformation required to end segregation of all people with disability. The CRPD negates ableism by embedding the human rights model of disability. This model affirms that human rights apply to all people with disability on an equal basis with others; it recognises our inherent dignity along with all other human beings; it frames disability as a social construct and impairment as one aspect of human diversity; and it asserts that human rights cannot be limited or taken away because of the existence or degree of impairment. No longer can impairment or diagnosis or disability be used to justify segregation and exclusion from community life or be used to limit human rights protections for people with disability. Importantly, the CRPD reflects international human rights law, which affirms that segregation and segregated facilities are a prima facie form of discrimination.³¹

The CRPD Committee reviewed Australia's progress in implementation of the CRPD in 2013 and in 2019. Following these reviews, the CRPD Committee issued its recommendations, or concluding observations to Australia.³² On both occasions, these recommendations included a focus on ending segregation and segregated facilities, particularly in relation to 'special' education, institutional living arrangements, and segregated employment.³³ The recommendations also called for an end to substitute decision-making arrangements,³⁴ which undermine autonomy, enable forced treatments and medical interventions and facilitate forced placement of people with disability in segregated facilities, such as institutional living arrangements, psychiatric facilities and segregated employment.

The CRPD Committee has elaborated on interpretation and implementation of the CRPD through its general comments, including those relating to autonomy and decision-making,³⁵ equality and non-discrimination,³⁶ inclusive education,³⁷ and living independently in the community.³⁸

Both the CESCR Committee and the Committee on the Rights of the Child (CRC Committee) have made recent recommendations to Australia focused on ensuring the right of people with disability to inclusive education;³⁹ and the CESCR Committee has issued a general comment that reaffirms that segregated employment for people with disability is not in compliance with ICESCR.⁴⁰

It has been twelve years since Australia ratified the CRPD, and despite CRPD Committee and other UN treaty body recommendations and guidance through numerous general comments, Australia continues to conceptualise segregated settings and substitute decision-making arrangements as consistent with the CRPD. It continues to support, maintain and fund substitute decision-making arrangements, and segregated settings and facilities through its law, policy and practice frameworks. Australia is yet to make a serious investment in supported decision-making mechanisms and the absence of these mechanisms continues to enable the segregation of people with disability to continue.

Disability reform processes are not supported by a national disability research agenda based on disability inclusive research principles and underpinned by the CRPD. Such an agenda would deliver a comprehensive evidence base informed by rigorous disability inclusive research and data that incorporates the views of those subjected to segregation and substitute decision-making.

Disability reform processes continue to focus on improvements to existing ableist systems, which prevents implementation of actions to end segregation and achieve the social transformation required by the CRPD. The principles and standards of the CRPD must underpin disability reform processes, rather than disability reform processes continuing to maintain and justify ableist standards and principles.



PRINCIPLES TO END SEGREGATION MUST INCLUDE:

Human rights cannot be limited or denied, and segregation cannot be justified based on the existence or degree of impairment, diagnosis or disability.

Segregation and segregated facilities for people with disability need to be recognised and conceptualised as inherently unequal and discriminatory.

Full and effective participation and inclusion in society for people with disability is dependent on the end of segregation and upholding individual autonomy.

The individual autonomy, will and preferences of people with disability must be respected and upheld by replacing substitute decisionmaking arrangements with fully supported decision-making arrangements.



Actions to end segregation must include:

- 1. In line with the CRPD and the general comments from the CRPD Committee, ensure that the human rights model of disability and the principle and standard of equality and non-discrimination underpin the development, implementation and review of law, policy and practice frameworks, including by providing training and guidance to policy makers and legislators at all levels of government and within all portfolio areas, to law reform bodies, to the Parliamentary Joint Committee on Human Rights and to the National Disability Insurance Agency (NDIA), the NDIS Commission and the Disability Royal Commission.
- 2. In all areas of its work, the Disability Royal Commission must explicitly recognise and conceptualise the segregation of people with disability as discrimination, that segregation is an underpinning enabler of violence, abuse, neglect and exploitation, that segregation constitutes systemic neglect and exploitation; and the Disability Royal Commission must hold governments and other stakeholders to account for supporting, maintaining and funding segregated systems.
- 3. In line with the CRPD and the general comments from the CRPD Committee, and in close consultation and active participation of people with disability through their representative organisations, Australia should review and amend existing law, policy and practice frameworks for potential or actual support and/or funding of the segregation of people with disability or limitations on their autonomy, including mental health laws and systems, guardianship laws and systems, the NDS, the NDIS Act, NDIS policy and practice and NDIS Commission policy and practice.
- 4. In line with the CRPD and other international human rights treaties to which Australia is a party, and in close consultation and active participation of people with disability through their representative organisations, Australia should recognise the legacy of inequality and discrimination, including the segregation of people with disability, by reviewing and taking action to eliminate this segregation, including by developing and implementing:
 - a national, time bound Disability Employment Strategy aimed at the transition of workers with disability from segregated employment to open, inclusive and accessible forms of employment and that ensures equal remuneration for work of equal value; that incorporates recommendations from previous employment inquiries, such as the Willing to Work Inquiry;⁴¹ and that contains targeted gender, age and culturally specific measures to increase workforce participation and address structural barriers.

- a national, time bound Deinstitutionalisation and Disability Housing Strategy aimed at closing institutional living arrangements for people with disability; preventing the building of new institutional living arrangements, including the building of new group homes through NDIS Specialist Disability Accommodation (SDA); repurposing existing group homes into genuine community-based housing options; providing resources to increase the supply and range of accessible social and public housing stock; and amending the National Construction Code to mandate minimum universal accessible housing design standards for all new and extensively modified housing.
- a national, time bound Action Pan for Inclusive Education aimed at establishing a nationally consistent legislative and policy framework that fully complies with the CRPD; that adopts a definition of inclusive education consistent with general comment No.4; that reverses the increasing rate of segregated education; that redirects resources to an inclusive education system; that recognises the denial of reasonable adjustment as unlawful discrimination; that contains measurable actions and accountability mechanisms for transition from segregated education to inclusive education; and that prohibits the use of restrictive practices in schools.
- 5. In line with the recommendations made to Australia since 2013 by the CRPD Committee and the general comment on article 12, Equal recognition before the law,⁴² Australia needs to accept that formal and informal substitute decision-making mechanisms are not compliant with the CRPD and that these mechanisms must be replaced with fully supported decision-making mechanisms. To this end, Australia should withdraw its interpretative declaration⁴³ on article 12 that maintains that the CRPD allows supported or substituted decision-making,⁴⁴ and implement a nationally consistent supported decision-making framework.
- 6. The National Disability Research Partnership (NDRP) must ensure that the development of a national disability research agenda is strongly underpinned by the CRPD, including explicit recognition of segregation as a form of discrimination and substitute decision-making as a denial of individual autonomy; and provide a comprehensive agenda that is not limited to existing service system improvement.



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ENDNOTES

- United Nations (2006), Convention on the Rights of Persons with Disabilities, United Treaty Series (UNTS), vol. 2515, p. 3 (entered into force 3 May 2008).
- Australia has ratified seven of the nine core international human rights treaties: International Covenant on Civil and Political Rights (ICCPR); International Covenant on Economic, Social and Cultural Rights (ICESCR); International Convention on the Elimination of All Forms of Racial Discrimination (ICERD); Convention on the Elimination of All Forms of Discrimination against Women (CEDAW); Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (CAT); Convention on the Rights of the Child (CRC); and Convention on the Rights of Persons with Disabilities (CRPD).
- 3 Department of Social Services, 'A new National Disability Strategy Stage 2 consultations'.
- In 2013, the National Disability Insurance Scheme Act 2013 (Cth) came into effect, along with the National Disability Insurance Agency (NDIA) and the introduction of the Scheme. Information on the NDIS is available at: https://www.ndis.gov.au
- The NDIS Commission commenced operating in NSW and SA from 1 July 2018, in the ACT, NT, WLD, TAS and VIC from 1 July 2019, and it will commence in WA from 1 December 20230. More information on the NDIS Commission is available at: https://www.ndiscommission.gov.au
- After decades of disability advocacy, the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability was established in April 2019. Information on the Disability Royal Commission is available at: https://disability.royalcommission.gov.au
- 7 Universal Declaration of Human Rights, art 2.
- 8 International Convention on the Elimination of All Forms of Racial Discrimination, arts 2 and 3.
- 9 Brown v. Board of Education of Topeka, 347 U.S. 483 (1954).
- 10 Committee on Economic, Social and Cultural Rights, 'General comment No. 5: Persons with disabilities', eleventh session (1994), UN Doc E/1995/22 (9 December 1994) para 15.
- 11 Ibid para 35; Committee on Economic, Social and Cultural Rights, 'General Comment No. 13 The right to education (article 13 of the Covenant)', twenty-first session 1999, UN Doc E/C.12/1999/10 (8 December 1999) para 32.
- 12 International Covenant on Economic, Social and Cultural Rights, art 13(3) and 13(4).
- Rosemary Kayess, 'Drafting Article 24 of the Convention on the Rights of Persons with Disabilities' in Gauthier De Beco, Shivaun Quinlivan and Janet E. Lord (eds), The Right to Inclusive Education Under International Human Rights Law (Cambridge University Press, Cambridge UK 2019), 122-140.
- 14 Olmstead v L.C. 527 U.S. 581 (1999).
- Prof. Gerard Quinn, Prof. Grainne de Búrca, Prof. Lisa Waddington, Prof. Mark Bell, Prof. Anna Lawson, Prof. Michael Stein, Prof. Titti Mattsson and Prof. Luke Clements, op. cit., p. 9.
- 16 Ibid p. 8.
- 17 Committee on the Rights of Persons with Disabilities, 'General comment No. 6 (2018) on equality and non-discrimination', UN Doc: CRPD/C/GC/6 (26 April 2018).
- 18 Ibid paras 30, 57, 58, 64, 67(a), 73(c) and (d).

- 19 Committee on the Rights of Persons with Disabilities, 'General comment No. 4 (2016) on the right to inclusive education', UN Doc CRPD/C/GC/4 (25 November 2016).
- 20 Ibid para 11, provides that "Segregation occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairment, in isolation from students without disabilities".
- 21 Committee on the Rights of Persons with Disabilities, 'General comment No. 5 (2017) on living independently and being included in the community', UN Doc: CRPD/C/GC/5 (27 October 2017).
- Committee on the Rights of Persons with Disabilities, 'General comment No. 6 (2018) on equality and non-discrimination', op. cit., para 29.
- Prof. Gerard Quinn, Prof. Grainne de Búrca, Prof. Lisa Waddington, Prof. Mark Bell, Prof. Anna Lawson, Prof. Michael Stein, Prof. Titti Mattsson and Prof. Luke Clements, op. cit., p. 15.
- See Fiona Kumari Campbell, 'Exploring internalised ableism using critical race theory', Disability and Society, (2008) 23 (2), p. 151; Martha Minow, Making All the Difference: Inclusion, exclusion, and American Law (Cornell University Press, 1990), Chapter 2, pp 70-76.
- Gerard Goggin and Christopher Newell, Disability in Australia Exposing a Social Apartheid (University of New South Wales Press Ltd, 2005).
- See e.g., Community Affairs References Committee, <u>Violence</u>, <u>abuse and neglect against people</u> <u>with disability in institutional and residential settings</u>, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability, November 2015, Commonwealth of Australia.
- 27 Disability Services Act 1986 (Cth).
- For example, in 1979 deinstitutionalisation became Victorian policy, although the closure process has been extremely slow with the last large-scale institution closing in November 2019; the 1983 Inquiry into Health Services for the Psychiatrically III and Developmentally Disabled led to the closure of many large-scale institutions in NSW, although a number are yet to be closed. The shift from large-scale institutional settings in Australia has led to the establishment of small institutional settings, predominately group homes.
- 29 Disability Discrimination Act 1992 (Cth).
- Council of Australian Governments, National Disability Strategy 2010-2020 (Commonwealth of Australia, 2011).
- 31 Prof. Gerard Quinn, Prof. Grainne de Búrca, Prof. Lisa Waddington, Prof. Mark Bell, Prof. Anna Lawson, Prof. Michael Stein, Prof. Titti Mattsson and Prof. Luke Clements, 'Segregation and segregated facilities as a prima facie form of discrimination. The Impermissibility of using the ESIF to invest monies in long term care residential institutions for persons with disabilities' (Legal Memo, 17 March 2018).
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- Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 September 2013), op. cit., paras 41, 42, 45 and 46; Committee on the Rights of Persons with Disabilities, Concluding observations on the combined second and third periodic reports of Australia, op. cit., paras 37, 38, 45, 46, 49, 50.
- Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 September 2013), op. cit., paras 24, 25, 26, 33, 34; Committee on the Rights of Persons with Disabilities, Concluding observations on the combined second and third periodic reports of Australia, op. cit., paras 23, 24.
- Committee on the Rights of Persons with Disabilities, 'General comment No. 1 (2014) Article 12: Equal recognition before the law', UN Doc CRPD/C/GC/1 (19 May 2014).
- Committee on the Rights of Persons with Disabilities, 'General comment No. 6 (2018) on equality and non-discrimination', UN Doc: CRPD/C/GC/6 (26 April 2018).
- Committee on the Rights of Persons with Disabilities, 'General comment No. 4 (2016) on the right to inclusive education', UN Doc CRPD/C/GC/4 (25 November 2016).
- Committee on the Rights. of Persons with Disabilities, 'General comment No. 5 (2017) on living independently and being included in the community', UN Doc: CRPD/C/GC/5 (27 October 2017).
- Committee on Economic, Social and Cultural Rights, 'Concluding observations on the fifth periodic report of Australia', UN Doc E/C.12/AUS/CO/5 (11 July 2017) paras 55 and 56; Committee on the Rights of the Child, 'Concluding observations on the combined fifth and sixth periodic reports of Australia', UN Doc CRC/C/AUS/CO/5-6 (1 November 2019) para 43(c).
- Committee on Economic, Social and Cultural Rights, 'General comment No. 23 (2016) on the right to just and favourable conditions of work (article 7 of the International Covenant on Economic, Social and Cultural Rights)', UN Doc E/C.12/GC/237 (April 2016) para 47(c).
- 41 Australian Human Rights Commission (2016) <u>Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability</u>, AHRC, Sydney.
- 42 Committee on the Rights of Persons with Disabilities, 'General comment No. 1 (2014) Article 12: Equal recognition before the law', UN Doc CRPD/C/GC/1 (19 May 2014).
- An interpretative declaration is a unilateral statement made by a State Party to a Convention to clarify how a specific article or articles is interpreted by that State Party at a given time. Australia made three interpretative declarations at the time it ratified the CRPD in 2008, on article 12 Equal recognition before the law, article 17 Protecting the integrity of the person and article 18 Liberty of movement and nationality.
- The interpretative declaration on article 12 states: "Australia recognises that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards."