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Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Via email: community.affairs.sen@aph.gov.au

Dear Committee Secretary,

The adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

1. Australian Lawyers for Human Rights (ALHR) is pleased to provide this submission to the inquiry on the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.
2. ALHR was established in 1993 and is a national network of over 2600 Australian solicitors, barristers, academics, judicial officers and law students who practise and promote international human rights law in Australia. ALHR has active and engaged National, State and Territory committees and a secretariat at La Trobe University Law School in Melbourne. Through advocacy, media engagement, education, networking, research and training, ALHR promotes, practices and protects universally accepted standards of human rights throughout Australia and overseas.
3. ALHR provides submissions on points (d) and (f) of the Terms of Reference in relation to Australia's compliance with international human rights obligations in accordance with the *Convention on the Rights of Persons with Disabilities (CRPD)* and the *Convention on the Rights of the Child (CRC)*. Australia ratified the CRPD in July 2008 and the Optional Protocol in 2009. The CRPD "elaborates in detail the rights of people with disabilities and sets out a code

of implementation”.¹ Australia ratified the CRC in December 1990 and it applies to all human being under 18 years of age. The rights outlined in the two Conventions should be the central focus of Australian policy and law reform concerning young people with disabilities.

The appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities

4. As a starting point, the CRC requires that:

- a. States Parties respect and ensure the rights of children without discrimination of any kind, irrespective of disability (art 2.1);
- b. The best interests of the child shall be a primary consideration (art 3.1);
- c. States Parties must ensure to the maximum extent possible the survival and development of the child (art 6.2);
- d. States Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development and, in accordance with national conditions and within their means, shall in case of need provide material assistance and support programmes, particularly with regard to housing (art 27.1 and 27.3).

5. However, in 2010, the Young People in Nursing Homes National Alliance reported that there were 6465 young people living in nursing homes in Australia.² Young people in nursing homes often “find themselves without enough support for their physical health needs, resulting in constant health crises and admissions to hospital, not to mention the almost complete absence of connection with their friends, community and family”³. This state of affairs is discriminatory and does not promote the best interests and development of young people.

6. The CRC also requires that children who are capable of forming their own views must have the right to express those views freely in all matters affecting them, and for their views to be given due weight in accordance with their age and maturity (art 12.1). Young people with disabilities who are capable of forming a view on where and how they would like to live must be given the opportunity to express that view and have it taken into account.

7. Article 23 of the CRC relevantly provides:

¹ United Nations Department of Public Information, *The Convention in Brief*, viewed at <<http://www.un.org/disabilities/convention/convention.shtml>>

² Young People in Nursing Homes National Alliance, Statistics, viewed at <<http://www.ypinh.org.au/statistics>>

³ Young People in Nursing Homes National Alliance, FAQs, viewed at <http://www.ypinh.org.au/resources/faqs>

1. States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

2. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

3. Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development

8. In accordance with article 19 of the CRPD young people with serious and/or permanent mental or physical disabilities have the right to live independently and be included in the community, providing:

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- 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 needs.*

9. The placement of young people with serious and/or permanent mental or physical disabilities in the aged care system violates this human right. Young people with disabilities must not be obliged to live in a particular living arrangement (art 19(a)). Instead, access to in-home, residential and other community support services should be made (art 19(b)). It is not an acceptable defence to this human rights violation that resources do not permit alternative housing for young people with disabilities. In most settings, the aged care system fails to offer inclusion in the community by failing to offer age-appropriate community programs which would otherwise be available to the general population (art 19(c)).

10. Further, young people with serious and/or permanent physical, mental or intellectual disabilities have the right to adequate standard of living and social protection which is provided in article 28 of the CRPD:

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.

2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

- a. To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;*
- b. To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;*
- c. To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;*
- d. To ensure access by persons with disabilities to public housing programmes;*
- e. To ensure equal access by persons with disabilities to retirement benefits and programmes.*

11. The aged care system denies young people with disabilities this basic human right by failing to provide an adequate standard of living that offers continuous improvement in living conditions. Alternative accessible housing options must be provided to ensure young people currently or at risk of living in residential care have access to public housing programmes (art 28(2)(d)). Such alternatives have been explored by the Young People Nursing Homes National Alliance, in *Shaping the Future for Today: Transforming housing policy for Australians with Disability* which puts forward a number of policy and design reforms that are aimed at informing thinking around the core issue of “Australians with disability need[ing] to have the same housing choices as other Australians and to have choice about their support and how it is delivered”⁴.

12. ALHR respectfully submits that it is entirely inappropriate for young people with disabilities to be placed in the aged care system and the placement of young people in aged care facilities is a breach of Australia’s international human rights obligations.

⁴ Young People in Nursing Homes National Alliance, *Shaping the Future Today – Transforming housing policy for Australians with Disability*, 2014, page 7.

The options, consequences and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities

13. Young people with serious and/or permanent mental, physical or intellectual disabilities who may have previously been accommodated in the aged-care system may require complex health and disability support services⁵ which need to be properly serviced to enable full participation in the community and access to an adequate standard of living. Accordingly, the de-institutionalisation of these young people demands that the right to habilitation and rehabilitation is recognised. Article 26 of the CRPD provides:

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- a. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;*
- b. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.*

2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.

3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

14. Emphasis on making available multidisciplinary assessment of individual needs and strengths and support (art 26(1)(a)) required for participation and inclusion in the community (art 26(1)(b)) is paramount for young people with serious and/or permanent mental, physical or intellectual disabilities being de-institutionalised. Denying this human right will result in a poor transition into the community and leave the young person open to vulnerabilities and exploitation.

15. The process of de-institutionalisation of young people must be conducted with a human rights framework emphasizing the right to habilitation and rehabilitation (art 26) so that young people with serious and/or permanent mental, physical or intellectual disabilities enjoy recognition and respect of their human rights in the community.

⁵ Young People in Nursing Homes National Alliance, *YPIRAC2: The Next Steps*, February 2011, p. 11.

16. ALHR has grave concerns regarding the adequacy of existing residential care arrangements, especially the use of aged care facilities including nursing homes as places of residence for young people with disabilities. Existing residential care arrangements which are not consistent with the rights of people with disabilities to live independently or access an adequate standard of living are a breach of international human rights obligations and must be rectified immediately.

17. If you would like to discuss any aspect of this submission, please email me

Yours faithfully,

Nathan Kennedy

President

Australian Lawyers for Human Rights