



Catholic Women's League Australia Inc.

National President
Mrs Carolyn Metcalfe
P.O. Box 6072, Lake Munmorah, NSW 2259
0421 838 014
president@cwla.org.au

National Secretary
Mrs Robyn Miller
P.O. Box 2043 Bowral, NSW 2576
0419 977 187
secretary@cwla.org.au

**'Open our ears to hear God's word by entrusting ourselves
fully to Him and to believe in His love'**

Submission from the **Catholic Women's League Australia Inc.**
to the
Senate Standing Committee on Community Affairs
**Inquiry into the Adequacy of Existing Residential Care Arrangements Available
for Younger People with Severe Physical, Mental or Intellectual Disabilities in
Australia**

February 2015

1. Introduction

Catholic Women's League Australia Inc. (CWLA) is the national peak body representing the League's six member organisations located throughout Australia. We are a Non-Government Organisation and have consultative (Roster) status with the Economic and Social Council of the United Nations. We are also a member organisation of the World Union of Catholic Women's Organisations.

One of the CWLA's four principle aims is to influence legislative and administrative bodies at all levels of government in order to preserve the dignity of the human person, with a particular focus on women and children. Further, addressing social justice and ethical questions is one of our primary tasks. Thus, the subject matter of this particular issue is of particular interest to our members, and we are grateful for the opportunity to contribute to this important and timely inquiry.

"I'm sick of watching all the friends I make here die" (quote from a younger person with a disability living in an aged care facility, 2014)

Do not withhold good from those to whom it is due, when it is in your power to do it. Proverbs 3:27



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2. Human Rights Framework

It is evident from an analysis of the international human rights framework that the current situation of accommodating younger persons with physical, mental or intellectual disabilities in aged care facilities is in direct contravention of internationally accepted human rights standards. The principle law on this topic is derived from Article 19(a) of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which states the following:

"...all people with a disability should have the opportunity to choose their residence and where and with whom they live on an equal basis with others, and not be obliged to live in particular living arrangements".

The CPRD was ratified by the Australian Government in July 2008 and is therefore compelled to abide by the articles contained therein.

The rights of younger people forced to rely on aged care is further reinforced by Article 12(1) of the International Covenant on Civil and Political rights (ICCPR), which states the following:

"Everyone lawfully within the territory of a State shall, within that territory, have the right to liberty of movement and freedom to choose his residence."

The ICCPR was ratified by Australia on 13 August 1980.

The situation is thus clear: no person with a disability, whether it be physical, mental or intellectual, should be forced to live in any accommodation which is not of their free choice. The right to choose where to live is fundamental to every human being as is the inherent right of all people with disabilities to be able to move freely. It is submitted that the current situation vis a vis people with disabilities in Australia is that younger people with disabilities in Australia often lack the care and support they require, need and want, to enable them to live in the community and enjoy their lives on an equal footing with other younger people who do not have disabilities. The situation can be elucidated even further via a consideration of the Catholic Social Justice Principles.



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3. Catholic Social Justice Principles

The Catholic religion espouses and embodies specific Social Teachings, which we believe can provide guidance with regards to how younger people with disabilities living in aged care can be supported and assisted to lead independent lives.

The social teaching of human dignity recognises the sacredness of life and the dignity of each individual person as inviolable. Inherent within this principle is the belief that every person, in particular those who are disadvantaged and marginalised, has access to more than just the basic necessities of life. Thus, it is not enough that younger people with disabilities are able to access accommodation, care and food, while living in aged care. The dignity of people living in such circumstances demands a greater recognition of their rights to live as many younger people do, within the community, enjoying their right to choose the direction and path that they want their lives to take.

The principle of common good furthermore demands that we all actively seek conditions that enhance the good of all and contribute to the achievement of a common life, with marginalised people being the focus of particular concern. People who are marginalised and vulnerable need even more support from others, as more often than not they lack a voice to enable them to demand their inherent human rights. Thus, our efforts in ensuring that every person in society is able to enjoy their human rights requires us to concentrate our focus on those who are particularly vulnerable and greatly needing support and assistance. Having a preferential protection for the poor and vulnerable ultimately enhances society via the extension of compassion and care.

An additional important Catholic Social Justice principle is the right to association. Younger people with disabilities in aged care clearly have limited association with the wider community and are unable to participate in society to the fullest extent of their capabilities.

It is submitted that an application of the above social justice teachings would ensure that the current senate inquiry reaches an effective and lasting solution to the concerning issue of younger people with disabilities living in aged care facilities.

4. Statistics in Australia relating to Younger Persons with Disabilities in Aged Care

Younger people with disabilities living in aged care facilities often suffer greatly as a consequence of the situation in which they find themselves. The following statistics paint an alarming situation, calling on a solution to be found to solve this problem:

- More than 7,000 younger people are living in aged care;¹
- A further 700,000 are being cared for at home by family and friends, who often struggle to support them²;

¹ National Disability Agreement 2011 – 2012.

² Australian Institute of Health and Welfare 2011.

³ Australian Institute of Health and Welfare 2011 – 2012.



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- The average age of people living in aged care is 83³;
- The aged life expectancy of people living in aged care is just three years⁴;
- 44% of younger people in aged care will receive a visit from friends less than once a year⁵;
- 34% will never participate in community based activities such as shopping⁶;
- 21% will go outside the home less than once a month⁷;
- 70% of all relationships involving the care of a young person with full-time care needs will end in divorce, indicating that not only the person requiring care is often in crisis but the family that care for them often suffers greatly from both stress and strain⁸;
- 50% of carers are defined as being moderately depressed⁹;
- 40% of carers are found to be severely or extremely depressed¹⁰; and
- Carers have the lowest level of wellbeing of any group in society¹¹

5. Issues Affecting Younger People with Disability in Residential Aged Care

Younger people with a disability are frequently at risk of being forced to live in aged care because there is a paucity of available options for them. Many face this risk because they are being cared for by aged parents who, as they age, find it increasingly difficult to care for their adult children or because their medical needs are so significant that they cannot be supported by community services. It has been noted that "it is widely acknowledged in the disability sector that aged care facilities are inadequately resourced to facilitate the active involvements of younger residents with high clinical needs in everyday activities or support their continued participation in the life of the community. This may be largely attributed to the design purpose being to provide accommodation, personal and nursing care to frail

² Australian Institute of Health and Welfare 2011.

³ Australian Institute of Health and Welfare 2011 – 2012.

⁴ Australian Institute of Health and Welfare 2011 – 2012.

⁵ Di Winkler et al Winkler, D.L., Farnworth, et al. (2006) Australian Health Review.

⁶ Ibid.

⁷ Ibid.

⁸ www.mamamia.com.au/news/caring-about-youngcare/

⁹ Ibid.

¹⁰ Ibid.

¹¹ Dr Robert Cummings The Wellbeing of Australians – Carer Health and Wellbeing 2007.



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older people at the end of their stage of their life"¹² and goes on to report that younger people are admitted to such facilities typically because more appropriate accommodation is unavailable"¹³.

Morkham states that young people in residential aged care are there due to a range of acquired disabilities from catastrophic accidents, or unpredictable health events, or degenerative neurological diseases, such as muscular dystrophy. Further, the advances made in medical technologies and improved health care services allow people to survive injuries, unpredictable health events, as well increase the life span of people with degenerative neurological conditions. Subsequently, the number of people with acquired disabilities in Australia is growing¹⁴

Aged care is an inappropriate accommodation option for younger people with disabilities. The myriad of factors that make them so are detailed below:

- Staff in aged care facilities are trained to care and support older people and not younger people with disabilities. Aged care is known to suffer from low staffing and thus it can be problematic to locate the level of support from staff in aged care that a younger person with a disability may need;
- The food consumed by older people is prepared and is of a nature that is not targeted towards younger people with disabilities. Food is often prepared in such a way to be easily digested by older people and to suit their nutritional needs. A younger person may want to try food of different tastes, textures and cuisines, which is often not an option for residents in nursing homes;
- Social activities are frequently limited or non-existent for younger people. Younger people may want to socialise with people from their own age category, form romantic relationships, or make new friends. Aged care is not able to provide nor facilitate such opportunities;
- Entertainment in aged care facilities focuses on the interests and capabilities of elderly people and not younger people. Many of the activities arranged by activities officers accommodate the experiences and interests of older generations and more often than not fail to address the interests of the younger generation. Examples include playing Bingo games, listening to music from the war period, etcetera;

¹² Winkler, D L Callaway and S Sloan. 2007 *Younger people in residential aged care: Support needs, preferences and future directions*. Melbourne: Summer Foundation Ltd, p100.

¹³ Ibid, 101.

¹⁴ Morkham, B. 2004. 'Moving young people out of nursing homes'. *The Australian Health Consumer*. Number Three 2004 – 2005, p 9.



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- Many younger people living in nursing homes suffer from depression or other mental health issues, which may arise as a consequence of the living circumstances in which they find themselves living. Support services to address these mental health issues are not readily available for the younger person. The focus of support for medical professionals working in aged care facilities is often more on cognitive impairment such as dementia, rather than treating mental health issues commonly faced by younger people;
- The nature of exercise for older people is very different from the kinds of exercise that a younger person with a disability may be able to or may want to engage in. The ability to participate in sports activities is rarely available for them;
- Medical support in nursing homes is targeted towards older people and not younger people. Essential services that a younger person may need, such as physiotherapy, is frequently unavailable for the younger person within the aged care context.

6. Recommendations

Taking into consideration the present situation for younger people with disabilities living in aged care facilities in Australia, it is evident that urgent action needs to be taken in order to properly address this situation. The following are some recommendations that could be implemented with a view to finding a solution to this injustice:

- A current, comprehensive study should be conducted identifying all the younger people with disabilities living in residential aged care facilities throughout Australia. Research to date has tended to be state focused and not nation-wide;
- Comprehensive research should be instigated to understand the depth of the problem and to elicit the needs and wants of the target group;
- A targeted strategy should be developed and implemented with a view to ensuring that younger people with disabilities are able to develop a long-term strategy so that they are able to eventually leave aged care and live in the community;
- More housing stock should be made available with public housing to ensure that younger people with disabilities are able to access such accommodation and live in the community;
- Funding should be available to community organisations to ensure that the required carers are available so that younger people with disabilities are able to live independently;
- Funds should be allocated to ensure that additional supported accommodation options are made available to people attempting to exit aged care;



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- The National Disability Insurance Scheme (NDIS) should be developed so as support plans created by people with disabilities to develop exit programmes so that they can leave aged care and live in the community;
- Officers working within the National Disability Insurance Scheme should be provided with information, training and education so that they are made aware of the challenges presented by people facing such challenges and are equipped with the ability to help people with disabilities to formulate plans that enable them to leave aged care;
- The Community Volunteer Scheme, which provides volunteer visitors to visit residents in residential aged care should be expanded to include targeted visits to younger people living in aged care, to ensure that the social contact they have with people living outside the residential aged care facilities is expanded and that they are not left isolated while they are living in aged care. This approach should only be implemented as a short term solution, while a longer term solution of integrating younger people within the wider community is sought and implemented;
- Understanding that it will take time before younger people can exit aged care volunteers working for the Community Volunteer Scheme assisting younger people in aged care should be provided with information and training with a view to raising awareness of the younger people and how they can be best assisted with social interactions and support;
- While a longer term solution is sought staff in aged care facilities accommodating younger persons with disabilities should be provided with training and information so that they are better able to meet their wants and needs;
- Efforts should be concentrated on diverting entry for younger people who are at risk of having to enter aged care through lack of options;
- For younger people living in aged care who are awaiting a pathway to living in the community there should be a focus on enhancing the delivery of disability services to ensure that they receive the care they need;
- Younger people with disability should be provided with greater choice and control over the services provided, which should include the types of services they receive, the timing, location and staffing;
- Younger people with disability should be provided with access to a diverse mix of services that are flexible and are able to meet their changing needs. In formulating a way forward it is imperative that a "one solution fits all" approach should be avoided, recognising that each person is different and has different wants and needs;
- Voluntary participation and the ability to decide the path they take should be inherent in all support provided to younger people with disability; and



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- Liaison with the Home and Community Care services provided by councils and shires should be developed so that young people can be taken outside the aged care context for an hour or two so that they might be able to engage in social activities, such as visiting the shops, going to the movies etcetera.

It is possible for the current situation to be changed but it is evident that real and lasting change can only take place with a collaborative will to ensure that better options are provided for younger people with disabilities in aged care than is currently the case.

Thank you once again for the opportunity to contribute to this inquiry. We wish the Committee well in its deliberations.

Prepared by: Sonia Di Mezza
Research Officer

Authorised by: Carolyn Metcalfe
National President,
Catholic Women's League Australia Inc.