

Chapter 1

Introduction

1.1 This inquiry is concerned with young people with severe disability aged 65 years or under who currently live in or are at risk of entering a residential care facility. This includes those who live in some form of congregate or institutional care. The inquiry has provided an opportunity for young people, their families, carers, service providers, and state and federal government agencies to reflect on the policies and systems that have led to young people being placed in this situation. The committee wishes to highlight the fact that nearly 90 per cent of young people living in aged care are aged 50–64 years. It is the needs of this group that have not been adequately addressed in previous programs such as the Younger People with Disability in Residential Aged Care initiative (YPIRAC) and it is imperative that the needs of this group are front and centre of any response.

1.2 The committee notes that this inquiry is conducted at a time of transition as the National Disability Insurance Scheme (NDIS) is being phased in. The Commonwealth Government has assured the committee that the needs of this cohort will be met once the NDIS is fully rolled out across the country. The committee has a number of concerns with this approach. First, the full rollout of the NDIS is not scheduled to be completed until at least 2018. Second and most importantly, this is a discrete group of people with complex needs. The NDIS has not demonstrated that it has a methodology to provide support services and accommodation that meet the needs of these people. It is the committee's view that too much time has already been lost and that young people in residential care require a solution now to improve their lives in the interim period between the NDIS trials and full roll-out of the NDIS. This report offers a range of practical recommendations that can be utilised during this interim period to provide a dignified and just pathway forward through appropriately supporting the accommodation and other needs of these young people.

Terms of Reference

1.3 On 3 December 2014, the Senate referred the following matters to the Senate Community Affairs References Committee for inquiry and report by 30 June 2015:

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

- (a) the estimated number and distribution of young people in care in the aged care system in Australia, and the number of young people who require care but are not currently receiving care;
- (b) short- and long-term trends in relation to the number of young people being cared for within the aged care system;
- (c) the health and support pathways available to young people with complex needs;

- (d) the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities;
- (e) alternative systems of care available in federal, state and territory jurisdictions for young people with serious and/or permanent mental, physical or intellectual disabilities;
- (f) the options, consequences and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities;
- (g) what Australian jurisdictions are currently doing for young people with serious and/or permanent mental, physical or intellectual disabilities, and what they intend to do differently in the future;
- (h) the impact of the introduction of the National Disability Insurance Scheme on the ability of young people in aged care facilities to find more appropriate accommodation;
- (i) state and territory activity in regard to the effectiveness of the Council of Australian Governments' Younger People in Residential Aged Care initiatives in improving outcomes for young people with serious and/or permanent mental, physical or intellectual disabilities, since the Commonwealth's contribution to this program has been rolled into the National Disability Agreement and subsequent developments in each jurisdiction; and
- (j) any related matters.¹

Conduct of the inquiry

1.4 Details of the inquiry were placed on the committee's website and the committee wrote to over 80 organisations, inviting submissions by 6 February 2015. Submissions continued to be submitted after that date.

1.5 The committee received 167 submissions from a diverse range of individuals and organisations including young people and their families, community service providers, aged care providers, advocacy groups, and Commonwealth, State and Territory agencies and departments. A list of the individuals and organisations who made submissions is provided at Appendix 1.

1.6 Public hearings were held throughout Australia: Perth on 17 February 2015; Sydney on 19 February 2015; Melbourne on 11 March 2015; Hobart on 12 March 2015; Darwin on 1 April 2015; and Canberra on 15 May 2015. Transcripts of the hearings are available on the committee's website, and a list of the witnesses who gave public evidence at the hearings is provided at Appendix 2.²

1 *Journals of the Senate*, No. 73—3 December 2014, pp 1965–1966.

2 See: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Young_people_in_aged_care

1.7 The committee also conducted a site visit to the Uniting Church's Rowallan Park Intentional Community south of Hobart on 12 March 2015. This visit is discussed further in Chapter 4. The committee extends its sincere thanks to the residents of the Intentional Community for inviting the Committee and Secretariat into their homes. The committee would also like to thank Reverend Colin Gurteen, Mr Richard Romaszko, Mrs Janine Romaszko, Ms Lucia Fitzgerald and members of the Kingston Congregation.

Acknowledgements

1.8 The committee acknowledges those that contributed to the inquiry through submissions or as witnesses. The committee thanks young people and their families who have shared their personal accounts as part of this inquiry.

Structure of the report

1.9 The committee's report is structured in the following way:

- Chapter 2 provides the statistics and trends for young people living in residential care;
- Chapter 3 discusses the appropriateness of the residential care system for young people and issues around deinstitutionalisation;
- Chapter 4 examines current health and support pathways available to young people with complex needs, and alternative systems of care available;
- Chapter 5 discusses the National Disability Agreement, the Younger People with Disability in Residential Aged Care Initiative (YPIRAC), and the National Disability Insurance Scheme. It also considers actions taken by state governments since the conclusion of the YPIRAC program; and
- Chapter 6 presents the committee's conclusions and recommendations.

