

“Time’s Up”: The Experience of Entering Residential Aged Care for Young People with Acquired Neurological Disorders and Their Families

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Background and aims: Previous research has highlighted that living in residential aged care (RAC) is associated with a range of negative outcomes for adults with acquired neurological disorders. This study sought to understand the lived experience of entering RAC for young people and their family members and characterise their needs during this process.

Method: Data included 64 written and verbal submissions to the 2015 Senate Inquiry into the *Adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia*. In line with hermeneutic tradition, text was analysed using thematic analysis.

Results: Entry to RAC was experienced as a complex process that coalesced around three key events: an unexpected *health crisis*, a directive that *time’s up* and the individual is required to leave the healthcare setting, with a subsequent *decision* to move into RAC. This decision was made in the absence of time, knowledge of options or adequate support.

Conclusions: Findings suggest that there are both immediate practice changes and longer term policy responses that can support the health and disability systems to uphold the rights of people with acquired disability to choose where and how they will live their lives.

Keywords: qualitative, brain injuries, nursing home, residential aged care, accommodation

Introduction

The purpose of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is to ‘promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity’ (United Nations General Assembly, 2007). Article 19 of the Convention outlines the right of people with disability to choose where they live and have access

to support to enable them to live in the community. As one of the original member states to sign and ratify the UNCRPD, Australia has accepted an obligation to recognise the choice and preferences of persons with disabilities in relation to their living situations and to provide appropriate support to enact those choices.

Despite these international obligations, many young people with high and complex support needs continue to have little choice about where they live.

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