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The Secretary
Senate Community Affairs References Committee
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CANBERRA ACT 2600

SUBMISSION TO THE INQUIRY INTO AGED CARE
Younger People with a Physical Disability
Living in a Residential Aged Care Facility

Why younger people should not live in nursing homes

There is tacit acceptance of nursing homes as places where old people go to die. During 2002-2003, 39,674 people died in nursing homes, 27% of all people living in nursing homes. Of those that die in a nursing home, 54% die within one year of admission.

It is common ground among all government and non-government agencies and other stakeholders that, for younger people (i.e. people under 65), living in a residential aged care facility is not *a* last resort but *the* last resort. They do not belong there. Younger people admitted to a residential aged care facility are people with a disability who have been admitted because of their disability, not because they are nearing the end of their lives or are ill.

Aged care focuses on the slowing of further deterioration. Disability services focus on developing people's ability and potential.

Anecdotal evidence suggests that the main reason younger people with a disability end up in residential aged care is a break-down in the triangle of care consisting of accessible accommodation, equipment and personal care. In many cases, it seems appropriate accommodation is available, but for the person to move in an expensive piece of equipment is needed and no funding is available. Or accommodation and equipment are available, but personal care services are not, or not in a sufficient measure. It would seem to be rare that all sides of the triangle are missing. It seems it is usually lack of funding for equipment and personal care at state level that forces younger people into residential aged care.

In residential aged care facilities the triangle of care is always intact. This is what residential aged care facilities are about. They offer a package of accommodation, equipment and personal care that is appropriate for our ageing population.

However, for younger people with physical disabilities accommodation, equipment and personal care provided in residential aged care facilities is not appropriate.

The standard of accommodation provided in residential aged care facilities means that younger people live in an environment where death is a common occurrence. Younger people may share their room, successively, with four or five other residents in a single year. Younger people's friends will cease to visit them because of the accommodation they are in. It makes for an environment where younger people become increasingly isolated and this often leads to clinical depression.

Equipment provided in residential aged care facilities is, in many cases, not appropriate. There have been cases where people with quadriplegia have not been provided with an electric wheelchair, because staff can move them around in a manual wheelchair. This compromises a younger person's ability to participate in life - to seek professional qualifications, to go to work and to go out and have fun - and makes for further isolation.

The standard of personal care provided in residential aged care facilities is appropriate for aged care, but not for younger people. For example, there are cases where younger people have been discouraged from holding down employment, because this complicates personal care arrangements in the residential aged care facility.

The availability of twenty-four hour personal care is not consistent with the aim of disability services to develop people's ability and potential. Living independently, a person with a physical disability would typically receive personal care in the morning and at night.

There are other issues that nursing staff in residential aged care facilities are ill-equipped to deal with, such as autonomic dysreflexia in people with quadriplegia.

The beginning of a solution: information

Admissions of people under 65 to residential aged care facilities have numbered approximately 2,000 annually for many years and the total number of residents under 65 is stable at around 6,000, or about 4% of the total population of residential aged care facilities.

Accommodation for people with a disability is a state and territory government responsibility and is funded under the Commonwealth and State Disability Agreement. Aged Care is a Commonwealth responsibility and falls outside the Commonwealth and State Disability Agreement. The Commonwealth allows younger people with a disability to be admitted to residential aged care where no alternative exists. In those cases, the Commonwealth, in whole or in part, funds the accommodation, equipment and personal care services required.

There is therefore no incentive for the states and territories to ensure all people with a disability are able to live in appropriate accommodation, have the equipment they need and receive the personal care they need.

The Commonwealth, having provided this accommodation option of last resort, cannot withdraw it or impose a moratorium on further admissions without causing acute hardship.

Neither is the Commonwealth in a position to cause the states and territories to ensure appropriate accommodation, equipment and personal care are available to all people with a disability. Aged care, and as a consequence care for younger people with a disability who are in residential aged care, falls outside the purview of the Commonwealth and State Disability Agreement, under which funding for disability services provided by the states and territories are negotiated.

The first step towards a solution of the problem of younger people in residential aged care is the creation of a mechanism that ensures all younger people with a disability, without exception and including those already admitted to a residential aged care facility, will receive care under the Commonwealth and State Disability Agreement. This will enable access to state equipment and personal care programs and provide a potential route to appropriate accommodation.

Meanwhile, Aged Care Assessment Teams need to be educated in the needs of the younger people with a disability to ensure that they resist admission of younger people to residential aged care as much as possible.

At the same time, the lack of authoritative data on younger people in residential aged care facilities should be addressed to inform a strategy and implementation plan to move younger people out residential aged care into appropriate accommodation. Information required includes information on the reason for admission, location, age, diagnosis of disability and level of care provided.

It should be noted that the current lack of published information is unnecessary, because the information is collected as part of assessments by Aged Care Assessment Teams. It is just not collated and published. For example, to solve the problem of younger people in residential aged care it is crucial to know the precise reason why each younger person in residential aged care was admitted. The Aged Care and Assessment and Approval Guidelines developed for use by the Aged Care Assessment Teams specifically state that admittance should only be approved if no other options are available. The Aged Care Assessment Teams therefore must investigate what options are available. This investigation identifies the reason why a younger person is admitted.

The annual statistical reports on residential aged care facilities by the Australian Institute of Health and Welfare (AIHW) should include statistical information about residents under 65 to identify the location, type and quantity of accommodation needed and the associated equipment and personal care requirements.

The annual AIHW report should also include information on younger people leaving residential aged care. With 2,000 admissions annually and a total number of younger residents of around 6,000, where do the 2,000 younger people go when they leave residential aged care? This might provide useful pointers for an overall solution.

Information will allow the states and territories to integrate the requirements identified in this way into their respective disability accommodation, equipment and personal care programs funded under the Commonwealth and States Disability Agreement.

Recommendations

Spinal Cord Injuries Australia recommends:

1. that residential aged care for younger people should be brought under the Commonwealth and State Disability Agreement at the next iteration of the Agreement with adequate funding to prevent further admissions of younger people to residential aged care and to relocate younger people currently in nursing homes;
2. that the AIHW should include information in its annual statistical overview of residential aged care in Australia on the reason for admission of younger people into residential aged care, their location, their age, the diagnosis of their disability and the level of care provided to them; the overview should also include information on where younger people who leave residential aged care go;
3. that, on the basis of information gathered, an independent body should develop and oversee the implementation of an adequately funded (see recommendation 1) plan to relocate all younger people in residential aged care to appropriate accommodation.
4. that, in the interim, Aged Care Assessment Teams should resist admission of younger people to residential aged care as much as possible;

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