

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE INQUIRY INTO AGED CARE

YPACA (Younger People in Aged Care Alliance) Submission

Introduction

The Young People in Aged Care Alliance (YPACA) consists of a diverse number of individuals and groups in Queensland who, since 2001, have taken collective action around the growing numbers of younger people with disabilities (under 65) who are:

- inappropriately placed in or likely to be placed in residential aged care facilities; or
- using aged care services that are inappropriate for younger people.

While each person or group may have varying perspectives we have reached common agreement that: **In principle, aged care facilities and services are inappropriate for younger people with disabilities.**

Our submission will focus solely on the issues associated with the institutionalisation of people with disabilities in aged care facilities and therefore we will refer only to point (c) from the terms of reference.

(c) the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements;

YPACA considers the broad term “aged care facilities” to including respite care, hostels and nursing homes.

Key Messages

- The number of younger people placed in aged care facilities is **increasing**. (see Table 1 – Qld Residential Aged Care Population under 65 years)
- The aged care culture is one that is vastly different, antagonistic towards, and inappropriate for young people with disabilities. It cannot provide younger people with support to develop, build relationships and participate in life.
- The impact of institutionalisation on younger people who live in aged care facilities is devastating.
- The Commonwealth Government needs to take a leadership role by linking outcomes (ie no of people no longer in aged care facilities who are leading quality lives in accommodation of their choice) to State Funding levels, which ensure that funds are quarantined for this purpose.
- Special purpose nursing homes, cluster housing and other forms of enforced congregation and segregation are contrary to the Disability Services Act (1986) and are not acceptable as alternatives. Don't de-institutionalise people only to re-institutionalise them in another setting.

Snapshot of the issue in Queensland

The intent of Commonwealth policy on young people in aged care is that younger people should only enter an aged care facility as a last resort. Increasingly in Queensland, the last resort is becoming the ONLY resort. See the figures in Table 1 below. Our concern is that in the absence of appropriate supports and funding, aged care facilities are growing as a common option for younger people with disabilities.

Table 1 – Qld Residential Aged Care Population under 65 years¹

Year	No of people under 65 in Qld living in residential aged care
2004	1298
2002	1293
2000	1232
1999	1202
1998	1162
1997	643
1996	602

In fact, nursing homes are perceived as “dumping grounds” for people that the system has given up on and, while these options remain all people with existing disabilities or to be newly acquired disabilities are potentially at risk. The Alliance has been told that some Disability Services Queensland (DSQ) staff have inappropriately recommended nursing home placements to individuals and families. Some children with disabilities under care orders have also been placed in nursing homes with the absence of suitable family based options. Considering DSQ is the lead government agency and largest provider of disability supports in Queensland, this direction is very disturbing. It is also inconsistent with the Principles and Objectives of both Commonwealth and State Disability Services Acts and CSTDA.

Once a person has entered an aged care facility it becomes almost impossible to get out. Many people are unaware that there may be other options. The loss of relationships for people who enter aged care facilities also impacts on their ability to leave, as there can be no one to assist with what becomes a real struggle and fight. The limited coverage of individual advocacy in Queensland means that people and families have few allies in their search for a decent life.

People are often forced to make difficult decisions, including where they should live, at times of crisis in their lives. Parents have spoken to YPACA of having to make life long decisions while their son or daughter remains in a hospital environment hovering between life and death.

Originally we accepted that a short-term placement in an aged care facility was necessary. Unfortunately this turned into a period of two and a half years. It took two and a half years of fighting for what was right for our family member. We had no idea of the hurdles we would need to jump to be able to get her out.

- YPACA member

¹ Statistics from Australian Institute of Health and Welfare – www.aihw.gov.au

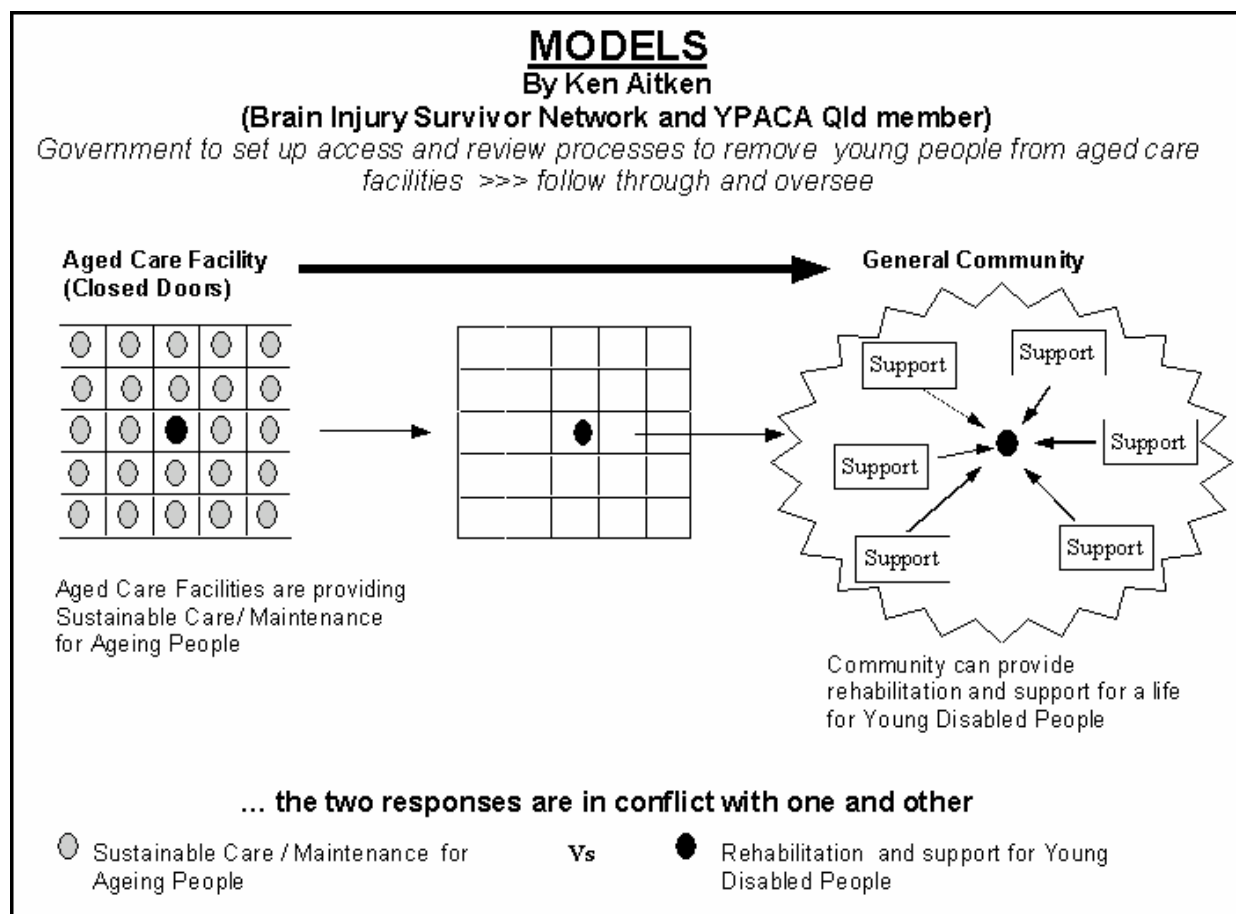
Inappropriateness of young people with disabilities being accommodated in residential aged care facilities

Throughout Australia the disability support system has adopted a **developmental and life-enhancing** approach to supporting people. This philosophy is most notably articulated in the Principles and Objectives of the Commonwealth Disability Services Act (1986). Best practice in providing supports to people with disabilities includes focusing on the person and finding individual ways to support them to increase their inclusion in the community and life in general.

Conversely, the aged care sector has a legitimate and necessary role to provide high levels of care for elderly people to **live in the latter stages of their lives**. The support system is rightly aimed towards caring for and assisting people to maintain their skills rather than to gain new skills. Most elderly people do not leave nursing homes voluntarily, with many facilities requiring residents to have funeral arrangements in place prior to their admittance.

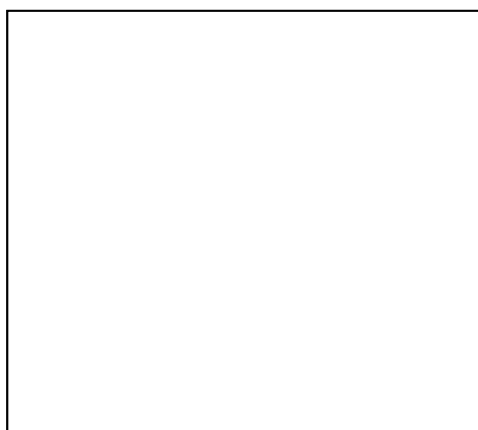
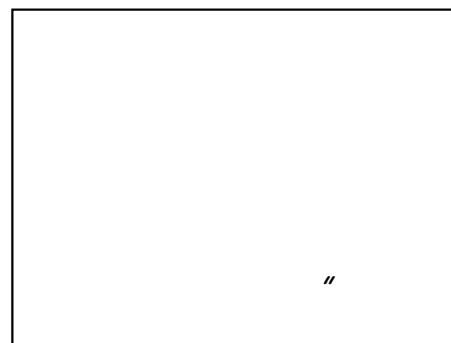
Therefore, the aged care culture is one that is vastly different, antagonistic towards and inappropriate for young people with disabilities. It is not in a position to provide younger people with support to develop, build relationships and participate in life.

Below is a diagram developed by a YPACA member which shows the conflict between the aged care model and the disability support model.



The impact of institutionalisation on young people who live in aged care facilities is devastating. Younger people involved with YPACA describe their experiences as including:

- Facing verbal, emotional and sexual abuse
- Being taken advantage of
- Feeling older – being seen as old before your time
- Losing valued roles
- Being seen as a source of income
- Losing abilities
- Not developing or growing
- No opportunities to have a real life – wife/husband, job
- Increase in stress and related health problems
- Being forgotten
- Financial exploitation



- Being over medicated
- Losing relationships
- Losing citizenship
- Losing of identity, individuality, “innocence”
- Becoming institutionalised
- Not having fundamental health and nutrition needs met
- Being restrained
- Being hurt repeatedly
- Being seen as a behavioural challenge

Extent to which residents special needs are (not) met under funding arrangements

Most of the people YPACA has met or been informed about in Queensland need personal care NOT nursing care. The medical model makes certain assumptions about people, which in the past has denied their citizenship and participation in community life. For example: last century thousands of people with disabilities defined as being “incurable” were placed in institutions staffed by nurses. The disability movement rejected this framework decades ago and has been working hard to rid its invasive influence on our human service system. YPACA see grave dangers in promoting a medical model that assumes that all people living in nursing homes need specialist-nursing care and assuming it can best be provided in a specialist nursing facility.

The cost of aged care placement can be highly expensive in both human and economic terms. For example, it is common that people are considered for nursing home placement when they can no longer “transfer” by themselves. What people in these situations need is some assistance at certain times of the day, yet what they get and, what funding is spent on, is 24-hour supervision. The gap between what is available through Home and Community Care resources and aged care placement is too wide. Extended Aged Care Packages have only been recently introduced in Queensland and very few people have been able to access this resource.

Ironically, a younger person living in an aged care facility is not considered to be a priority for funding through DSQ as the individual is seen to be receiving “care” and “a roof over their head”. This means they can potentially remain in the aged care system for decades. Many people are unaware they are even entitled to apply for Adult Lifestyle Support Funding or that there is a State government department dedicated to people with disabilities.

YPACA has consistently called for the State and Commonwealth Governments to resolve their claims over who is responsible. The number of younger people living in aged care facilities is increasing and action needs to be taken now. YPACA has come to the conclusion that the Commonwealth Government needs to take a leadership role by linking outcomes (ie no of people no longer in aged care facilities who are leading quality lives in accommodation of their choice) to State Funding levels, which ensure that funds are quarantined for this purpose.

What are better options?

YPACA believes there are many alternatives to aged care facilities, however, in accordance with the Disability Services Act (1986), they need to be:

- As close as possible to what all people have (ie ordinary, least restrictive)
- Created around the person
- With the person's informed choice
- Developmental and capacity building

It is very tempting for Governments and Services when discussing the life situations of people with disabilities to look at models of service delivery and try to fit people into those models rather than starting with the person and crafting a life around their needs. YPACA challenges the community held assumption that all people with disabilities have the same needs and that those needs can be met through the creation of group homes. Special purpose nursing homes, cluster housing and other forms of enforced group housing are contrary to the Disability Services Acts and not acceptable as alternatives.

YPACA believes that a **person centred response** provides an opportunity to focus on the individuals concerned and to work upwards to an answer rather than impose a model from the top which may not be suitable in meeting the person's needs. A person centred response would start with:

- Who is the person?
- What has been their life experiences?
- What haven't they experienced?
- Who are the people in their life?
- Who are not in their life?
- Where do they feel most comfortable/uncomfortable etc?

From these questions, which would be explored over a period of time not just one meeting, it may become clear that the person feels more comfortable living with other people. A response to the person's need to live with others does not assume that group housing is the only way to do this. A person centred response would look at all the ways people live together and from there work out the possibilities. For example: it could be decided that the person could live with their closest friend in a block of units (lots of other people) in West End of inner Brisbane, which has lots of community centres and places to visit or it may be that a granny flat attached to a family home where the person can interact as needed is a possibility.

Do no harm

De-institutionalisation has been carried out across Australia many times in the last two decades. While most people have benefited greatly, YPACA has witnessed that in many such reforms some people are made more vulnerable either by:

- Being re-institutionalised in another setting (eg. aged care facility)
- Being abandoned with little or no support

YPACA has also observed that initially some people are resistant to change however, as they grow more confident or gain new information, change their minds. Some of these people remain trapped in old institutions because they were too late in making their decisions.

Therefore all approaches to rectifying the “inappropriateness” of placing people in aged care facilities through facilitating their return to the community needs to:

- Draw upon past experiences
- Be responded to person by person
- Allow for flexibility
- Be properly resourced

Contacting the Alliance

YPACA welcomes this Senate Inquiry into Aged Care. To discuss any part of this submission further contact:

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