SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE

ADEQUACY OF EXISTING RESIDENTIAL CARE ARRANGEMENTS AVAILABLE FOR YOUNG PEOPLE WITH SEVERE PHYSICAL, MENTAL OR INTELLECTUAL DISABILITIES IN AUSTRALIA.

OCCUPATIONAL THERAPY AUSTRALIA (OTA) SUBMISSION

FEBRUARY 2015
1. INTRODUCTION

Occupational Therapy Australia welcomes the opportunity to make a submission to the Senate Community Affairs References Committee inquiry into the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.

Occupational Therapy Australia (OTA) is the professional association and peak representative body for occupational therapists in Australia. As of September 2014 there were over 16,300 registered Occupational Therapists working in Australia.

Occupational Therapists are health professionals whose role is to enable their clients to participate in meaningful and productive occupations. Occupational therapists are experts in assessing the fit between person, occupation and environment. Occupational Therapists deliver a range of healthcare, environmental and psychosocial interventions. Occupational therapists work across a range of sectors including health, vocational rehabilitation and the disability sector: at all times seeking to enhance the inclusion and participation of Australians in all aspects of our community.

OTA believes that a coordinated policy approach involving workforce development, funding arrangements, health policy and assistive technology provision is the best way to address the inadequacies in the current residential care arrangements available for young people with severe physical, mental or intellectual disabilities.

2. SUMMARY RECOMMENDATIONS

OTA believes there are a number of practical, cost effective and timely actions that can be put in place to improve the quality of residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia. These are explored in our submission. They include:

- Investing in upskilling and developing the professional carer workforce so that Residential Care Facility (RCF) staff are able to provide the care and support young people in RCF’s really need. The short term costs of this investment would be met by an increase in productivity and professional carer workforce outputs. Similar workforce development projects are currently underway in preparation for the rollout of the NDIS, and savings could be made in partnering in these upskilling programs.

- Preventing mental illness development and also preventing future increased expenditure in mental illness by addressing mental health now and giving young people in RCF more control of their environment, allowing them to engage and minimising isolation,

- Preventing ongoing issues of young people suffering occupational deprivation by developing and implementing person centred care plans

- Ensuring facilities are accessible for young people with disabilities and that they have access to the assistive technology they need to ensure their independence and mobility.
3. CONTEXT – OCCUPATIONAL THERAPY EXPERIENCE AND EXPERTISE

This inquiry covers many core areas of practice for occupational therapists who specialise in a person centred approach to assessing and delivering services in getting clients engaging in meaningful activity, providing access to assistive technology, and delivering community engagement and mental health.

Occupational Therapists regularly work with young people in Residential Aged Care Facilities (RACF) and conduct comprehensive assessments of their overall functional capacity to determine their need for supports.

In particular, Occupational Therapists are engaged in high level policy design and also directly in service provision with young people in RACF in the following ways:

- in developing Assisted Daily Living (ADL) plans for clients to maximize participation in tasks and activities of meaning, within residences and within the community
- in case management and developing interdisciplinary care plans,
- in the prescription and customization of assistive technology, and addressing access and design issues in buildings and housing,
- in the development of standards for residential care in areas of health management, personal satisfaction and participation in goals and activities of client choice.
- in the assessment and planning of future residential care facilities around principles of universal inclusive design,
- in review panels of bodies who accredit residential care facilities, and,
- as key service providers in National Disability Insurance Scheme

4. SUBMISSION FOCUS AREAS

The Senate Community Affairs References Committee has established an ambitious agenda for this inquiry. Occupational Therapy has chosen to focus on some specific priority areas where there can be practical immediate change:

- the health and support pathways available to young people with complex needs;
- the appropriateness of the aged care system for care of young people with serious and/or permanent psychosocial or physical disabilities;
- 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;

We believe the roll out of the National Disability Insurance Scheme will significantly impact the development and implementation of policy around young people in RACF however we have not addressed these issues in this submission.

OTA has a significant policy concerns in this space and will continue to bring them to the NDIA, the NDIS Joint Parliamentary Committee as well as relevant state bodies.

5. CONTEXT – RIGHTS AND INCLUSION – SOCIAL INCLUSION

An important preamble for any discussion around the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in
Australia is a discussion around broader social inclusion policy and the importance of current international and domestic frameworks that underpin the current understandings of social inclusion.

**International Disability Law**

There are a number of pieces of legislation in Australia, both at a Commonwealth and state level, that sit beneath the international benchmark offered by the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

On 17 July 2008, Australia became the thirtieth country to ratify the CRPD, which created an obligation on the part of the Australian government to deliver on its intent.

The Commonwealth Government explicitly states that the key aims of its National Disability Strategy (NDS) will be aligned with the principles of the CRPD, envisioning that people with disability and their carers will have an “enhanced quality of life and participate as valued members of society”.

Other Australian legislation dealing with the rights of people living with impairment includes the Disability Discrimination Act (1992) and the Age Discrimination Act (2004). These pieces of legislation are enacted through a variety of means.

**Importance of Social inclusion:**

OTA’s view on social inclusion is highly congruent with The World Health Organisation (WHO) International Classification of Functioning, Disability and Health. The ICF outlines full inclusion for all humans as engaging in activity & participation across the following areas:

- Major life areas (includes educational and work-related life);
- Community, social and civic life. (includes recreational, political and spiritual life);
- Learning and Applying Knowledge;
- General tasks and demands;
- Communication;
- Mobility;
- Self-care;
- Domestic life; and
- Interpersonal interactions & relationships;

**Applying this to social inclusion policy**

OTA believes a multi-dimensional focus is important when approaching social inclusion policy for people with disability. Dimensions are interdependent with the individual at the centre remaining reliant on support from concentric dimensions to experience social inclusion.

They include:

- Carers and direct family support
- Environment: Community, social
  - engagement, economic inclusion and
    - service providers,
- Environment: The wider political
  - and economic
  - environment – its policies and
The housing options available to a young person with a disability and their family may be impacted by a number of critical factors, including:

- Funding available to the person (access to insurance)
- The family’s social support network
- Capacity of the family to look after the person in the family home
- Services available in the area
- Level of support (full time or occasional) a person requires and service providers (community, government, commercial, not for profit) who can provide in home support
- Availability and proximity of accommodation services to the person.

Unfortunately many of the RCF’s do not adequately provide the appropriate level of care and support for young residents with intellectual and physical disabilities.

Often the focus of residential care facilities is almost exclusively aimed at an aged care demographic, which leads to many problems for young people.

Below is a brief introduction to some of these current problems:
6. PROBLEM: OCCUPATIONAL DEPRIVATION

Young people moved into residential care environments experience significant occupational deprivation issues following the admission.

Occupational deprivation describes a state in which people are precluded from opportunities to engage in occupations of meaning due to factors outside their control. Moving to RCF profoundly alters the nature of daily life in terms of temporal factors (such as the timing of the daily schedule, for example when to get up, when to eat dinner), and in terms of choice and control (for example what to do during the day, what to eat).

Additionally, as most younger people in RCF are working and parenting age, the loss of valued work and parenting roles are a particular area of occupational deprivation.

Occupational deprivation in RCF occurs in many ways:

Social isolation

Recent studies by Monash University’s Dr Rachael McDonald have looked at the impact supported accommodation has on client’s social exclusion.

“76% of our sample of people living in supported accommodation had occasional, or no known contact with friends and outsiders” Dr Rachael McDonald.

Example: My client slept in his wheelchair each night as the staff at the aged care facility wanted to place him in bed at 5pm each night and not transfer him out until nearly 10am each morning. This was not acceptable for a man in his 40s.

Lack of involvement in basic tasks

Often in RCF the potential for work-related activities in a young person’s life – limited they may be, are often overlooked. Things like ringing the bell for dinner, folding the washing, using a microwave oven to make the hot drinks, watering pot plants – all basic but key occupational tasks offering elements of autonomy and symbolic work-related roles that could involve clients, however in many RCF such duties are the sole responsibility of nurse or care staff.

Inappropriate activities and community engagement

Often activities are organized by RCF staff that are not age appropriate for younger residents.

For example, community outings focus on “care and comfort” rather than exploring opportunities for occupational engagement across self-care, productivity and leisure domains.

Example: The care facility I was working at booked a day at a rotary club where the residents on the trip made cup-cakes, tea and learnt knitting. This was boring and not at all engaging for the two 21 year old men with acquired brain injuries.

Example: I often find one of my clients sitting in his bedroom, alone in the dark. Activities of the nursing home are not age appropriate. This was minimal stimulation for young 22 year old man. I have reviewed the activities available for the nursing home and they are all targeted towards a very elderly age group.
Example: Really is playing bingo or sing-a-longs appropriate for young people? No. Occupational Therapists could do appropriate groups or individual work with these clients. There is need to be much more engaging and creative.

Recommendations to address occupational deprivation

Develop and implement person centred plans
Residential Care Facilities must develop and implement Person Centred Assisted Daily Living (ADL) approaches to planning and goal setting for young people with disabilities.

Occupational Therapists have skills and are trained in person centred therapy. This is an evidence based approach that focuses on ensuring people, no matter their level of intellectual disability, spend their time engaged in meaningful activities and relationships and experience choice and control as valued members of their community.

For example – a lot residential facilities do not provide any choice of food, or opportunity to engage in the preparation and pack up of meals everything is done for the person. An occupational therapists would be able to design programs, facilities and system to assist with engaging the client in the whole process of food preparation, consumption and clean up.

Developing person centred care plans requires a significant investment in workforce development. See more detailed discussion on workforce development below.

Design of Residential Care Facilities,
Building choice and control over aspects of daily life is possible if the environment is set up to ‘mirror’ age-relevant spaces and time-frames. Examples of enriched RCF environments include:

- separate break out areas which allow occupations of choice, such as listening to the football or engaging with a toolbox and car chassis in a ‘men’s shed’ area;
- Facilities and staff procedures allow for late nights and overnight guests

Partner with other community organisations
Opportunities to link up with support groups, engage other community groups: Evidence clearly demonstrates clients thrive better in environments which facilitate individual needs, beyond the rigid restrictions of the residential care facility. Examples include proximity to community hubs, schools or nature, with structures to enable exchange and engagement as directed by the client.

Utilise technology
Information and communication technology (ICT) represents a key facilitator of occupational engagement. For example, members of the chronic illness community, while unable to travel to or sustain meeting attendance in person, successfully utilize Facebook and international blogs and social media to connect virtually.

Technological developments are such that even clients without a reliable yes/no response, are able to control their environments and to communicate using proximity switches. These technologies, a combination of mainstream and specialist systems, are rarely funded or supported by RCF.
7. **PROBLEM: POOR MENTAL HEALTH**

Occupational Therapists specialize in occupation based mental health service provision.

A lack of control and sense of self competence and change in self-identity affect many young people moved into RCF.

As such, a number of relevant mental health issues have been identified facing young people in residential care facilities, which are not adequately being addressed.

They include, but are not limited to:

**Grief, loss and depression:**
These are all associated with often sudden and early onset of catastrophic loss of function faced by those with acquired brain injuries and related impairments.

As well as loss of function and loss of choice over accommodation, clients must adjust to the loss of life roles. The inability to carry out work roles as well as the frustration and lack of choices evident within RCF, are linked to grief, loss and depression. Anxiety regarding the future, and a lack of choice over future options, can compound these problems.

**Temporal concerns:**
A range of challenging behaviours, as well as lethargy, are evident in young people in RCF, and is closely related to lack of tailored daily structures and lack of engagement in meaningful occupations.

Clients experience boredom, a lack of things to look forward to, lack of autonomy and a sense of engagement and achievement

**Loneliness:**
Loneliness and isolation are significant issues for many of these young people. Often in inappropriate RCF environments young people avoid leaving their rooms because the activities available to the rest of the care facility population are tailored to different generations.

*Occupational therapist example:* I work in both acute neurosciences, and chronic neuro clinics, I have had experience in working with young people with a variety of disabilities living with residential care settings.

One negative example, would be a young man requiring high level care following a hypoxic brain injury. Although his physical dysfunction was significant, his cognitive issues were lesser and he had awareness and insight as to his surroundings. The aged care facility in which he was placed significantly impacts on his mood and mental health and his parents reported that he was extremely upset by the social isolation from his peer group. They physical environment (colour scheme, background music, activities, food choices) were also not reflective of the interest of a young person who previously enjoyed a full and active life. Whilst his parents tried to address some of these issues and improve their son’s quality of life the impact on the individuals mood remained an ongoing issue.
Recommendations to address mental health problems:

It is important to invest in policies that address mental health because such early intervention is proven to prevent the development of serious future mental illness.

Good policy therefore, would be to allocate resources to prevent mental illness development. This would also ensure savings in future expenditure in mental illness by addressing the root cause now, by giving young people in RCF more control of their environment, allowing them to engage and minimising isolation.

Client choice and control
It is important that while maintain best practice care and support services, RCF staff give the client more control and say over their activity. People with disabilities are usually in the best position to instruct their own support services

Person-centred ADL
RCF staff must invest in developing specialized individual activity programs for young people in there care. This includes prescription and customization of assistive technology to enable social participation and developing Community Access Plans about increasing accessibility and encouraging social integration – see next point below.

An ‘age appropriate’ life: Involve clients family, friends and people their own age
Mental health is supported through the presence of multiple, varied and ongoing opportunities to engage with the community at large, and with preferred subsets such as clubs and chosen sporting codes. Strategies to retain the client’s circle of support, including friends and peers, must commence early and be actively evaluated, to build and sustain valued networks. This entails supporting access into the community, as well as facilitating connections by welcoming community visitors into the RCF.

Conduct regular mental health assessments
Goal setting with young people in RCF must take a lifespan approach, and part of this is the availability of regular and ongoing mental health assessments and planning.

8. PROBLEM – POOR FACILITIES

Housing is not just an individual or community based issue, but a complex relationship between both. For this reason occupational therapy is able to bring unique skills to this complex issue.

The essential problem facing young people in residential care facilities is that they are living in facilities that were not designed for young people with disabilities - they are designed for elderly residents in need of care.

Room share:

Example: I had an intellectually disabled young male client (21 years old) who shared a tiny room (3.2m x 4m) with an elderly man who had dementia. There was insufficient space for the young mans hoist transfers to wheelchair without getting close to the residents bed. Furthermore the man with dementia requires lights to be dim/off and curtains closed at all times, which greatly exacerbated the mental health issues of my client (depression, anxiety)
Recommendations to address poor facilities:

Importance of assessment of facilities
Models exist for community visitors to review and audit facilities against community standards: it is proposed the current extensive body of knowledge regarding enriched environments for people living with severe and profound disability, is developed into an assessment tool for clients and families to self-evaluate facilities. Auditing facilities must happen regularly.

Importance of client assessments
Following client assessments an OT can connect other professionals, design systems and programs that works for the individual as well as the community as a whole. An occupational therapist will look at the person and identity with the person want they want to engage in, and provide a program that assists the person in participating and engage in their chosen occupation.

Inclusive design:
As experts in inclusive environments and the person-environment fit, OTs are well placed to inform policies and tools to futureproof the design of RCF and contribute to new and varied models of care for this population

Assistive technology provisions:
Significant evidence identifies the effectiveness of assistive technology in minimizing carer burden, increasing self-efficacy and independence, and enriching the lives of people living with disability. It is also clearly evidenced that a small fraction of those who could benefit, are provided such technologies.

RCF’s have been demonstrated to fail in providing tailored, age appropriate assistive technologies to support participation. It is essential to ensure accessibility of and affordability of assistive technology.

9. PROBLEM: RESIDENTIAL CARE FACILITY WORKFORCE

Often the focus at residential care facilities is providing basic nursing and care. In aged care settings, there are personal care workers, division 1 and 2 nurses who’s focus is on client comfort support, not ADL needs of those with disabilities.

Occupational Therapists Example: The nursing home I was working in had no understanding of how to treat young person with disability and there were limited equipment and resources available. Consequently clients contractures quickly became worse affecting is seating and positioning and pressure points in lying.

Often RCF employ a recreational officer providing for the majority who are older. Staff may not know how to engage young people on occupations activities that are meaningful.

Monash University’s Dr Racheal Mcdonald recently found these current RCF workforce arrangements are contributing to social exclusion:

many staff within these supported accommodation facilities view their roles incorrectly as care providers and are not actively facilitating social inclusion for their clients, despite social inclusion being specifically mentioned in the Residential Services Practice Manual as a key staff priority. Enabling social inclusion of people with significant disabilities is
difficult, and staff require more training and access to professionals who can help them in their role of promoting and enabling social inclusion for people living in supported residential care.

In care facilities it is difficult for staff whose main focus is nursing care, to take a wider view of health and occupation - so it is important that the carer and nursing workforce be trained in these skills.

Additionally, there is often a disconnect between carer and nursing staff and their ability to deliver ADL plans for clients, as designed by occupational therapists.

Example: 47 year old man, locked in syndrome after massive stroke, had no speech and no functional movement except slight movement of head and blinking. In nursing home for three years, severe contractures of upper and lower limbs due to inadequate positioning. Spends all day in princess chair or bed despite having a suitable tilt-in space wheelchair as nurses are not willing or able to position client properly – keeping him in bed means they don’t take him for walks or outside activities. They treat him like he does not understand, talk over him, don’t ask him anything despite him being able to blink yes or no. He gets put in front of TV showing kids programs but the client loves cricket and action films and music. Staff are not following up on OT directions re interest and not adjusting head switch and controller for client to be able to choose program.

Recommendations to address workforce problems:

Develop and implement workforce plan to develop RCF carer and nursing staff: The support required for young people with disability is around a person centred ADL approach – this is different to the aged care model.

It is essentially about tailoring plans to the skills and capacity of staff and the service in enabling engagement of the person with a disability in meaningful activities and relationships.

Developing the RCF workforce can be completed through a 3 step process.

Step 1: It is important the government conduct a review and confirm the current workforce deficits and implement a workforce development program to address the current significant skills gaps.

Step 2: Involve experts in developing residential care facility workforce development. This professional carer workforce development plan must involve specialist allied health professions in training the nurses and carer staff at residential care facilities – such as occupational therapists.

Occupational therapist’s study and experience in person centred care, means they know how develop and deliver ADL plans that are catered specifically to individual client needs. Occupational Therapists have a holistic focus and are trained to develop and implement person centred plans around assisted daily living.

Furthermore, the government should utilize those experienced in building capacity and working across health disciplines. Occupational Therapists currently work with teams of health and community care professionals across a range of government funded community
health program ensure that meaning activities are not overlooked in a person’s life. This may entail an OT drawing up the plan and then training staff to implement it.

Step 3: Assess risk and review: The government should regularly monitor the newly trained workforce to ensure safety and best practice care.

Occupational therapists are trained in undertaking holistic risk assessments for a person with severe disabilities to determine certain tasks that will be safe for the person and the broader community.

10. JURISDICTIONS DOING WELL - ACT

There are some good news stories regarding how different state and territory jurisdictions are providing quality residential care for young people with disabilities. Some are doing better than others.

The ACT for instance, has a positive housing arrangement for people with severe physical, mental or intellectual disabilities, with a very progressive community exploring diverse living options and plan.

Previously, group houses were the only option in Canberra – staffed and supported by local government disability services. While most experiences were positive, and staff did a great job with limited resources, there was a high incidence of occupational deprivation and a lot of families still felt their families were isolated.

Today, the community Services Directorate has invested significant time, and resources into developing a Housing Options Program.

One of the successful aspects of this program is the easily accessible Housing Options Facilitators who assist people with disability to identify and develop housing options that best meet their individual need.

Furthermore, Housing Options Facilitators seem to have varied, skilled and experienced backgrounds. It is important these role continue to be staffed not just be community carers, but experts in ADL and inclusive design – such as occupational therapists.

The Housing Options Facilitators deliver practical services such as:

- Assist by providing a housing options planning service to people with disability, their families and advocates,
- Assist by working in partnership with community agencies who are responsible for planning,
- Provide community education about housing options for people with disability, and;
- Provide information tools including the housing options decision making framework.

11. JURISDICTIONS DOING WELL – Inner-West Melbourne

In the inner west of Melbourne there is an over representation of people with Acquired brain injury from Alcohol and Drug use.
Example: Western ACAS assesses more under aged 65 than the state average. They have complex needs with many comorbidities and often insecure housing in private boarding houses and SRS. 2 facilities Salvation Army James Barkher House and Wintringham in Williamstown have been established to cater for this group. Both of these facilities have been established to provide appropriate environment with facility physical design reflecting this and work effectively with this population. I have worked with a number of clients aged under 65 residing in these facilities where quality of life is supported well.

OTA would like to see other states implement such arrangements.

Research by occupational therapists
A body of recent research demonstrates the potential of a variety of residential care options, and the outcomes possible with home-like environments and tailored supports (see for example Sloan, Callaway, Winkler, McKinley, Ziino) (2012) Accommodation Outcomes and Transitions Following Community-Based Intervention for Individuals with Acquired Brain Injury, Brain Impairment 13 (1) 24-43)

It is proposed the body of work from organistaions such as the Summer Foundation and Young People in Nursing Homes Alliance, contains key building blocks for improved options for these individuals.

12. SUMMARY RECOMMENDATIONS

There are a number of practical, cost effective and timely actions that can be put in place to improve the quality of residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia. They include:

- Investing in upskilling and developing the professional carer workforce so that Residential Care Facility (RCF) staff are able to provide the care and support young people in RCF’s really need.

  The short term costs of this investment would be met by an increase in productivity and professional carer workforce outputs. Similar workforce development projects are currently underway in preparation for the rollout of the NDIS, and savings could be made in partnering in these upskilling programs.

- Preventing mental illness development and also preventing future increased expenditure in mental illness by addressing mental health now and giving young people in RCF more control of their environment, allowing them to engage and minimising isolation.

- Preventing ongoing issues of young people suffering occupational deprivation by developing and implementing person centred care plans.

- Ensuring facilities are accessible for young people with disabilities and that they have access to the assistive technology they need to ensure their independence and mobility.