



## Australian College of Care Workers

Submission to the

Royal Commission into Aged Care Quality and Safety

31 July 2020

***Person-Centred care for elderly and young people with  
disability residing in Aged Care.***

Janet L Lawrence FACN

Commissioner the Honourable Richard  
Tracey AM RFD QC

Commissioner Ms Lynelle Briggs AO

13 July 2020

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Dear Commissioners,

I am the President of the Australian College of Care Workers, Inc. (ACCW), I write this Submission on behalf of the Board – Australian College of Care Workers, Inc., and members of ACCW Care Workers working in Residential Aged Care Services. As a Fellow of the College of Nursing Australia, and CEO/Director of Studies, and completed Doctor of Education Exploring the Effect of Aged Care Education on Quality of Care. I had the opportunity to do the following:

1. I submitted to the Royal Commission into Aged Care Quality and Safety on 19 September 2019 to Commissioner the Honourable Richard Tracey AM RFD QC, Commissioner Ms Lynelle Briggs AO into a Response to Terms of Reference item: *a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response.* The Submission was based on my extensive knowledge and experience of over three decades into aged care.
2. Participated in a Survey 29 June 2020, into 'Aged Care Worker Regulation Scheme Consultation' the initiative of Australian Government Department of Health.
3. Today 31.7.2020 I submitted on behalf the Australian College of Care Workers, Inc., Board Members and Care Workers to provide definitive recommendations on how best to prevent the spread of infections in residential aged care services, including COVID-19. The impact on residents has been severe and, in some cases, fatal, with ongoing impact on family, their representatives and staff. To learn how care facilities, avoid an outbreak and seek to manage future pandemics or infectious disease outbreaks (31.7.2020). The Commissioners focus is on the best possible ways to react to future pandemics while balancing the need for safety and wellbeing for all.
4. On behalf of the Board Members and ACCW Care Workers submit a response to Terms of Reference item:
  - b. 'how best to deliver aged care services to:*
    - i. people with disabilities residing in aged care facilities, including younger people; and*

*e. 'how to ensure that aged care services are person-centred, including through allowing people to exercise more excellent choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters.*

The above two terms of reference are related to each other.

As an Aged Care Consultant, Nurse Educator, and past member of the Commonwealth Panel of Administrators and Advisers, External Quality Assessor since 2000 to 2018 and Director of Nursing for five Aged Care Residential Aged Care Services, and after three decades committed to aged care through work and education, I can confidently, on behalf of the Board Members provide a submission to the Royal Commission in regard to the above Terms of Reference b and e.

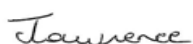
The Australian elderly and young adults in aged care facilities are entitled the highest standards of care. Care that include: respect, dignity, choice risk-based personal Care and clinical Care with ongoing assessment and planning with the older adult and their representative. The older adult needs to feel empowered, supported in activities of daily living; free to provide feedback and complaints. It is also essential to understand how best to deliver aged care services to people with disabilities under the age of 65 years, residing in aged care facilities.

On 30 September 2018, the Department of Health reported there were 5,905 people aged under 65 years of age living in residential aged care facilities across Australia. Of these 5,905 people, 188 were aged under 45 years of age (AIHW accessed 15.7.2020). Most of these younger people who reside in aged care have acquired their disability as adults. Close to half are in partner relationships, and more than 1 in 4 are parents of school-aged children when they entered aged care. As the Summer Foundation (2020) points out, being in aged care leads to marginalisation and isolation for these younger people –‘tragically, 82% rarely or never visit their friends. The distress this causes these people and their families is immense.’

Implementing Person-centred Care, care staff in aged care is a valuable model of the philosophy of care. The elderly residents and young people in which all Care Workers working in the community, residential aged care services, require support due to ageing, disability, dementia/mental health and in the community.

The ACCW Board Members submission must be considered for the safety and wellbeing for all older adults and young adults living in Australian aged care services. Thank you very much for the opportunity to submit to The Royal Commission into Aged Care Quality and Safety.

*Sincerely yours,*



Janet L Lawrence- FACN  
Founder and Chairperson  
Australian College of Care Workers, Inc. (ACCW)

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# 1. BACKGROUND TO PERSON-CENTRED CARE

Many Residential Aged Care Services have some form of a model of care based on the philosophy they hold. Some of these models and philosophies of care include 'Consumer-Directed Care', 'Person-Centred Care' for Alzheimer's Disease and Related Disorders, 'Eden Alternative', 'Early Neighbourhood', 'Household', 'Greenhouse', 'Wellspring' and 'Gentle Care' of which little is known in the aged care industry.

Many providers and managers aspire to provide person-centred care without much understanding of how it can be delivered. While some aged care services claim that they provide person-centred care, there is inconsistency in how it is implemented. Besides, lack of education on the concepts of person-centred care, lack of mixed staffing, lack of resources, all of which compromise care.

The Person-Centred care approach places the individual as the most valued individual. It is essential to allow individuals or their representatives to express their care-related choices. Care workers can share the older person's ideas and past routines related to activities of daily living that are meaningful to them. It also encourages care workers to seek feedback to advance the individual's quality of life, by delivering care that respects older adults' rights, religious beliefs, cultural and diverse needs in a sensitive and caring environment.

The person-centred approach is a choice not only in Australia but also around the world (Edvardsson et al., 2010; Brownie & Nancarrow, 2013). The Australian Government supports person-centred care, even though it is not available to all elderly older adult Australians. The person-centred approach in aged care is not sustainable and cannot achieve the quality of care, mainly because of reduced numbers of nursing and care workers. Aged care services are unequally distributed, mainly to ATSI, culturally, and linguistically diverse (CALD) in metropolitan, rural and regional Australia.

The Aged Care Training Packages includes person-centred and consumer-directed models of care, however, the information is inadequate ([training.gov.au](http://training.gov.au)). At the same time, other types of care which are not mentioned in the training packages, are operating sporadically across the aged care sector. These models include: 'Consumer-Directed Care', 'Person-Centred Care' for Alzheimer's Disease and Related Disorders, 'Eden Alternative', 'Early Neighbourhood', 'Household', 'Greenhouse', 'Wellspring' and 'Gentle Care'. The person-centred model must be implemented in all aged care services to enable care workers to provide a consistent approach to meeting care needs based on older adults' choices. Education from management to care, workers, working across aged care services and community must understand and support the person-centred approach model to improve the quality of care that impact the quality of life of an individual.

Aged care organisations are accountable for the funding they receive from the Government and must responsibly invest in a person-centred approach to care. The organisational, operational policies, staffing structures and related activities must encourage excellence in care. Australian older adults must not be limited in deciding who provides their care. In the past, they have had limited choices about their medical and nursing care and rehabilitation. The lack of sensitivity for the older adults' choices related to personal hygiene, food and drinks, and other activities of daily living are limited because the individual must fit within the working hours of the staff.

Person-centred care must be employed across all residential aged care services, even though residential aged care services employ their philosophy of care based on religious and cultural needs. The conceptual Person-Centred Model of Care must be employed for consistency in care. The model must be backed with funding, teaching, and training, monitoring for quality of care, and evaluation of this Person-Centred Care model for continuous improvement. The understanding and implementation of person-centred care must be employed that will respect the choices of the older adults, empower them to maintain their independence within their capability to receive the quality of care that will impact on the quality of life of residents in RACS.

## 2. CONCEPTUAL PERSON-CENTRED MODEL OF CARE

Person-Centred care philosophy of care can be provided across the care sectors: Residential Aged Care Services; Disability; Mental Health; Community Services; Other Care related services such as Supported Residential Services; Independent Living Centres; Home and Community Centres; Day Care Centres; Respite Care Services; Retirement Village and any field where care is provided.



*Figure 1 Conceptual Person-Centred Model of Care*

A peak body, Young People In Nursing Homes National Alliance (YPINHna), have worked extensively with governments since 2002 in developing policies and systemic changes that are necessary for providing 'effective and sustainable life term care' and a 'support system' for all Australians with disability. The Alliance are firmly committed to the fundamental themes of a person-centred care philosophy. For example, The Alliance (2020) states that they strive to ensure young people have:

- a voice about where they want to live and how they want to be supported
- the capacity to participate in efforts to achieve this, and
- 'a place of the table', so they can be directly involved in developing "lives worth living" in the community

Yet, it should be acknowledged principle advocates, The Alliance and Summer Foundation, do not place a great emphasis on a person-centred care model. They do not present a full workable definition of 'person-centeredness' and the necessary steps for its application or, moreover, accentuating the necessity for residential care workers to develop further their capacity to apply person-centred models.

Person-Centred care model concept is a philosophy of care for the resident's physical, mental and social wellbeing.

1. Values of older adults' nursing, medical, allied health, and Care workers
2. Engagement with individuals to exercise more excellent choice, control, and independence in relation to their care
3. Meeting the individual's social-emotional, complex needs, rehabilitation, and mental health wellbeing
4. Improvement with engagement with family and carers on care-related matters
5. Health Education for the older adult and their representative
6. Support from Government, Providers, Management, Staff and Care Workers

These concepts are included in the following ways to deliver person-centred care.

### 3. WAYS TO ENSURE THAT AGED CARE SERVICES ARE PERSON CENTRED TO CARE AND SERVICES

Person-Centred care model concept is a philosophy of care for the resident's mental and social wellbeing. The outcome of person-centred care is a way of providing quality of care which will impact on the quality of life of residents in RACS. A recent study on 'Exploring the Effect of Aged Care Education on Quality of Care' examined quality in the residential care services, in which person-centred care is employed in some residential aged care services. The person-centred model philosophy of care is appropriate for older adults and disabled persons less than 65 years of aged. Person-centred care enables nursing and care workers to decide when and who provides their care according to their choices. These choices involve doctors and other health services, types of meals and drinks, personal hygiene, leisure activities, family visits and other outdoor activities.

1. Provide service delivery within a quality framework
  - 1.1 Follow procedures for service delivery for the individual in line with the organisation's quality system
  - 2.1 Identify any barriers that may impact on the delivery of high-quality service and refer to supervisor
  - 3.1 Regularly review procedures for service delivery to reflect industry best practice and relevant legislative changes
  - 4.1 Regularly review procedures for service delivery to reflect the changing aspirations, needs and preferences of the person with a disability

## 4. STRATEGIES TO ALLOW INDIVIDUALS TO EXERCISE GREATER CHOICE, CONTROL, AND INDEPENDENCE

Person-centred care is a way of using a consultative approach with the older adults and their representative, health personnel, nursing, and care partners in planning, developing, and monitoring care to meet the needs of the individual resident.

1. Develop the required responses that cater to individual differences, rights, needs and preferences through the following:
  - a. Person-centred approach,
  - b. Person-centred planning,
  - c. Catering for individual rights,
  - d. Strategies for reinforcing the rights of people with disability to contribute and to be heard,
  - e. Develop and support strategies to promote independence
2. Communicate the needs of the person to family and carer and relevant others as appropriate
  - a. Employ communication principles when communicating with the older adult, representative, nursing, and allied health personnel
  - b. Make available appropriate resources enhance the communication needs, interests and requirements for the older person.
3. Seek provision of services from other workers or agencies as required
  - a. Advocacy support
  - b. Contacting other agencies
4. Maintain all relevant documentation relating to the person and the service delivery and communicate per organisation procedures
  - a. Maintain documentation and employ well-developed electronic documentation that is accessible and efficient.

In Australia, service delivery models tend to focus primarily on the physical needs of young people in nursing homes, such as relocation to purpose-built apartments, and to a much lesser extent on the social and emotional needs of this population. Yet, as one study points out (Rissanen et al.: 2013,p.191), 'changing the physical environment alone is insufficient to improve quality of life and satisfaction for young people with complex disabling health conditions'.

Young disabled people accommodated in the aged care system and adequately equipped to provide the vital additional support and needs for this population, such as extra staff to assist with clinical needs, rehabilitation therapists and community access, the social and emotional needs of this population must adequately meet person-centred practice.



In the study mentioned above, four main themes relevant to person-centred practice are identified (*ibid.*,p.190.)

- 1) Recognition of the person in time and context
- 2) Recognition of individuality
- 3) Recognition of the relationship
- 4) Promotion of autonomy.

The purpose of this qualitative study was to identify the significant ways in which residential workers understood and articulated person-centred practise for young people with complex disabilities. The study revealed problems relating to a commonly agreed definition of person-centeredness, the perception of person-centeredness by care workers, and other main concerns such as system and organisational constraints which hindered the ability of care workers to reframe their professional role. Moreover, the study concluded that

*Participants needed support, education and/or mentoring to improve their capacity to apply person-centred models and also to create meaningful care partnerships (ibid).*

In focusing on the area of rehabilitation for young disabled people in aged care, The Alliance have called for a National Rehabilitation Strategy. Which would address the fact that these young people have many different needs to older Australians who are nearing the end of their life and that nursing homes are not set up to support them? The Summer Foundation has also emphasised the importance of access to rehabilitation services for young disabled people by focusing on the need for governments to invest in community-based rehabilitation services.

## 5. MEETING THE INDIVIDUAL'S SOCIAL, EMOTIONAL, COMPLEX NEEDS, REHABILITATION AND MENTAL HEALTH

Several older adults are frail, have chronic health conditions and unable to communicate their needs. The following must be implemented:

- Education of staff is it from management to ground staff Care Workers.
  - Policies and procedures that guide staff to support the person to maintain their activities of daily living. Must consider the person's individual needs, strengths, capabilities, and preferences when engaging in activities of daily living and routines
  - Assess and develop a behaviour support plan for the individual resident. This plan must identify the supports required for the person, their family representative, to address the unmet needs. This may involve management modifying or redesigning the environment, acquisition of skills and changing the systems already in place.
  - Implement positive interactions must be characterised by the following to minimise concerning behaviours:
  - Cultural sensitivity, eye contact, be patient and give the resident time to respond, respect for personal preferences, overcome difficulties through effective communication.
  - Treat each resident as an individual by identifying their interests, needs, strengths and preferences, to deliver a much more personal and tailored service and care.

- Identify problems with engaging or motivating the person and seek appropriate assistance.
- Recognise behaviours of concern outlined in the individualised behaviour support plan
- Consider the type, frequency, and triggers of the behaviour
- Employ a strength-based approach by empowering the individual. For example, take the opportunity to move away from looking at what the resident unable to do and focus on what they are capable of undertaking.
- Provide a safe environment for the person conducive to positive and adaptive responses. They are providing a safe and predictable environment. A positive response is where the person responds to the environment with a desirable behaviour and does not react unexpectedly. The adaptive response is where the person with a disability uses their other functioning aspects of the body to adapt to their environment and complete tasks.

## 6. APPROACHES TO IMPROVING ENGAGEMENT WITH FAMILIES AND CARERS ON CARE RELATED MATTERS

Residential aged care services accommodate older adults with health conditions that require support and assistance. Some older adults have dementia, chronic health conditions, frailty, physical and intellectual disability requiring complex health care needs.

1. Work with the person to develop and implement person-centred responses
  - 1.1 Collaborate with the person with a disability and their family and carer and relevant others in actively developing responses that meet the individual's aspirations, needs, rights and preferences
  - 1.2 Put in place mechanisms to ensure the person's support information is accurately recorded, maintained, and applied to future support activities and responses
  - 1.3 Develop the required responses that cater to individual differences, rights, needs and preferences
  - 1.4 Communicate the needs of the person to family and carer and relevant others as appropriate
  - 1.5 Make available appropriate resources
  - 1.6 Maintain all relevant documentation relating to the person and the service delivery and communicate by organisation procedures
2. Review and monitor person-centred responses
  - 2.1 Review and measure the effectiveness of responses in meeting the person's needs and preferences, in consultation with the person, family and carer and relevant other
  - 2.2 Identify and take action to improve areas of the responses that have not met the person's needs and preferences
  - 2.3 Ensure changes to service delivery are within policy and budgetary frameworks
  - 2.4 Modify specified aspects of service delivery as required, to meet changing service requirements and the needs and preferences of the person with a disability
  - 2.5 Identify potential training opportunities for the person to meet their changing needs
  - 2.6 Ensure changes to service are within procedural and legislative requirements and maintain high standards of delivery

## 7. HEALTH EDUCATION FOR THE INDIVIDUAL PERSON

Individuals with disabilities, the emphasis in health education is to “wellness” and “health promotion” to improve health prospect. Physical therapy and other rehabilitation professionals can play an essential role in the integration of health promotion as person-centred. Enabling the individual choice will continue to constitute to the vision of achieving maximum independence within their capability and enjoy the social life out of the aged care services. Have rehabilitation centres to find ways to reduce costs while still trying to maintain quality by being close to resuming a regular daily routine.

There is a lack of attention to people with disabilities in health promotion. If a person has a congenital disability such as spina bifida or cerebral palsy, developed multiple sclerosis, or have severe asthma, the individual is not considered for physiotherapy and rehabilitation. It is because they are not the right candidate for a health promotion program because the aim of health promotion was not to take care of the “sick” and “disabled,” but instead to prevent disease and disability in the “healthy.”

<https://academic.oup.com/ptj/article/79/5/495/2837103>

In recognition of years of extensive work and the steps taken towards a resolution of the high numbers of young people in nursing homes, Summer Foundation has contributed mainly to the provision of accessible housing for this population by emphasising four strategic priority areas: NDIS, Housing, Community and Primary Health, Pathways Home. In acknowledging the policy work of the Summer Foundation, especially the Monash University/Summer Foundation White Paper of 2011 and other contributions by peak bodies, the Australian Government has committed to stopping younger people going into aged care by 2022, and to making sure that all younger people leave aged care by 2025.

## 8. CONTINUING PROFESSIONAL DEVELOPMENT AND TRAINING FOR CARE WORKERS

Care Workers to contribute to the quality of care must be supported in consultations with aged care training institutions and approved providers operating in the aged, mental health, the disability community and other care-related industry to develop specific training to meet current trends and workforce demands. Educating the aged care workforce on person-centred care approach has been the subject of much scrutiny. It is viewed by many as a key to improving aged care.

A meaningful career pathway based on Continuing Professional Development is crucial for Care Workers to stay motivated to provide quality care. Care workers are the largest-growing group in the Workforce. To maintain a strong care workforce, appropriate education, and training to address the responsibilities of Care Workers who manage

challenging behaviours, palliative care, and complex and technical procedures in caring for the elderly.

Continuing Professional Development involving participation in short courses, workshops or webinars including accredited and non-accredited courses; work-related training, attendance at conferences or seminars; enhancing or adding to the graduate's skills, full and part-time tertiary study, undertaking quality activities or research; writing papers and delivering work-related presentations, in-service education; and formally arranged mentoring.

Care Workers working in aged care (aged care, mental health, disability, community) The following model below provides an option for Continuing Education, and Professional Development provides Care Worker's a career pathway. These Care Workers would be able to work in conjunction with nurses and allied health professionals in the provision of quality care.

## 9. MONITORING THE APPLICATION OF PERSON-CENTRED CARE MODEL

Review and monitor person-centred responses

- Review and measure the effectiveness of responses in meeting the person's needs and preferences, in consultation with the person, family and carer and relevant other
- Identify and take action to improve areas of the responses that have not met the person's needs and preferences
- Ensure changes to service delivery are within policy and budgetary frameworks
- Modify specified aspects of service delivery as required, to meet changing service requirements and the needs and preferences of the person with a disability
- Identify potential training opportunities for the person to meet their changing needs
- Ensure changes to service are within procedural and legislative requirements and maintain high standards of delivery.

## 10. MANAGEMENT COMMITMENT TO STAFFING AND QUALITY IMPROVEMENT TO PERSON-CENTRED CARE

1. Provide service delivery within a quality framework
  - 1.1 – Collaborate with the person with a disability and their family and carer and relevant others in actively developing responses that meet the individual's aspirations, needs, rights and preferences
  - 1.2 – Put in place mechanisms to ensure the person's support information is accurately recorded, maintained, and applied to future support activities and responses
  - 1.3 – Develop the required responses that cater to individual differences, rights, needs and preferences
  - 1.4 – Communicate the needs of the person to family and carer and relevant others as appropriate
  - 1.5 – Make available appropriate resources
  - 1.6 – Seek provision of services from other workers or agencies as required

1.7 – Maintain all relevant documentation relating to the person and the service delivery and communicate following organisation procedures  
Maintaining documentation

## SUMMARY

Australian elderly and young adults with a disability are accommodated in aged care facilities. They are entitled the highest standards of care that include respect, dignity, choice risk-based personal care and clinical. Having young adults with disability in residential aged care services has its challenges, and with this group of people, needs are not met to their full potential.

Implementing Person-centred care, care staff in aged care is a valuable model of the philosophy of care. The elderly residents and young people in which all Care Workers working in the community, residential aged care services, require support due to ageing, disability, dementia/mental health and in the community. Many providers and managers aspire to provide person-centred care without much understanding of how it can be delivered. While some aged care services claim that they provide person-centred care, there is inconsistency in how it is implemented. In addition, lack of education on the concepts of person-centred care, lack of mixed staffing, lack of resources, all of which compromised care.

The Person-Centred care approach places the individual as the most valued individual. It is essential to allow individuals or their representatives to express their care-related choices. Person-centred care must be employed that will respect the choices of the older adults, empower them to maintain their independence within their capability to receive the quality of care that will impact on the quality of life of residents in RACS.

The Submission provided a brief background to Person-centred care that is not operating consistently across aged care services yet necessary. 1) A Conceptual Person-Centred Care model is provided and would need to be developed and implemented in each aged care service for consistency. This Submission has covered areas related to Person-Centred Care:

- ways to ensure person-centred care;
- strategies to allow an individual to exercise choice, control, and independence;
- meeting the individual's social, emotional, complex needs, rehabilitation and mental health;
- approaches to improving engagement with families and careers on care-related matters;
- health education for the person residing in aged care;
- continuing professional development and training for care workers; 8)
- monitoring the application of person-centred care model, and
- management commitment to staffing and quality improvement to person-centred care.

The Australian College of Care Workers, Inc. Board Members and Care Workers Submission on Person-Centred Care must be considered and respected for the safety and wellbeing for all older adults and young adults living in Australian aged care services.

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## APPENDIX: 1 JANET J LAWRENCE: PROFESSIONAL PROFILE RELEVANT TO THIS SUBMISSION

- **Current**
  - Registered Nurse
  - Fellow of the College of Nursing
  - Delegate Liberal Party for Cooper
  - Independent Aged Care Nurse Consultant
  - Legal expert witness on aged care issues
  - CEO/Director of Studies: ALACC Health College, Australia
  - Member of the Quality Society Australasia and RABQSA International Quality Assessor (2000-2013) Renewed 2018 to present with the Australian Organisation for Quality Ltd.
  - Australian Association of Gerontology (AAG) 2018 to present
- **Past**
  - Commonwealth Panel of Administrators and Advisors
  - Director of Nursing,
  - Director/Secretary: Professional Development Consultants

- Board Member: Footscray Society for the Aged (Not-for-Profit organisation)
- Board Panel Member of Australian Nursing Midwifery Accreditation Council
- External Quality Assessor: Australian Aged Care Quality Agency

**Qualifications:**

- Doctor of Education – Graduation December 2020
- Master of Nursing
- Graduate Diploma in Health Administration
- Graduate Diploma in Gerontological Nursing
- Bachelor of Applied Science (Advanced Nursing), major Nursing Administration
- Diploma in Business
- Diploma of Nursing Education
- Diploma of Vocational Education
- Diploma of Training Development and Design