



Submission to Australian Government
Productivity Commission - Caring for Older
Australians

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Introduction to Queensland Aged and Disability Advocacy Inc. (QADA)

QADA is jointly funded by the Queensland and Australian Governments to offer free, confidential and client directed advocacy support to people receiving aged care packages (Community Aged Care Packages CACP's) / Extended Aged Care at Home packages (EACH)), Home and Community Care services (HACC), Residents of Commonwealth funded Aged Care facilities, and Carers of recipients of these services.

QADA also provides professional advice, support and representation by Legal Advocates to assist adults whose decision making capacity is being questioned, with guardianship and administration matters.

QADA is an independent advocacy service that operates throughout Queensland with a head office in Brisbane and regional offices in Cairns, Townsville, Rockhampton, Mackay, Wide Bay and the Gold Coast. QADA's mission is to provide information, education, support and representation to enable people to understand and exercise their rights and their responsibilities within the context of aged care services, and to ensure their voice is heard.

Executive Summary

QADA recognises that through its involvement with consumers of aged care services there is a need for a consumer directed service model. This is to ensure greater consumer involvement in care provision, with an emphasis on consumer choice and accountability measures for providers.

In order to achieve this it would be beneficial to the aged care system to have a greater awareness of the benefits of advocacy for both aged care service recipients, and also for providers of services. Advocacy plays a valuable role in the provision of aged care services. It is an effective means of early resolution of issues; often preventing issues going through formal complaints

processes such as the Complaints Investigation Scheme (CIS), and promotes an environment of continuous quality improvement.

QADA actively participates in consumer engagement and along with Carers Queensland and Council on the Ageing Queensland (COTAQ) conducts consumer consultations, focus groups and draws out emerging client issues both positive and negative throughout the state. This is an opportunity to identify local issues affecting individuals and communities, to gather information to influence service planning, and to suggest recommendations to make changes at a systemic level for service providers and government.

QADA values this opportunity to provide feedback into the review of the aged care system in Australia, and to share information and recommendations gained through its advocacy services representing a consumer perspective.

Our Principles

QADA is guided by the following core principles to ensure effective and efficient advocacy services that promote and empower people's rights through social justice values and professional ethics:

Respect:

Our practice is guided by a client's right to be treated with respect as recipients of services.

Integrity:

Our advocacy practice is undertaken to ensure transparency and full accountability to our clients.

Confidentiality:

We recognise all clients have the right to maintain their confidentiality.

Collaboration:

Whilst representing clients and ensuring their rights are upheld we work in a collaborative and consultative manner.

Performance Excellence:

Our advocacy practices are focused on ensuring our client's rights are upheld.

Continuous Improvement:

Our advocacy practice in supporting our client's rights works to facilitate sustainable improvements to their service experience.

As a consumer advocacy organisation QADA can provide unique and valuable insights into aged care services as shown in this submission.

Aged Care Packages

In order to achieve appropriate aged care services which meet the individual client care needs, QADA's advocacy service shows that it would be beneficial to allow more flexibility between aged care packages. QADA receives many calls from clients we have supported that could be resolved with increased flexibility, including the matters like those outlined below:

- QADA receives calls from consumers whose needs are greater than the level of support provided on a CACP, but who do not have the support needs required to receive an EACH package. Support which bridges the gap between the packages would be beneficial to clients whose care needs are currently at this level in order to improve their quality of life.

- QADA has supported consumers in situations where they have been assessed as requiring an EACHD package, but there are not any EACHD packages available in their area. The consumers have instead been offered a CACP which does not provide adequate support to meet their needs. In some cases CACP's have not been available and consumers are offered an EACH package, which then results in the unavailability of EACH packages for clients who require them. As an independent advocacy service supporting consumers this raises the question of the effectiveness of the allocation of packages and the client's right to access a level of care that meets need.

- In some instances the lack of, or affordability of packages, may result in people going into residential aged care facilities prematurely to receive the level of care they require to meet their needs. This however is not the preferred option for the client nor does it service their overall well-being and assist to maintain their quality of life.
- Extended waiting lists for packages can be a concern for a number of clients requiring services. In some areas, including Townsville, there have previously been long waiting lists to receive services. The introduction of a new service provider in the area will hopefully help to alleviate this matter. On the Gold Coast waiting lists of 70 people have existed for EACH and EACHD packages. Whilst in some areas there is a surplus of CACP's packages which are not being taken up.
- QADA's advocacy case work identifies that many consumers are not familiar with their care plan or what their entitlements are when receiving a package. Often there is also a lack of awareness about what other services are available to them. Adding to this confusion is the fact that there appears to be little transparency with packages as the support offered seems to vary depending on who the service provider is. A standardised easy to understand care plan, including what hours they are entitled to, what services, and the unit costs required would be beneficial to raise the awareness of client entitlements.
- Clients can sometimes require assistance outside of the days they usually receive support. Meals on Wheels staff are often asked by clients to do other tasks when they are delivering meals. Workplace Health and Safety Qld report that injuries amongst this group of often older volunteers are very high.
- In some instances it could be beneficial if the consumer owned the package instead of the service provider, allowing the consumer greater

freedom to choose the services they require from a provider of their choice. This would allow for greater independence, flexibility and choice with the aim of meeting the needs of the consumer. However this system would need to be carefully administered to ensure accountability to reduce the risk of financial abuse by a carer and also to reduce stress placed on the carer or care recipient in managing finances related to their care.

- In some areas clients are sometimes receiving services from providers who are based some distance away, meaning a large part of their package is consumed by travel time. This has been the case on the Gold Coast where care recipients were receiving services from a provider located at the other end of the coast to where their home is situated. Another example is clients in remote locations where providers have to travel distances. Although QADA advocates for client choice, use of resources which provides minimum impact on direct service delivery needs to be considered.
- QADA recently received a call regarding an issue where a CACP recipient was admitted to hospital, with the prognosis that they were unlikely to return home due to health issues. The consumer's partner informed the service provider that the service was not required; however as a direct bank debit had been set up the recipient continued to be charged for the service. The partner rang the Department and was reportedly told that nothing could be done to recover their costs due to legislation. Another example is a client who continued to be charged for a package (without the meal component) whilst in hospital in order to remain as a client of the service.
- Concerns regarding services provided by some Indigenous providers have been raised, including in the Sunshine Coast area. Some clients have expressed concern regarding the level of information provided and lack of referrals to other services to meet their needs. The issues are

compounded when there is not a choice of other Indigenous providers in the area.

- There are concerns amongst some clients that the fees they pay for their package are used in the administration of services, or for travel time for transport services / social support, which they see as reducing the direct support they receive. QADA also receives calls from many clients who are confused with the accounts they receive. A review of accounts involving consumer input would be beneficial, along with greater accountability from service providers.

Residential Aged Care

QADA is regularly contacted by clients where there is not appropriate accommodation available to support their needs. For example, in a recent case of an older woman in her 80's with severe mental health issues, the only accommodation available was in a secure dementia unit. In New South Wales some aged facilities employ mental health nursing staff. It would be beneficial to offer this level of support in Queensland to clients with mental health issues.

The availability of services such as physio therapy would assist to promote the rehabilitation and independence of people in residential aged care facilities, thereby reducing their care needs, improving their quality of life, and the potential to move back into the community.

Transition Care

A greater focus on transition care would enable older people to remain living in the community for as long as possible. Where these services are unavailable the clients are more likely to be admitted inappropriately into residential aged care to ensure their needs are adequately met. QADA receives calls from clients returning home from hospital and are unaware of

transition care, resulting in the client receiving either no services or inadequate services.

Rural and Remote Issues

QADA through its delivery of advocacy services recognises that there is a great level of inconsistency with aged care services throughout Queensland. This is particularly an issue in rural and remote areas. A common consumer concern is the apparent lack of uniformity regarding assessments. There have been reports of clients in rural areas being assessed as CACP level, but when the assessment is sent to the ACAT in the main centre the client is then assessed as EACH level (this has arisen in Rockhampton but may also be an issue in other areas). Evidence suggests that assessments need to be consistent and not dependant on whom the assessor is as to what level of care is offered to a client.

There are also inconsistencies with the services available in regions and remote areas, with no aged care services available in some areas, whilst in other areas there are vacancies. The ability to receive services appears to be based on where you live and what support is available rather than on a needs basis. In some areas there is only one service provider, not allowing for client choice. This can particularly cause concern if the client has an issue with the service provider. Clients often state that they do not want to raise the issue for fear of retribution (see retribution section in submission).

Another issue in rural areas is that some clients are assessed as requiring an EACH package, however the service providers in the area cannot apply for EACH packages as access to registered nurses are limited. Therefore there are not any EACH packages available, despite clients being assessed as requiring them. QADA would like to see services which are more based on needs rather than location based. This highlights the breadth of workforce issues now and in the future in aged care (also covered later in the submission).

Aboriginal and Torres Strait Islander Clients in Remote Areas

In 2009 QADA conducted extensive consumer consultations throughout Queensland, including with Aboriginal and Torres Strait Islander consumers in the Northern and Eastern Capes. Consumers stated that an Aged Care Hostel is badly needed in Bamaga to address the needs of the older people and keep them in their community. This is a fundamental part of their culture. Currently people have to be transported to take up residency in different locations across Queensland, including Thursday Island, Townsville and Brisbane, when they can no longer safely reside in their homes. This is extremely distressing to Aboriginal and Torres Strait Islander peoples. This is also an issue in many other remote Aboriginal and Torres Strait Islander communities, including Palm Island where QADA has worked extensively. If a client's care needs change they need to go to Townsville as there is not appropriate accommodation on the Island to meet the needs of community members with high care needs. Aboriginal and Torres Strait Islander consumers in remote areas throughout Queensland consistently emphasised that it was critical that they remained in their community for as long as possible to maintain their own mental and emotional health, and fulfil their role as elders in the community. QADA advocates for aged care consumers to be safely able to remain living in the community of their choice.

Another issue brought to QADA's attention is that Aboriginal and Torres Strait Islander communities are limited to who can provide care to the elders, as they require family members who they consider trust worthy to enter into the consumer's home, because of a concern for their safety and a sense of vulnerability. Due to local Aboriginal Lore it is often difficult for staff members from the community to provide care for certain members of the consumer group. An example of this is that a daughter in law is not to speak to her father in law; therefore due to communication issues she cannot provide appropriate care.

Workforce

QADA regularly receives calls in relation to the aged care workforce. There needs to be adequate and appropriate training provided to staff in residential aged care facilities. Often staff are limited to what level of support they can offer residents due to their level of training. This puts extra strain on more qualified staff to provide the support that less experienced staff cannot provide.

Aged care staff and consumers often complain of the high staff turn-over for both nursing staff at the hospital and the community health service. Community members state that they are 'tired' of having to tell their story over and over again. Often agency staff are utilized which do not build the beneficial long term relationships and awareness of individual care needs with residents.

QADA also regularly receives calls from clients who are concerned with the difficulties of communicating with some staff for whom English is not their first language, or who sometimes have different cultural beliefs as to how the elderly are treated. This matter is compounded when the client has hearing difficulties making communicating very complicated which can result in a variety of issues.

QADA considers that it would be beneficial for clients to have more comprehensive guidelines around the number of staff required in residential aged care facilities. QADA receives many calls from clients, whose care is being adversely affected by low staff to resident ratios. Some examples of this include lengthy buzzer response times where residents are left on the toilet for periods of over 30mins, or directed to go to the toilet in their continence aids instead of being taken to the toilet, as well as inadequate assistance with feeding at meal time and lack of continued mobility support as per their care plan.

It has been brought to QADA's attention that there is an issue with regard to criminal history checks of community and residential care staff, in relation to change of employment. The current policy states that criminal history checks only need to be completed every 3 years, which also includes changes in employment. This means that if an incident has occurred within the last 3 years and the employee changes employment a criminal history check will not be completed until the 3 year period has lapsed, therefore incidents of alleged abuse cannot be identified until after employment has begun, causing potential risk of abuse for residents.

Support for Non Paid Carers

It is essential that informal carers have access to appropriate support to enable them to fulfil this valuable role. In remote areas there are some instances where care recipients must be admitted to hospital to receive care when the carer is away from the community. This is not a long-term sustainable option as the solution is dependant upon bed availability at the hospital. In one example, the wife (carer) had to go to Cairns for a specialist appointment and had to leave her husband (client) at home. The wife was concerned for his safety as her husband has dementia. On her last visit to Cairns her husband was found wandering around the community and was admitted to the Bamaga Hospital for his safety. Carers need a break from the constant care of the person they are caring for. Some carers of consumers, particularly those with very high care needs, cannot access adequate respite, or flexible options like overnight care. In remote communities the distances makes it even harder for carers to have a break.

Information and Communication

QADA advocates regularly provide information sessions to aged care staff and clients/residents to raise awareness of advocacy. However often participant numbers are low, particularly staff numbers in sessions provided to residential aged care facilities. This reflects the low importance placed on

advocacy by some residential aged care facilities, who may not understand the benefits or role that advocacy has to play in ensuring resident rights are upheld. This suggests that there is a need for staff at management level to be aware of the benefits of advocacy to ensure a culture of advocacy exists throughout an organisation.

QADA, along with Carers Queensland and Council on the Ageing (COTA), has conducted extensive consumer consultations throughout Queensland over the past 3 years. One of the focus areas of the 2009 consultations was information. Consumers throughout the state have consistently stated that word of mouth is the best form of information dissemination. Many consumers indicated that they are often initially inundated with written information which they do not read until a situation arises when they require the information, but then it can be difficult to find easy to understand information which is specific to their individual needs and situation. This is particularly an issue for consumers from Culturally or Linguistically Diverse backgrounds, who also have the contributing factor of language barriers. This highlights the importance of the availability of information in all languages. Consumers who have visual impairments or those with literacy problems favoured audio information. Feedback from QADA's Indigenous advocates and Aboriginal and Torres Strait Islander communities is that pictures are an effective communication method.

Communication breakdown is an area which continually results in issues for aged care recipients. Lack of consultation and due process for clients in regards to reduction and withdrawal of service provision is a progressive issue in relation to community care and lack of communication between providers' results in issues surrounding accessible and appropriate care services.

Retribution

Through QADA's advocacy work it is identified that recipients of aged care services are often not aware of their rights when receiving a service, and

QADA's experience with its clients is that often care recipients are concerned to speak up about an issue for fear of retribution or being looked badly upon for complaining. This is particularly the case for care recipients in rural and remote areas as well as Aboriginal and Torres Strait Islander communities, where often people know each other and are concerned about who might find out about their issue. Care recipients can also feel more isolated in these areas, and the ability to receive choice of services is often limited due to high waitlists or lack of service provision, therefore care recipients are more unlikely to complain. An example of this is that QADA has been approached by several clients recently whose incontinence aids were being limited by aged care facilities, and the clients were afraid to raise the matter for fear of retribution. In some cases the client's families have purchased additional aids rather than raising the issue with the facility. QADA also recognises the long term impact raising issues can have on the care recipient. By allowing the client a safe and positive option like advocacy to resolve issues rather than to go through the formal complaint process the client feels empowered, communication is established and the client is more likely to raise future issues with their service provider once the advocacy process is finalised. Many clients are not aware of complaint bodies such as the Aged Care Complaints Investigation Scheme (CIS), especially those receiving packages.

Recommendations

From the above observations QADA makes the following recommendations:

1. That the role advocacy plays in supporting consumers to exercise their rights in aged care is recognised and valued
2. That there is more flexibility between aged care packages that are client needs focused
3. That aged care packages are affordable to clients to avoid premature admission into residential aged care due to affordability
4. That waiting lists for aged care packages are reduced

5. That there is greater consistency, accountability and transparency from service providers as to services provided and resources expended
6. That all people have access to appropriate residential aged care, including people with mental health issues
7. That residents in aged care facilities have access to rehabilitation treatment as appropriate
8. That all people leaving hospital have access to appropriate transitional care
9. That there is greater consistency with aged care assessments
10. That there is greater access to culturally appropriate aged care services in remote areas
11. That there is a greater emphasis on recruitment and retention of a skilled aged care workforce
12. That there are stricter guidelines regarding staffing ratios in residential aged care to reduce negative impact on residents care
13. That unpaid carers have access to appropriate care to support them in their role