SUBMISSION TO SENATE INQUIRY INTO AGED CARE 2004

Advocacy Tasmania

Advocacy Tasmania Inc(ATI) is a state-wide advocacy service for people who are frail aged, have a disability including mental illness or are a carer. We auspice both State and Commonwealth Government funded advocacy programs including the National Aged Care Advocacy Program (NACAP) and advocacy for people receiving HACC funded services.

The Department of Health and Ageing funds ATI through NACAP to provide:

- Free, confidential, independent individual advocacy, information and support to residents of aged care facilities, recipients of CACP and EACH packages and their representatives.
- Information and education sessions to residents and staff of aged care facilities, CACP and EACH packages.
- Systemic advocacy to foster improvements in the quality of life of consumers of aged care services.

This submission was compiled from our 15 years of advocacy that has provided first hand feedback from individual residents and family representatives about their experiences as consumers of community and residential aged care services. It also includes information put together from feedback from staff working in aged care services and related academic publications. The submission addresses selected aspects of the terms of reference.

Performance & Effectiveness of the Aged Care Standards & Accreditation Agency (ACSAA)

The assessment made by the ACSAA against the 44 Expected Outcomes is primarily based on documentation of processes and procedures provided by each aged care facility. Although the documentation and accountability process is thought to be ongoing, most homes spend considerable time & resources preparing for each round of accreditation. During the Accreditation Site Audit visits the assessors also speak to some residents and staff members and make first hand observations. The discussions and observations constitute verification of documented evidence for compliance with the Expected Outcomes.

Problems with current system of verification

Residents and Family or representatives:

- Residents are often not aware of their right to contribute to the process of accreditation or understand the level of care required to be provided by facilities to meet each standard.

- Many residents have reported the fact that conditions, activities and staff numbers vary significantly across the accreditation cycle.
- Residents are not aware that meeting many of the 44 outcomes requires a facility to demonstrate a process of consultation with residents /family members. Facilities are thus able to produce a policy or procedure but do not always carry out the consultations such as care plan reviews with individual residents or family members.
- Residents and family members have often been "prepared for accreditation". Comments have been made directly or indirectly by management about the importance of meeting the outcomes and the fact that negative feedback may lead to a poor outcome. Management may also imply the negative outcome to be, "possible closure" of the facility.
- Comments by residents & family members are meant to be confidential but residents fear that staff will know who has spoken to ACSAA and therefore any negative feedback could be attributed to them. Many residents & family fear any form of retribution for speaking up.
- High numbers of people in facilities have cognitive impairment due to dementia (70% in high care & 40% in low care). This means family members or other representatives should to be consulted in relation to care and lifestyle and to verify claims made by facilities. Generally family members report that they have not been informed about the accreditation process or their right to be involved in it.
- In many instances complaints made to the Aged Care Complaints Resolution Scheme (ACCRS) have not been accepted because documentation and staff reports have not been available to substantiate a breach of standards. However, this doesn't mean a breach has not occurred.
- Facilities are not required to inform the ACSAA of the number or nature of complaints they have received from residents or family members. Prior to accreditation the DH&A is only required to provide the agency with a list of complaints against a facility where the ACCRS have made a visit to "investigate" a complaint. This means that other complaints are never recorded and serious systemic issues within facilities may go undetected.

Staff:

- As with residents, staff believe management will know who has spoken to assessors and that any negative comments made will be attributed to them.
- Direct care staff often have little detailed knowledge of the accreditation process or the standard of care required to be provided to residents.
- In many instances staff have not received training or information about residents' rights, complaints processes and the availability of independent advocacy services.
- In many instances staff are unaware of their own rights and are actively discouraged from involving unions in discussions with management.
- During education & information sessions provided to staff in aged care facilities it is common for direct care staff to report that senior management, particularly in large facilities, have little consideration of the day-to-day quality of life of residents. Their concern appears to them to be "how to meet

the standards of care required by the ACSAA with the minimum financial outlay".

- Staff and unions report a cycle of staff cuts following the accreditation round and hiring in the lead up to a round. Staff in some instances have been warned not to speak to Advocacy Agencies on behalf of residents. Direct care staff are aware of the affects of staff cuts on the quality of care provided to residents but they fear for their jobs if they speak up.
- In many instances when residents/family members make complaints about care or quality of life it is the direct care staff who are blamed or made to take responsibility when the cause is often due to a chronic shortage of carers.

Best Practice

A possible way to alleviate the fear of reprisal and retribution expressed by both residents, family members and staff would be for the ACSAA to conduct a mid-cycle survey of all residents/family and staff of each facility. The survey would cover all 4 standards and would help to alleviate the fluctuations in conditions that are reported by many residents and direct care staff.

Residents With Special Needs

A major systemic issue is created by the fact that an aged care facility is able to pick and choose the people it will provide care to. The result is that most choose to admit residents who will attract a high level of funding with minimum demands being placed on staffing hours and direct care needs. These residents will often be those with mobility problems but who otherwise are able to manage their social and emotional needs.

Residents with mental illness or dementia can be demanding on staff resources. When housed with other residents they can often be disruptive and challenging. Situations can arise where the interests and rights of individual residents are in conflict and in extreme but not uncommon instances, a resident's security of tenure may be challenged. Family are frequently asked to consent to a move to "a more appropriate facility", in the interests of other residents. Occasionally residents are sent to hospital because a facility cannot manage their challenging behaviour.

Current funding arrangements need to be reviewed so that additional staff can be employed to enable such residents to remain in facilities. This is particularly true for residents in rural and regional facilities where they have family or are known and supported by the community.

There are a growing number of people with dementia who are admitted to hospital from residential respite care. There may have been an incident, usually behavioural, and the facility has dealt with it by sending them to hospital. The outcome can be catastrophic as people are restrained by medication that can leave them immobile. Many people recover when they are provided with appropriate accommodation and dementia specific care. In some instances people deteriorate dramatically and do not recover. Family members are left feeling bewildered and guilty because they agreed to use residential respite care, often on the advice of GPs or other professionals.

People with dementia who have been cared for at home by a family member can become disoriented and difficult to manage when they are placed in an unknown setting. This is a well-documented occurrence and facilities offering respite should be prepared for the situation. There is an urgent need for more residential respite for people with dementia and other psychiatric illness. This has to be provided in a well-resourced setting where people have advanced training in dealing with challenging behaviour.

Current Funding Arrangements

Current funding arrangements encourage dependency of residents. The higher the level of care required by a resident the higher the funding that a facility can claim for them. However, this must be balanced with the increasing cost of staff required to provide the higher level of care.

A very commonly reported issue or complaint from residents and families is the fact that staff are often slow to respond to call bells to assist residents with toileting. As a consequence many residents have accidents and are then reported as incontinent which attracts additional funding points. Many cases are documented where residents who are aware and able to use the toilet when assisted, are told by staff to urinate in their continence pads. This is an unacceptable practice but one commonly reported by residents & family members. It is also not an occurrence that would be documented by staff and if it were the subject of a complaint it would be difficult to prove except in cases where family members are witnesses.

Another example of this increasing dependence is residents' mobility. If residents who are mobile when provided with some assistance to stand etc and are not being given assistance because of demands on staff time, then they will have falls and/or quickly lose their limited mobility. Immobile, incontinent residents attract a high level of funding and can be assisted and managed by staff to fit their schedule & convenience and not the residents' welfare.

Industry Accountability to Consumers for their Funding Allocation

Australia wide the vast majority of providers of residential aged care services are private not for profit organizations. It has been roughly calculated that on average facilities that provide high level care to a large number of residents can receive over $40,000 per resident per year. Added to this they also receive a minimum of $9,900 in payment from each resident in daily fees. The amount can rise to12,360 for non pensioners. In a climate where many industry representatives are blaming lack of funding for cuts to staff and services, it is not unreasonable for consumers to request greater accountability from providers about how government funds and their fees are spent. Residents/family members would then be able to compare what they say they are spending on services with what they are receiving.

In the allocation and provision of community care to people who receive an EACH (Extended Aged Care in the Home) package (available for people assessed as requiring high care) recipients are assessed and allocated care that is usually provided to them in blocks of time. People receive an average of 15- 20 hours of one to one direct care per week. Many residents in high care facilities would not receive an hour of staff time per day despite the fact that they contribute significantly more for the service.

Depression, Consumer Satisfaction and Models of Care

It is now documented that as well as high levels of decreased cognitive capacity resulting from dementia many residents in facilities suffer from depression. In the report "Challenge Depression- A manual to help staff identify and reduce depression in aged care facilities", it is estimated that 50% of high care and 30% of low care residents suffer from depression. There are many explanations for this high level of depression and it is important to note that a high proportion of people were depressed before they entered care. If the estimates are correct then it is vital as the report states that all facilities should:

- test residents for depression
- ensure medical management is in place
- ensure they have depression sensitive policies & procedures
- provide social networks and emotional support
- create a happy, helpful environment with plenty of appropriate recreation activities

The comprehensive list of rights presented in the Charter of Residents' Rights and Responsibilities paints a picture of opportunities for self-determination within a homelike environment. Such an environment should help to alleviate depression. Anecdotal evidence from residents who are lucky enough to live in a facility that provides "Rights Based Care" report greater satisfaction with their life, the facility and their care.

Unfortunately for many residents in aged care facilities their lives are governed by staff routines. They frequently comment that staff are very busy and that they don't want to be demanding and ask for help. They don't want to speak up and complain for fear of being labelled as a nuisance. Many residents have experienced and others fear reprisal for making requests or complaining about care.

Great inequity exists in the level of care provided between aged care facilities. Much of the difference relates to the 'culture" and attitudes towards residents within facilities. Many residents feel demanding and unnecessarily grateful to staff and have expressed their feelings of worthlessness and a wish to die. In some instances residents in high care receive fewer direct care hours per day than people with equivalent care needs living alone in their own homes.

Research by Ruth Marquis (2002) examined residents' views on quality in aged care services and she sums up her findings in this way:

"Aged care services need to adopt relational ethics as a guiding principle in creating quality services. Relationships with aged care workers may be central in the lives of people living in aged care facilities and their only opportunity for personal validation. Evaluating quality in services needs also to address the daily relational experiences of residents. Recruitment and training of aged care workers need to consider relational competencies as an integral characteristic of quality of care. Relational deprivation and abuse is not addressed by current evaluation procedures."

Conclusion

There is an urgent need to undertake significant research into residents' experiences of aged care and to use the results to inform future directions in the design of facilities and models of care. Increasing numbers of facilities provide care to over 150 residents on a single site. Given the overwhelmingly critical appraisal of various forms of institutional care it is vital to assess the ability of large-scale aged care facilities to meet the holistic needs of frail aged residents. It is questionable whether such large facilities can ever provide a "homelike" environment for residents.

Residents are increasingly older, frailer and have diminished cognitive capacity. They are extremely vulnerable and often lack family to look out for their interests. There is a risk that loneliness, isolation and neglect may be contributing to depression and premature death from despair. Whilst this may only represent the experience of a small minority of residents it is nevertheless vital to establish the factors that contribute to and also inhibit the quality of life of residents. The consumer voice of residents, particularly those in high care, is very weak. In order to qualify as a caring society it must be strengthened, listened to and acted on.

I am available to speak to The Committee at a hearing. For clarification or further discussion of matters raised in this submission please contact:

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References

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Ruth Marquis "Quality in Aged Care: a question of relational ethics?"
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