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Speech by Adam Graycar:

"The right to shelter - elderly people in residential care"

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NATIONAL HUMAN RIGHTS CONGRESS

FIRST NATIONAL CONFERENCE

SYDNEY

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THE RIGHT TO SHELTER - ELDERLY PEOPLE IN RESIDENTIAL CARE

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The looming explosion in social care poses formidable challenges for policy makers in the gerontological area. Policies, programs and services that reflect the interests of our older population, of families of older people, of workers in the aged care industry, and of the community generally would ideally exhibit characteristics of equity and efficiency, of accessibility and accountability, and most elusively of all, they would exhibit characteristics of wide acceptability.

Our residential care system which provides sheltered and supported accommodation for disabled people both young and old, is on the verge of significant and monumental change. The Commonwealth Department of Community Services has made considerable moves in identifying the strengths and weaknesses in the present system, in gathering vast amounts of data, and in considering sympathetically and humanely how people requiring residential care can live with dignity and have services appropriate to their needs.

The changes mooted in the system are based on the principle of rationalizing the number of institutional beds, providing better community support so that people are not unnecessarily institutionalised, providing appropriate assessment to ensure that the services received by people match their needs and, if institutionalised, ensuring that the rights are maintained, that the services they receive are appropriate, and are geared towards enhancing and maximising their life chances.

If, as is the aim over time, the ratio of nursing home beds is reduced from 80 to 40 per 1,000 persons aged 70 or more, then it follows that this reduced proportion of nursing home beds to older people will result in them being filled by people who are considerably more dependent than many of the people who are in nursing homes today. There will be no place in Australia's nursing homes for people who are not highly dependent and who have not been assessed as such. While no more than 4% to 5% of Australia's elderly population (those aged 65 years and over) is resident in nursing homes at any particular point in time, changes in Commonwealth policy will ensure that those who are, will have some physical condition requiring such accommodation. Furthermore, their disabilities and dependencies will require good professional and other support to ensure that their needs are met so they can be maintained at a quality of life that is deemed appropriate. With the high prevalence of older people suffering from strokes, cancers, and Alzheimers disease in particular, strict attention will need to be paid to issues of social justice and maximisation of opportunities and rights.

It is important to recognise that nursing home residents are among the most powerless, most isolated and most dispossessed in our society. Many of these people are unable to organise and lobby on their own behalf. Most people in nursing homes will be

there because they have chronic multiple diseases resulting in progressive disability and impairment, and these realities must be recognised in policy and planning.

While it has been argued that the fall in mortality rate currently occurring may be accompanied by better health and less dependency, the sheer volume growth will ensure a large pool of potential nursing home residents.

Almost half (45.2%) of Australia's nursing home residents are over the age of 85, and all indicators point to an even higher proportion over 85 in years to come. As we look forward to those years, those who will be over 85 over the next 25 years are all with us today, already over the age of 60 with established diet and exercise patterns.

Policy considerations have to take account of philosophical issues, especially of what is expected of our nursing home system. In simplistic terms a continuum can be drawn from basic custodial care to holistic care.

A custodial level of care supports quality of life related programs aimed at keeping the physical, social and mental capacity of each individual to a maximum. A holistic approach

to care focuses on the positive aspects of life, on a state of high resident satisfaction.

Any choice involves a philosophical stance of what is desirable for our older population and ideally a commitment to back that stance with tangible resources. As well as providing tangible resources there needs to be some tangible product that describes, demonstrates and codifies residents rights in this situation.

Many residential institutions have a code of practice or a code of rights. What should be included in such a code? There should be statements which address personal and social issues, physical environment, and staff management issues. The Centre for Policy on Ageing in England has developed a comprehensive Code of Practice for Residential Care which includes some of the following:

- . Residents should have a signed agreement which states the terms and conditions under which the accommodation is offered. This reinforces the fact that the resident is buying a service and is entitled to rights and protections as in any other such exchange.

- . Residents should be able to see their visitors, wash, dress and use the toilet in private, as they would do in their own home.
- . The staff and management of the home should not become involved in the residents' financial affairs.
- . No medical treatment should occur without a residents or guardians valid consent.
- . Residents who are able to look after their own medication should be encouraged to do so.
- . Medication should not be administered as a means of social control.
- . All homes should have a complaints procedure.

The Commonwealth government has recently prepared a booklet entitled Living in a Nursing Home - Outcome Standards for Australian Nursing Homes. In this booklet there are seven objectives and each of the objectives has attached to it a set of measurable outcome standards which are not dissimilar to a code of practice.

The objectives are categorized under:

1. Health Care
2. Social Independence
3. Freedom of Choice
4. Homelike Environment
5. Privacy and Dignity
6. Variety of Experience
7. Safety

To take one example, under Social Independence the sub-objectives include freedom to maintain friendships; freedom to manage financial affairs; freedom to come and go; freedom to practice religious or cultural customs; freedom to maintain obligations as citizens. The appropriate Outcome Standards propose that residents be enabled and encouraged to have visitors of their choice and to maintain personal contacts; that residents be enabled and encouraged to maintain control of their financial affairs; that residents have freedom of movement within and from the nursing home, and that they be restricted only for safety reasons; that provision is made for residents with differing religious, personal and cultural customs and so on.

All of these proposed outcomes involve freedoms and personal values which we would never question as applying to people living in their own homes. Institutional living has such an enormous impact on a resident's life that we need to ensure that structures are created to ensure that their rights are recognised.

As was mentioned earlier approximately one half of Australian nursing home residents are aged 85 and over. The incidence of disability, illness, and in particular incontinence, immobility, and dementia is very high for this population.

Conclusion

We are dealing with a population whose structure is changing so that the proportion of very old is increasing and the incidence of many of the disabilities associated with age is increasing. If we are to assume that nursing homes should be about people and not just responding to their disabilities then we should examine several approaches that can be taken to try to maximise the rights of these people. First of all a charter of rights is essential for all residential facilities. I quoted

earlier from one such charter of rights and in the South Australian Ministerial Task Force (referred to a moment ago) two other charters of rights were listed. It should be mandatory on admission for senior staff to spend time with the resident and her or his family to go through with them the charter of rights explaining the rights and the obligations.

Another area is the development of a clear and coherent policy on the role of professionals in nursing homes. There clearly needs to be a policy on the role of medical practitioners in nursing homes, and on the activities of nurses, social workers, physiotherapists, etc.

As things now stand nursing home residents usually have no avenues of complaint and little awareness of any right to do so, beyond the administration of the nursing home. Both the Commonwealth and the South Australian Governments are considering the development of complaint mechanisms. Given that most residents are relatively powerless, any such mechanism must include an advocacy process which is both pro-active and re-active.

While every encouragement should be given to organisations to develop internal procedures for resolving disputes, there will also be a need for an independent forum to consider disputes which the internal processes do not resolve.

Of course, in a perfect world we would not need a complaints mechanism, but given the complexities of a pluralist society it is essential to set some parameters for everyone's protection.

To achieve a better deal for nursing home residents, to acknowledge their continuing rights as members of a democratic society, some major changes have to take place.

- . Each nursing home must have a charter which acknowledges the rights and responsibilities of its residents;

- . The charter must have a procedures document which demonstrates the 'practice' of these rights and establishes practices for resolving disputes and complaints of both residents and staff;

- . There must be acknowledgement of the need for an independent advocacy system which involves or is available to the resident, to family and to friends. The system should include training, education and support, should increase awareness of all groups, should focus on empowering (or re-empowering) the residents, and on achieving an equitable resolution of any difficulty;

- . There must be acknowledgement of special training needs and attitude change of staff, which includes both physical training for the dependencies involved and knowledge, awareness and acceptance of residents' total needs and the social skills needed to respond appropriately;
- . Staffing levels must acknowledge the special needs of the residents;
- . And finally, but not lastly residents must be represented in the decision making process within their own nursing homes.

They must not have change imposed on them as a result of any perfectly reasonable and laudable philosophy established by policy makers and administration.

The implementation of changes such as have been discussed should only take place following informed discussions with the residents. If change is imposed, with an "ends justifying the means" philosophy, this then becomes further evidence of the residents lack of power, and the imposed changes merely reinforce the existing imbalance.

We are faced with changes in the structure of our older population, and with changes in the institutional bed ratios which will lead to residents being admitted with increasingly greater physical and mental dependencies. As these changes take place we need to be aware of the impact of admission on the residents and to make it a priority to initiate practices which acknowledges the rights of each and every individual.

Institutional practices must be based firmly on the presumption of the continuing rights of every person, irrespective of their mental or physical ability to assert them.