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Speech by Adam Graycar:

"Basis for genuine consultation in aged care services"

presented at the Fourth Australasian Masonic Conference of Aged Care, Adelaide, 11th November 1987

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FOURTH AUSTRALASIAN MASONIC CONFERENCE OF AGED CARE

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BASIS FOR GENUINE CONSULTATION IN AGED CARE SERVICES

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In recent years we have seen significant and monumental changes in the fundamental make up of our society. More than one in four Australians is aged fifty and over. People today are in general having fewer children and are living longer than ever before. We have greater life expectancy at birth and at all advanced ages and substantial declines in age specific mortality rates at higher ages. The fact that there will be a substantial increase in the seventy-five plus population has huge implications in the provision of care. By the year 2001 it is expected that the population aged seventy-five plus will increase by seventy percent. The eight-five plus population is likely to increase by eighty-two percent. But not all old people and disabled are dependent.

The elderly population comprises a group spread across thirty or more years of life. In essence we have and will continue to have two older populations each defined as old - with very different and incompatible definitions. One population, (comprising people roughly aged over sixty-five and under seventy-five) is deemed too old for the paid labour force, and the other (comprising people aged seventy-five and over) is deemed too old to participate physically and emotionally in mainstream society. We are facing two explosions - an explosion of perceived uselessness and an explosion of care.

As we are faced with an explosion of care we can see the traditional care providing organisations - governments, community agencies and families are all under great pressure.

No one sector alone can provide all that has to be provided, not governments, not community agencies, not families. It would be naive to assume that any one sector can produce all the wonders we talk about. Any crisis of care can be addressed only by a partnership of government, community agencies, and families. The first step is to produce a genuine basis of consultation - not only for the provider but also for the consumers - those elderly people that make up our client group.

Families have the willingness but not the capacity to provide the care and support that is required. Governments have the capacity, but not the willingness. Although the bulk of care which is provided does come through the family, policy makers must ensure that boundaries of capacity are carefully understood and that unrealistic expectations of family care do not become the norm.

In aged care, what we are about is something broader than health care - we are about a total life enhancement and enrichment process - about ensuring adequate income, good social and community services that foster involvement and inclusion, and maximising social benefits in a personal rather than governmental manner. This involves, by and large determining of a structure of benefits and their distribution. This is intensely political, for there is often great disagreement about why anything should be allocated, what it is that is allocated, who the recipients ought to be, how generous the allocation ought to be, who should do the allocating, and how it might be financed. We are allocating residential care, health care, life enrichment, and most of all, money. We need to consult widely.

This is the basis of planning aged care policy in Australia - who gets what, when and how. The issues are clearly political.

The aged care industry is facing a crisis of uncertainty. Everything about it reflects the changes in our changing world - greater longevity and longer life expectancy mean more years in which to live but also more years in which to die. Dependencies are greater - disease patterns more entrenched and chronic, yet our professionals rarely rise to the task, and when they do they are often disparaged for doing so by those who see the solutions as a bit more tender loving care rather than professional support. No wonder the professionals in the industry have a morale problem.

Our administrators in aged care need to be highly skilled managers. They manage, not only the lives of many people, but millions of dollars of plant and capital and numerous staff. They're faced, almost daily, with gigantic changes in the rules. At one stage it was thought that being a kindly do-gooder was all that was needed. That clearly is no longer on.

Our residents are becoming more aware of their rights - and rightly so. Right across the aged care spectrum consumers have at times been patronised and exploited. Clients' conditions and life experiences are in a dramatic change process.

I have only mentioned staff, administrators and residents. All are struggling with changing rules, changing expectations and fewer and fewer dollars.

You really don't need me here today to make the point that it is sheer lunacy to undertake these changes without significant and meaningful consultation.

Individuals and groups make claims for well-being on the state, on their families, on employers, on their communities, and the future well-being of the elderly population depends on how these claims are presented, and on the capacity and willingness to respond, by those upon whom the claims are made. Elderly people make claims mostly for an adequate income, for appropriate living arrangements, for high quality services, for independence and dignity, and for institutional responsiveness and a sympathetic attitude towards ageing. Sometimes governments initiate and sometimes they respond. A good political nose will know when we are in the initiation mode or in the response mode.

Ageing is big business and big politics. The big political issues relate to the claims that are made in our society and the response to those claims.

There are four major delivery systems which can act on these claims, the statutory system, the commercial system, the voluntary system, and the informal system and politically and socially we have not been able to determine authoritatively, how they should relate to elderly people.

One of the main issues is to ensure that the things we care about, the items of importance get onto the policy agenda. Different strategies are used to get things on the agenda, and they all reflect levels of consultation. The greater and more genuine the consultation, the less the trauma and drama. Three types of change strategies can easily be identified, a co-operative strategy, campaign strategy, and contest strategy. The extent to which the various strategies are used depends on the amount of consensus that is deemed to exist, or that is deemed desirable.

A co-operative strategy is appropriate when there is a fair level of agreement about the general nature of the change objective; boat-rocking is not desirable, and the problem is to develop through co-operative methods the best course for achieving the agreed-upon objective. The tactics most generally used are rational planning, action research, consensus decision-making, genuine fact-finding studies and so on.

A campaign strategy is appropriate when there is no consensus on the need, and no will to move ahead towards mutually agreed objectives, but when it is believed that agreement can be achieved through persuasion of some sort. In campaign strategies the popular tactics are advocacy research, educational and propaganda campaigns, proselytising, 'consciousness-raising', rational persuasion and emotional appeals.

A contest strategy is appropriate where there is a basic disagreement about a change objective. In order to achieve that objective those who oppose it must somehow be defeated. The methods used here are the organising of opposition groups, appeals to third parties, disruption, and violent/non-violent action.

What we're really on about in the development of aged care is the making of and response to claims.

To make sense of the claims, and as a background to consultation it might be helpful to note three sorts of lobbies as part of the claim structure. First, there is the "direct interest" type. Claims are made by those who are the potential recipients and who thus have a direct interest. The "direct interest" lobby can be divided into two parts - a recipient section, the old people themselves, and a provider section. "Direct interest - recipient" groups include major organisations like the Australian Pensioners' Federation and the Australian Council on the Ageing, as well as many smaller organisations with limited interests. Activities include developing campaigns and pursuing them with varying degrees of intensity, deputations to Ministers and other political figures, and publicity dissemination through community radio and newspapers. "Direct interest - providers" include lobby groups such as the Voluntary Care Association, the Private Hospitals and Nursing Homes Association in Australia, the Australian Medical Association, groups within the pharmaceutical, health insurance, and medical and hospital equipment industries. Industry lobbies have been profound in shaping residential and medical care policies directed towards elderly persons.

Second, there is an "executive initiative" approach, where expansion and increases in benefits come from, the authorities (for whatever reason).

The "executive lobby" covers politicians and bureaucrats, and the policies they propose and support vary with dominant political agendas. In Australia the executive lobby played a large part in the introduction of the age pension, went quiet for a long long time, and now is trying to assert itself with vigour and strength. What's in it for the politicians and bureaucrats? The rewards obviously are many and varied.

Third, there is the lobby of "conscience", comprising persons and groups acting out of a sense of noblesse oblige the do-gooders - those who have nothing to gain directly, other than the satisfaction of their humanitarian aspirations by positive social pay-off. This lobby includes individuals in the churches, voluntary organisations, professions and academics who possess a sense of social justice, a belief in a reduction of inequality, and a hope for a better social future. This forms the basis of their activism.

Anybody with an interest can identify the players, sort out roughly what they're on about, identify their tactics - do they have a co-operative strategy, a campaign or a contest strategy? Are they part of the direct-interest lobby - the executive lobby or the do-gooder lobby? The thread that links it all together is the degree of participation and the amount of consultation.

All of us in this industry have different skills and resource, but probably most important of all, different amounts of information. This is where participation and consultation are tremendously important.

Our political system emphasizes the formalized means of participation - voting, pressure group activity and individual representation to relevant authorities.

While it is widely accepted that increased participation is desirable very few opportunities are given by powerholders to participate. We all want to participate.

Participation simply refers to a process whereby people who are neither elected nor appointed officials of authoritative bodies influence decisions about programmes and policies which affect their lives.

On the overhead is a ladder of citizen participation containing eight rungs going from manipulation, therapy, informing, consultation placation, partnership delegated power, to citizen control.

Halfway up the ladder is consultation - a sensible mid point between manipulation and citizen control.

Consultation is not an activity directly linked to the decision making process; it is not designed to allocate resources; it is not designed to be advisory to any one person or officer; it is not designed to be a pressure group. It is in short, a process facilitating open discussion, careful deliberation, and effective conference. Consultation will need to have some influence on administrative and policy issues if it is to be meaningful. It is concerned with influence but does not involve the exercise of power.

Consultation brings together those who plan the services, those who deliver them and those who receive or consume them. In the field of ageing these unfortunately are three distinct groups with very few linkages between them.

We all find ourselves caught in the middle in this consultation business. We've all been accused of not consulting sufficiently and yet we've often accused others of the very same thing. How often have your staff muttered quietly or confronted openly about decisions you've made without consultation? How often have your residents had changes thrust upon them without adequate consultation?

When the boot is on the other foot I seem to get a steady run of representations about government operating unilaterally and with insufficient consultation. The present exercise of the Commonwealth's massive changes in the nursing home industry is one example. The Feds say they're consulting. People with whom they consult say "sure, they hold meetings, but they're not to listen, but to tell us what they believe. Then they go back to Canberra and tell their Minister they've consulted - it really is a joke!". Many of you were involved in the consultations over SAM and more recently over CAM. Here in South Australia we received four volumes of paper a day or two before the consultations, and many who went were really ill-prepared. The consultation didn't seem genuine, and the Voluntary Care Association motion pointed that out.

Of course there are some areas in which there is no pretence even at consultation. The implementation of a peculiar brand of normalisation seems to have defied us all. A group of self-appointed experts, with no background in aged care have learnt a few funny words, organised a few indoctrination workshops and presto, brought down a new philosophy of aged care. If we strip away some of the absurd jargon they are advocating what our good professional practitioners have been doing for ages - and doing well. It is not the practice that bothers me, but the process. For people who advocate consultation and shared decision-making, the heavy jackboot techniques used in their training workshops, and in their patronising attitudes towards clients is quite mistifying.

My Office has had numerous complaints from nursing home residents and their relatives and from staff working in nursing homes which have gone down the normalisation path. Complaints have included the removal of a public address system because it is 'not normal', refusal to allow elderly incontinent residents the use of a commode because it is 'not normal', the hiding of wheelchairs, because they are 'not normal'. What I object to is the imposing on older people without consultation the values of trendies who have no experience in aged care, and whose perceptions have been developed by attendance at expensive evangelical courses, masquerading as education workshops. There's not even a pretence at consultation in this normalisation exercise.

In something a little closer to home the State Government has recently passed the Retirement Villages Act. In our attempt to develop suitable, workable and equitable legislation we consulted, and we consulted, and we consulted. Several of you here today were involved in the process. Notwithstanding our efforts at consultation and our genuine willingness to listen I've had occasional comments back that the process wasn't fully workable.

Many who claim that government doesn't consult adequately often don't consult adequately with their residents. Residents are often treated formally and dealt with in a legalistic manner with no genuine consultation about their rights. The Act requires that residents' meetings are to be held annually, but if the residents aren't organised, it's all fairly shallow as a consultation exercise. We're seeing the establishment of residents' committees in several retirement villages, and SACOSS is presently drawing up a draft constitution as a model for residents' associations. This is one element in providing a genuine basis for consultation.

Perhaps there is something wrong with the nature of the consultation beast. We have to distinguish, I suppose one-off specific item consultations, and ongoing process consultations. In the Office of the Commissioner for the Ageing, we are involved in both.

There is a great danger that consultation could become a one-way affair, an exercise in window dressing and futility. This can happen if the authorities see their place in the Westminster system as sacrosanct, and become reluctant to share information, reluctant to respond promptly to questions and requests from participants in the consultative arrangement as credible actors.

In discussing the context then it can be argued that meaningful consultation involves a retreat from aloofness and secrecy, and further that it involves some inconvenience to the bureaucratic staff. This inconvenience is a necessary and basic price that must be paid by the authorities if the consultative process is to be a genuine process. Procedures have to be indentified for

- a. establishing any consultative body, and
- b. its operations after establishment.

In general a consultative body can hope to:

1. Act as a mechanism for consolidating diverse views into an opinion for the authorities;
2. Promote public input into decision making;
3. Provide an opinion (which can be evaluated) on issues of concern where conflict exists;
4. Provide a means of raising new issues which arise from local feeling and analysis.

Different participants in the system have different objectives, and different expectations of any consultative arrangement. Some want to deal with planning and future development, some want to deal with immediate issues of funding, some want to make sure they are listened to, some want to make sure they can do the listening, some want to listen but not hear, some want to acquire information, some want to disseminate information and so on. In developing consultative arrangements it is necessary to be clearly aware of the objectives and interests of the whole range of participants.

Both sides must approach the venture, not as a contest, but rather as a co-operative arrangement, and in this light, consultation will require a slight retreat on both sides. This slight retreat will clear a space for co-operative activity. One example here, might be moves for greater information sharing, and this combined with an approach which treats other participants as participants, and not as contestants, might provide a worthwhile start.

There should be:

- * a clear determination of the scope of consultative activity;
- * a clear definition of goals;
- * trust among the various participants;
- * continuity and flexibility of procedures;
- * openness of discussion; concentration of real issues;
- * some political influence on policy;
- * a guarantee of suitably representative membership;
- * the availability of sufficient resources, together with the time needed for adequate discussion and action on consultative items.

The major pitfalls of consultation are the need to avoid the generation of unrealistic expectations; the importance of avoiding tokenism; and the need to refrain from politicking.

In this way the many big issues confronting us today, and in the future, issues of appropriate accommodation, transport, health care, home support services, recreation and leisure, work and retirement, and many more, can be analysed and acted upon in government, with the knowledge that opinions and experiences broader than those of the experts are considered.

Consultation is about identifying need, and this is a complex activity, with interest groups working hard at demonstrating need on behalf of their members. After all, why are we in this business? To respond to need, most people would say. An enormous literature has developed which derives, describes, defines and dissects the concept of "need". One must always be clear on the distinction between a need, a condition, and a problem, for conventionally policy prescriptions are aimed at need, sometimes at problems and less frequently at conditions.

Need is a relative concept.

There is need as defined by the expert, professional, administrator or social scientist. A desirable standard is set and compared with a particular situation. If an individual or a group falls short of the desirable standard then they are identified as being in need. For example, not having a certain level of income, or a certain level of functioning, or a staffing level in a nursing home are situations of need defined by experts as they draw poverty lines or functional charts. The individual may well get by comfortably or adequately, but the expert has drawn the line. On other occasions the expert may draw the need line too low.

There is need as perceived by an individual.

When assessing need for a service, people are asked whether they feel they need it. There are all sorts of complications about whether people know about the services they want, whether they are modest or excessive in expressing their wants (most older people are amazingly modest), and whether they're able to do anything about it.

Then there is need that is based on comparisons with others. If two people have similar incomes and similar levels of dependency, and if one is in a hostel and the other not, is the second in need? I'll let you work that out. I've seen some pretty basic residential facilities here in Adelaide. Compared with some of your places are the residents there in need? Would we say the same if we compared them with some exceptionally basic facilities I saw in Asia recently?

Understanding the different views about need is crucial to a genuine consultative arrangement. We have the experts perception, the consumers' perception of need and some comparative views too.

In a consultative arrangement we throw them all into the melting pot, add a bit of understanding of the backgrounds to the lobbies - the consumer and the provider, the bureaucrats and the do-gooders, sort out whether they're all going to be co-operative or get into campaign or contest strategies, and listen, listen and listen.

Bearing all of this in mind I like to think that we understand the basis for good consultation, and work hard at listening and passing around the messages.

One of the functions specified in the Commissioner for the Ageing Act, 1984 is to reflect the views and opinions of elderly people in the formulation of strategies and policies that affect their well-being.

There are two functions within the Act specifically related to consultation.

The Commissioner is

" to consult and co-operate with other bodies and persons that assist the ageing "; [Section 7(1)(k)]

and

" to consult with the ageing in relation to the means of promoting their interests and to represent the views of the ageing to the Minister "; [Section 7(1)(m)].

At a formal level, there are presently five formal committees which articulate and interpret views of the various types of lobbies to the Commissioner:

- * The Older Persons' Advisory Committee,
- * The Education Advisory Committee,
- * The Advisory Committee on Ethnic Aged Issues.
- * The Nursing Home Reference Group
- * The Age Discrimination Task Force

Other committees are under consideration.

The Older Persons' Advisory Committee grew out of my wish to have a strong representative group with which to consult on the major issues affecting older South Australians. It is a forum which meets at least quarterly and provides a good two way flow of information. It has as its base the South Australian Consultative Council of Pensioner and Retired Persons Associations, and representatives from other organisations have been invited to join the committee.

Matters brought to the committee cover a wide range of issues that impact on the ability of elderly people to maintain a satisfactory quality of life. Those issues of importance include the averaging of non-pension income, pharmaceutical benefits, the \$250.00 tertiary administration fee, retirement income maintenance, hospitalization issues, the erosion of concessions on property rates, entrepreneurial medicine, road safety, retirement villages legislation, access cabs and land tax issues, just to mention a few.

I don't want to go through the process of listing all the details of each of our committees.

CONCLUSION

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