Speech by Adam Graycar:

"Home and Community Care program"

presented to the Australian Nursing Home Association Seventh National Congress, Sydney, 8th August 1988

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THE HOME AND COMMUNITY CARE PROGRAM

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When faced with the complexity of our aged care system, it seems not unlike making a big, well-filled sandwich. We start with square bread, round ham, a rectangular slab of cheese along thin pickle, slices of tomato, chopped celery, shredded lettuce—we cut it diagonally, and then set butter and disappointed if any fell on the floor.

We have to think about making not only about making sandwiches, but also creatively thinking and academic psychology colleagues were doing cognitive tasking on a sprightly 90-year-old. In his patronizing manner, my ex-colleague said to the old fellow: “Can you tell me, how many plays in 10 weeks start with T—2—very good + can you tell me what play am—see, today’s program 2nd, here’s a hand on—how many records in a year—quick as a flash—12-second 드.
It is now a cliche to repeat again and again, that our population is ageing. In planning for this ageing population there are many key indicators which require analysis. One such indicator is survivorship. Understanding the indicators helps us formulate and comprehend the policies. The Home and Community Care Program (HACC) is a response to our changing age profile and survivorship rates.

Medical science has been able to keep people alive for longer than ever before, but their survivorship is often marred by loss of function, frequent pain, and constant isolation. In many cases such people move into nursing homes but in many cases we have no option to supporting people at home, and HACC makes the most of it. We have HACC because we have greater survivorship than ever before. In earlier times people did not live long enough to be dependent. Now our survivorship rates have changed dramatically.

Most people in Australia live beyond the traditional retirement age. Three quarters of all the boys and 86 per cent of all the girls born 65 years ago are alive today. Most girls born 80 years ago are still alive today (57 per cent) as are one third of the boys born 80 years ago. When we look at our 85 year olds, the proportion surviving to age 85 (almost 40 per cent for females and 20 per cent for males) is four times that which prevailed at the beginning of this century, and the proportion surviving to 75 is double that of the turn of the century.

| TABLE 1 |
While most older people are neither sick nor disabled, there are many who are, and the chronicity which comes with advanced age is rarely transitory or reversible. In many cases your moving parts don't move as well, and bits and pieces wear out. As they say, everything put together falls apart sooner or later. This loss of function has often been ignored in our ageing strategies.

I could reel off statistics on incontinence, diabetes, immobility, osteoporosis, dementia, and a whole host of other health losses which are exacerbated at advanced ages, but that would make me sound too much like an academic. The point I want to make is that the development of more nursing home care is not the most appropriate response to these high survivorship rates, or loss of functioning. As things now stand, over 90 per cent of people in the 80-84 age group are not in nursing homes, over 80 per cent of those in the 85-89 group are not in nursing homes and two thirds of those in their 90s are not in nursing homes. However, even to maintain these current proportions, given our rapidly increasing survivorship rates, we cannot look to equally rapid growth in the nursing home sector. But, given the certainty of loss of function and health and general living problems of many of these survivors, two courses of action stand out.

The first involves a greater commitment to primary health care,
health promotion and illness prevention, so that incontinence, diabetes, osteoporosis and many other conditions are not to be expected, regarded as a normal consequence of ageing and shrugged off as inevitable. Primary health care is being debated vigorously in Australia at the moment, and in South Australia our State Government has indicated its strong commitment to primary health care and health promotion.

For too long we have been defining health in medical terms – as a commodity to be purchased from the medical profession when running repairs are required. Rather than seeing health in negative terms – as the absence of illness, we should look positively to health as an asset, a state of physical, mental and social well-being, and achieving positive health is a social goal requiring substantial political action.

But setting in place long term strategies is not much help to those who now have health losses and difficulties in living independently, and so the Home and Community Care Program has a big role to play. We all are aware that different people have different needs and that no one solution is applicable to all situations. Twenty and thirty years ago, however, there seemed to be only one government sponsored solution, and that was the nursing home system. The government said to the voluntary sector "you hatch it - we'll match it" and it guaranteed the profits of the private sector, so much so that at that time nursing homes were a tremendously lucrative business - good returns, no planning by government, no accountability by operators. There was no ageing strategy. There were no long
term plans, there were no prescriptions of service style. There were no commitments to excellence. Twenty and thirty years ago survivorship rates were lower as was loss of function.

Eight to ten years ago I was making speeches saying that for every dollar the Commonwealth spent on supporting older people at home it spent ten dollars on supporting people in nursing homes, yet for every person in a nursing home or hostel there were 15 elderly people at home. There had always been a lot of rhetoric by politicians and academics saying that the home care to institutional care ratio was ill conceived, there were reports - kilos and kilos of them taking up so many metres of bookshelf space, saying that there ought to be more resources put into home care.

The reality is, and always has been, that the nursing home system - and your sector in particular, is only one part of the ageing enterprise. Lots of dollars go into nursing homes, about $1.22 billion this year, but most older people do not have any contact with nursing homes. Most sick old people have no contact with nursing homes. Most disabled old people have no contact with nursing homes.

As I said before the dependencies of old age are progressive, and thus contact with the nursing home system comes in most cases well down the line after contact and experience with other support and health agencies. As an industry it is necessary for you to be aware of the general and specific operations of the other systems that impact on your clients and
potential clients. HACC of course, is predominant among these.

As I said, the pundits had always been saying that the balance between home care and institutional care was inappropriate but nobody ever thought much would happen. I can remember, on March 2, 1983 I sat with John Gillroy and about 50 other people in the front room of the Social Welfare Research Centre at the University of New South Wales to discuss the McLeay Report and to determine whether it was really a goer. The Federal Minister at the time Senator Chaney had indicated general support, and the Opposition spokesman Senator Grimes was non-committal.

The report was tabled in October 1982 after receiving 221 written submissions and the testimony of hundreds of witnesses, including John Gillroy, the only witness to appear three times. It recommended all sorts of strange but logical innovations. Once you open a can of worms the only way to recan them is to use a larger can.

The basic recommendation was that the numerous federal programs be reduced to two - an Extended Care Program and a Nursing Home Care Program, and that one minister handle both programs. It was recommended that the Nursing Home Program have growth control procedures, that there be assessment for nursing home entry, that the deficit finance arrangements be abolished, and that all nursing homes be subsidised on a uniform basis, and that there be equity among the states. In very simple terms it was CAM SAM GAT and freezes in Victoria and South Australia.
The other recommendation, that there be an Extended Care Program, did not get any nice acronyms like SAM or CAM - it got the unfortunate acronym, HACC. One interesting sideline was that McLeay recommended that the Nursing Home Program be cost-shared with the States (and ultimately transferred) while the Extended Care Program be funded totally by the Commonwealth. In the end, the reverse has been the case, but one can never underestimate the importance of federal/state relations in such matters. We always have to move carefully - remember, it takes longer to glue a vase together than to break one.

The HACC program came into effect in 1985. The aim of the HACC Program is to enhance the independence, security and quality of life of frail aged and younger people with disabilities through avoiding inappropriate admission to long term residential accommodation, by facilitating and promoting the development of cost effective community care alternatives appropriate to, and according to, need. It seeks to provide a comprehensive range of integrated home and community care services for persons within the target population where possible and appropriate. Of course such services are not always possible or appropriate.

The Program is directed towards assisting those persons living in the community who, in the absence of basic maintenance and support services provided under the HACC Program, are at risk of inappropriate admission to long term residential care, including

- frail or at-risk aged persons, being elderly persons with moderate or severe disabilities;
younger disabled persons, being persons with moderate or severe disabilities;

such other classes of persons which are agreed upon by the Commonwealth Minister and State Minister; and

the carers of those persons.

A person is considered to have a moderate or severe disability if assessed as having difficulty, without personal assistance or supervision, in performing any of the tasks of daily living, such as dressing, preparing meals, house cleaning, home maintenance or using public transport.

The Program is intended to provide basic maintenance and support services appropriate to the needs of the individual and sufficient to sustain one, in a cost effective manner, within the community. It is very difficult to assess the relative costs of maintaining somebody in the community compared with supporting them in residential care. Professional support at home, on call 24 hours a day, and often involving multiple visits certainly is not cheap. My former colleague at the University of NSW Tim Philips captured my imagination some years ago with an informative seminar on the relative costs, entitled "Cheaper isn't always less costly." In addition to financial costs there are emotional costs. It is not always financially or emotionally cost effective to keep somebody at home. Many dependencies expect residential care as a natural response.
For the purpose of HACC, 'basic' maintenance services are those services essential to a person's well being; for example, nutritional food, functional housing, community nursing, home help and personal care. Support services such as information and training packages allow for a great level of understanding and expertise to be built up within the service provider and service user community about the care of the frail elderly and younger people with disabilities.

HACC is not intended to address intensive care needs of the kind which could more appropriately be provided in nursing homes or other residential settings. Service providers should ensure that through the close monitoring of, and in consultation with, service users, referral to other appropriate services takes place as necessary.

The types of services eligible for funding under the Program are:

- home maintenance or modification (or both)
- food
- community respite care
- transport
- a community paramedical service
- community nursing (which may include personal care)
- assessment or referral (or both)
- education or training for service providers and users (or both)
- information
. co-ordination
. such other service as is agreed upon by the Commonwealth
  Minister and the State Minister.

Each of these services can usually be provided either in a
person's home, or in or from a community based centre. Most
HACC funding has gone to established services such as home
nursing, meals on wheels, home care or domiciliary services and
locally based community care workers, though there has been
considerable scope and backing for innovation. Substantial
funds have been made available since 1985 for new and innovative
projects in addition to the solid basics.

We're quite proud in South Australia of the progress that has
been made. The first project we funded in November 1985 was for
the purchase of a bus for the Penola War Memorial Hospital, and
the most recent, the 230th just last week, was $268,080 for the
establishment of a continence advisory service.

The bus purchase was to bring older people to a day care
program, the continence service to keep old people dry. Both of
these, and the 228 projects in between have a significant impact
on your services. Success in keeping people in the community
and having transport to a day care program will have an impact
on the profile of your residents. Success in controlling
incontinence will have a monumental impact on you all.

Given that incontinence is one of the main causes for admission
to nursing home accommodation, given that incontinence causes
laundry bills to skyrocket, given that about a quarter of nursing time is spent managing incontinence and given the tremendous impact on individuals, the importance of HACC funds spent in this area cannot be underestimated. We still have a long way to go on incontinence, especially in prevention, assessment and treatment, especially long before people contemplate a move into a nursing home. The incidence of incontinence among Australian nursing home residents is around 60%, yet the main effort expended on their behalf is mopping up.

The HACC program has delivered a lot, but the resources available are quite limited. Since 1985 the funds available for HACC have doubled to $300 million yet there is still an enormous amount of unmet need. The program is difficult and cumbersome, and while less than 2% goes in administration the convoluted nature of the agreement and the astounding complexity of the proceeding make grown people almost cry. It is Murphy's Law writ large "If anything can go wrong, it will." And of course there are the corollaries - "Nothing is as easy as it looks" - "Everything takes longer than you think." - "If it jams - force it. If it breaks, it needed replacing anyway."

In the first two years of the program, 1178 new projects and 487 extensions of former projects were approved. That is more projects than there are nursing homes in Australia. And while nursing homes provide much the same thing, these 1665 projects are enormously diffuse and diverse. In addition to these 1665 new projects, 2380 former Commonwealth funded projects were subsumed into HACC when the program began. Every one of these
4045 projects was negotiated, not just with one, but with two levels of government. The nursing home negotiations almost look simple, straightforward and easy in comparison. I'm sure you're all aware of Murphy's golden rule - he who has the gold makes the rules.

Our first 200 projects were packaged up in 17 packages each containing an average of 12 projects. As a joint federal/state program, each package required the approval of both the State and Federal Minister. On average the turnaround for our State Minister to approve a package was 5 working days. For Commonwealth Ministerial approval, the average turnaround time was 28 working days. We all grizzle about the process and all think it could have been a lot easier, yet the results speak for themselves.

Notwithstanding resource limitations there has been a substantial growth in HACC and a commitment of expanded resources. When the Program started in 1985 the Commonwealth spent $941 million on nursing homes and $78 million on HACC, 12 nursing home dollars for every HACC dollar. This year the Commonwealth is spending $1.22 billion on nursing homes and $177 million on HACC, 7 nursing home dollars for every HACC dollar. (The States are matching the Commonwealth's HACC contribution with a further $130 million). In these 3 years Commonwealth funding for nursing homes has increased by 30 per cent, and for HACC services by 127 per cent. As a comparison, the total Commonwealth budget has gone up by 23 per cent and the number of nursing home beds by 1 per cent. If properly planned and
managed this change in emphasis will have a profound impact on your client group. Your dependency profile will have to get heavier, and if HACC is successful the conditions and disabilities of residents should change.

In South Australia, for example we have a strategic plan for HACC for 1988 which has the following priorities
- transport
- information
- carer training and support
- respite care
- home maintenance
- paramedical services
- continence services

On the basis of these priorities an expenditure plan is developed for project development on a regional basis. The HACC agreement is presently being reviewed and of concern are what have been deemed "no growth" areas, rehabilitation services, post-acute care, and palliative care. HACC funded services are not provided to people in residential care settings who receive Commonwealth subsidies, though they are provided to residents of retirement villages.

The point I want to get across is that we should all be well aware of our home care services, their strengths and weaknesses, their achievements and their limitations and the
socio-demographic and epidemiological bases from which they function. Nothing in our service system can operate in isolation. If a piece of string has one end, then it has another end. Every service has an impact on every other. When it's done well we talk about successful inter-sectoral collaboration; when not, about overlap, duplication and bureaucratic overkill.

In Australia we have about 75,000 people living in nursing homes. We also have about 75,000 people over 65 who live as "ancestors" mostly with their adult children. The family clearly has not abandoned elderly people.

Notwithstanding current thrusts in family policy it is obvious that the family cannot play all of the roles which are found within formal services. Changes in demographic patterns, marriage rates, life expectancy, fertility, as well as labour force participation rates for women mean that the traditional caretaking role expected of women cannot be taken for granted, as the pool of potential caretakers is diminishing. All the international research, including substantial Australian research, shows that families still provide most of the care and that the state is not replacing the family as the prime agent of care.

Both the family, and the formal systems have different supports to offer, and can meet different types of needs. Sociologists have shown that the family structure is able to deal with idiosyncratic events because it can define, as a result of its
intimacy and small size, that which is to be valued, and it can respond, where appropriate, with speed and flexibility. Formal services, on the other hand, whether residential or HACC type, are better equipped to deal with routine needs, and needs which require specialised knowledge or professional skills.

In planning our health and residential services we have different skills and abilities evident at different points on the planning and delivery spectrum. To plan and deliver will involve having a careful understanding of the social structures within which our care system operates. The high survivorship rates which I mentioned at the outset and the associated cumulative health deficits have meant that the care task is becoming longer and harder. One of the main target groups under HACC are not elderly or young disabled people themselves but the carers of these people. Support for carers involves respite programs and specific practical assistance, and information and group awareness and support.

The pressures on carers, in particular on middle aged women have been documented well in the literature. In my research I have found that carers themselves had health problems stemming from the physical and emotional burdens they carried, their relationships with spouses, other family and friends deteriorated, their work performance deteriorated, and many gave up paid employment, they were constantly "on duty" and often unable to relax and sleep at night, they were apprehensive about growing older. They provided the care, however with love and dedication, regardless of their skills, and to a large extent
said there was no way their loved one would go into a nursing home. When the research was done 5 years ago there was clearly an image problem about nursing homes. I wonder if it has changed.

When we think of all the things HACC services can do we have to be aware of the limitations also, $300 million per year buys a lot, but it doesn't solve all the problems of a community with unprecedented survivorship rates, growth controls on nursing homes, carers not able to provide all that is required, a community which in the past has had very little commitment to health promotion or preventive health care and of which the consequences are now being measured. An ideal HACC program would have services which are efficient, effective, flexible, comprehensive, accessible, acceptable, accountable and well co-ordinated. Perhaps we're asking the impossible. An ideal service will comprise three types of things - practical assistance, social contact and surveillance, personal development and health care.

### HOME CARE NEEDS OF ELDERLY PEOPLE

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<th>Social Contact and Surveillance</th>
<th>Personal Development and Health Care</th>
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<tr>
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<td><em>Bereavement counselling</em></td>
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<td><em>Meal preparation</em></td>
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<td><em>Shopping &amp; errands</em></td>
<td><em>Social work support</em></td>
<td><em>Chiropody</em></td>
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<td><em>Home repairs and maintenance</em></td>
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Since the McLeay Report we have seen significant and monumental changes. These changes have been debated at length and opinion is sharply divided. The changes are based on the principles of limiting the growth in 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 their rights are maintained, that the services they receive are appropriate, and are geared towards enhancing and maximising their life chances.

These changes have an impact on you. If HACC does what it says it will, even if it does only half of what is says it will, and if the primary health care thrust takes off, and if the assessment teams do their job, and the growth control principles continue, then it follows that the limited number of nursing home beds will, of necessity, be filled by people who are considerably more dependent than many of the people 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.

You won't be able to respond by simply mopping up or only by being nice, kind and gentle. Your response will have to be more professional, your staff will have to be more skilled, they will have to be better educated, they will have to have their skills continually strengthened, and you and they will have to be continually on the lookout to prevent the first incipient signs of burnout. HACC is going to make life better for a lot of older people, but make the professional task more demanding for hands-on caregivers and managers in residential care.
Whatever special services we have to offer, whatever caring we can provide, whatever we see as our targets and goals, we are all part of a larger system, a system which responds to individual parts to make up the whole. Policy issues in the ageing arena involve structuring an environment which responds effectively, efficiently and compassionately to a demographically changing elderly population. We all have a responsibility, organisationally and collectively to get the structures and processes to achieve excellent outcomes whether they be residentially based or home based, and if we get it right our deliverers will deliver well, and the main beneficiaries will be the target population - elderly people who will feel well cared for, valued and respected, and in turn our whole society will benefit and be enriched.