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A speech by Professor Adam Graycar, Social Welfare Research Centre, University of New South Wales:

"Family and community care of elderly people"

presented to the South Australian Council of the Ageing during Seniors Week, Adelaide, 2nd November 1983

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speech, not
a paper

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FAMILY AND COMMUNITY CARE

OF ELDERLY PEOPLE

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The 'graying' of Australia's population has been a regular topic of discussion in government, demographic, health, and social service circles in recent years. It has been noted carefully because shifts in population structure, particularly increases in the so-called 'dependent' populations have serious implications for resource allocation in areas of income support and service provision.

100 years ago life expectancy at birth was 47 years for males and 51 years for females. To-day it is around 70 for males and 77 for females. These of course are averages and many people live beyond these years. In some circles this increase in life expectancy is seen as a calamity for society - but I think it would be more reasonable to regard it as a major achievement. There is, however, a price to be paid for the privilege of living longer and that price is paid in the terms of an increase in the nature of degenerative diseases. The rates of chronic illness in all industrial societies are very high and Australia is no exception. What becomes important is trying to understand the network of the services - statutory and non-statutory - formal and informal - that can be blended together to improve the quality of life of the person suffering from chronic illness, and to ensure that those who care for these people have their needs met as well.

Chronicity increases with age. For every 100 Australians over the age of 65, 77 experience some chronic condition. What is even more interesting is that these 77 people

experience between them about 180 chronic conditions, or about 2.3 each. Not all chronic conditions involve activity limitations, but 15 out of every 100 females aged 65 and over, and 11 out of every 100 males aged 65 and over have activity limitations. Activity limitations mean that people with chronic conditions need some form of social and medical support. For many elderly people the source of that medical and social support is first and foremost the family. This has led many to a situation where elderly people come to live with their adult children.

Approximately 160,000 households or 3 per cent of all households in Australia contain an ancestor. Many of these would be people with activity limitations of which most would require some support from family members. Although Australia is reputed to have one of the highest rates of institutional care in the world, 55 per cent more elderly people live with adult children than in nursing homes or other institutions.

In South Australia approximately 10,800 people turn 65 each year. Each year approximately 6660 South Australians aged 65 or more die. The elderly population thus increases by about 4140 per year or about 80 people per week. This will obviously involve an investment in extra services and facilities. Of great interest is the internal shift in the age distribution of the elderly population. In 1901, for those aged 65 and over, the ratio of those aged 65-74 to those aged 75 and over was 75 : 25, that is, a quarter of the elderly people were over 75; By 1981 the ratio had changed to 64 : 36, that is over a third of the elderly people were over 75. By 2001 it is estimated that the ratio will be 53 : 47, almost half and half. This will have significant consequences for service provision and family care.

Again I should like to point out to the harbingers of gloom and doom that all is not lost and that the certain knowledge that there will be considerably more elderly people; that as a greater proportion will be aged 75 or more and that as these people are the greatest users of services; and that as chronicity has an element of "predictability", unlike episodic illness; planners have the challenge before them now, and certainly have the skills to develop workable, equitable and humane policies. As we look to the future in gerontological planning it will be necessary to develop the philosophical concepts, the framework for action, the process, and the product.

The key issue is that longer life in our society often means more chronic illness, and it follows that care within the family, and by family members, takes on a different dimension

to that which formerly existed. The care task is becoming longer and harder, and there has developed a special need to integrate statutory and non-statutory services as supports for those providing care. Without these supports, the dependent people who are being cared for will increasingly be cared for by family members who themselves will be locked into states of dependency. It is the effects on the people who provide care for their elderly relatives that I am concerned with today.

We have heard a lot lately about families abdicating their responsibility to care for their elderly members. What evidence there is suggests that the families are not at all abdicating their responsibility, but rather they are under enormous pressure because their capacity to deal with and provide adequate care for elderly dependent relatives is diminishing. Advocates of family care often assume that caring presents little difficulty for the family, and while caring for an elderly relative can be a positive experience, what is ignored are the many accompanying stresses and costs related to the caring role. The day-to-day responsibilities of care usually fall on one person - generally a spouse, a daughter, or a daughter-in-law. Most families continue to care for elderly relatives until a crisis point is reached where there no longer exists any alternative to institutionalising their relative. Usually the decision is made as a last resort after the family has exhausted both coping abilities and resources.

THE STUDY

In the S.W.R.C. we have recently completed a three-state survey of carers of dependent elderly relatives. We set out to determine some (non-monetary) costs - to the family and the state, of family care of dependent elderly relatives and to

examine the needs of the caring family in relation to the provision of formal services.

Data were gathered on the reasons leading to the decision to care, how that decision affected other family members, who was involved in caring in the home, the suitability of housing arrangements, the need for special adjustment or equipment within the home, the financial situation of the family, the day-to-day stress of caring, the availability and effectiveness of services in the area, and the private costs of caring (social and personal).

The sample, which was taken from home nursing recipients, consisted of 35 cases in Hobart, 68 in Sydney and 55 in Adelaide - 158 in all. Forty of these were no longer able to provide the care required and had had their relative admitted to a nursing home. We set out to discover what was the straw that broke the camel's back. One of the things we were looking for were State effects - that is did any different policies and services in the various States have an influence on caring experiences? The answer we found was no - pressures and difficulties were fairly uniform, and no State effects were detected.

Let me report some of the results before examining the policy consequences.

The mean age of the carees was 84, and three quarters of those being cared for were women. Almost all of those

providing care were women, and the mean age was 53. One third of the households contained only the carer and caree and these were ^{often} the most isolated, most disadvantaged, poorest and most distressed households.

Caring after household reformation was not a temporary phenomenon, as more than half had been caring for more than four years, and in the majority of cases, the elderly person being cared for had moved into the household of the people providing the care. Prior to that they had lived either alone or with a spouse and obviously found it impossible to continue ^{without some support.} Of those who had moved, one quarter were unwilling to have moved and were not happy at all about it. In deciding about whether a move ought to have taken place three quarters of the households claimed they had no option but to take the course of action they did, mostly they did so on the basis of a decision taken entirely within the family, though in a very small number of cases (10%) doctors were consulted.

In looking at functional ability of the elderly people it was found that by and large they required a great deal of assistance and support. Just over half were able to feed themselves without difficulty and just under half were able, without difficulty to get about the house a bit, and when the occasion required, get to the toilet on time. Most were not able to go to places outside walking distance, most were not able to prepare their own meals, they could not do light housework, most were not able to get up and down stairs, bathe

themselves, cut their toe nails, take their own medication or handle their own money. The most common condition experienced by the elderly people was arthritis but almost half had heart problems, just under half had failing sight while about a third had nervous conditions, or were recovering from strokes or paralysis. About 28% were reported as suffering from dementia.

The carers themselves felt a strong sense of obligation towards their elderly relative and accepted the caring task because they loved their relatives and in general believed the family has responsibility to care and they loved their parents. We also identified a lot of pressures on the people who were performing caring functions.

The carers by and large felt themselves fairly isolated. Few had anybody to provide any periodic relief when it was required. Those who had husbands and children found them generally supportive, but very often the support was only verbal and did not translate into action. Many of the carers themselves had health problems. When ill, they had no option but to continue offering care. 60% had not had a holiday for years. They resented their loss of independence and the decline in their health which was caused by stress. Also they experienced great anxiety - on the one hand they felt they could not leave their elderly relative for any length of time and on the other hand some felt that they were neglecting their responsibilities to other family members. Some felt a tremendous emotional drain on themselves and one said to us "at 80 I'm going over the Gap - I couldn't put my kids through this".

Overall, the research found that the carers :

- had less time for recreation and leisure activities
- had less time to complete housework and allied chores
- were less able to relax and sleep at night
- were apprehensive about their growing older

In addition to a decline in emotional state of the carers, the three negative features which stood out dramatically were :

- loss of independence for carers.
- loss of privacy/intimacy within the family
- tension/disruption of family life.

Surprisingly, 82% reported that caring did not present them with financial difficulties, even though our sample was predominantly low-income and 56% had as income only pensions or benefits.

We collected a lot of data on income, housing, and employment, and these appear in the published report and will not be dealt with here. Rather than go through the great mass of data we have, I want to mention only three items of interest, formal supports, informal supports, and reasons for giving up care.

We all know that domiciliary services are stretched to the limit, yet surprisingly we found service usage quite low. Our sample was biased in that we obtained it from home nursing services, yet apart from home nursing, the service mostly used was Day Care Centres, used by 31.% of the sample. The only others to reach double figures were respite beds (15%) and

home podiatry (12%). We provided a checklist of services (not all of which were necessarily available in all locations) and it is of interest to note that 75% had never heard of cleaning services; 41% had never heard of Home Help; 79% of shopping or delivery services; 65% of Home Visiting Services; 77% of Grannysitting Services; 20% of Meals on Wheels; 87% of Occupational Therapy, and 78% of the S.A. sample had never heard of domiciliary care services.

There is a particular dilemma relating to service knowledge and usage. Most services are already stretched to their limits and if more people were aware of the services an even greater crisis than presently exists could exist. Service providers have a responsibility to let the potential clientele know of the service, but the catch 22 is once they inform people of the service the chances are they will not have the capacity to deliver the service adequately. This points to a situation that requires very careful bolstering and support.

We also asked for suggestions for services which might make family care easier, and it is interesting to note that the formal services just listed were not the ones suggested to us. The most numerous responses were short substitute care while the carer went shopping etc (suggested by 28% of respondents); counselling and advice when caring began (suggested by 17%); respite care or holiday care (17%); visiting service (12%); 19% reported that "nothing was needed", and 7% reported that nothing could possibly help.

Informal support was forthcoming in 55% of cases, and in 45%, there was no informal support at all. Informal support came, when it did, from relatives (83% of cases), neighbours (40% of cases) friends (22%) and in a few cases through churches (5%). Informal support was nearly always provided by women and in a quarter of the cases, once a week, in another quarter more than once a week but for almost half, "occasionally". The most common types of informal support were visiting, and providing breaks in care.

In turning now to the factors which led people to give up care we have mountains of cross tabulated data on just about every variable, but the main reasons were pretty straightforward. Almost 70% simply exhausted their capacity to provide care as their elderly relatives became more and more disabled. Almost one half (people gave multiple responses) gave up on the advice of their doctor. There was no simple straw that broke the camel's back, but a progressively deteriorating situation.

CONCLUSIONS

What threads can we draw together? First of all our research indicates that aged people in the future will probably look more towards the formal system of care and less to their families. Many families want to look after their elderly relatives but they are not equipped to do so nor do they have the social supports they need.

Family care in reality is care by women. When I said that people were likely to look more towards formal care systems than informal care systems I was thinking of the fact that the potential pool of caretakers in Australia - those ~~un~~married women not in the labour force who formerly saw it as ~~their~~ their role to look after elderly parents - is rapidly diminishing. There are fewer never married women in middle age to-day than there ever have been. There are also more women in middle age in the labour force than there have ever been. The situation has been characterized by an American social scientist Elaine Brody, who in describing the phenomenon of "the woman in the middle" wrote :

"such women are in middle age, in the middle from a generational standpoint, and in the middle in that the demands of their various roles compete for their time and energy. To an extent unprecedented in history, roles as paid workers and as care giving daughters and daughters-in-law to dependent elderly people have been added to the traditional role of wives, homemakers, mothers and grandmothers. Many of them are also in the middle in that they are experiencing pressure from two potentially competing values - that is the traditional value that care of the elderly is a family responsibility vis-a-vis the new value that women should be free to work outside the home if they wish."

The women in our study found very often they could not manage all of these competing demands. An increase in overall dependency can result if we develop the idea that in the future women can provide care for their relatives because they will in any case be at home, financially dependent on a man. This seems a very shaky basis on which to plan the expansion of care.

There is no evidence to show that formal services weaken informal provision, and hence weaken the social structure. As families will always want to provide for dependent relatives (even though their capacity may be limited), public policy objectives must be re-oriented to bolstering and enhancing family care support. It would be a mistake to work on the basis of assuming that family care is always viable, and available, and ignoring the onerous burdens of care experienced by many families. While families are not likely to be able to extend caring functions they do play a significant role, and policies must be developed that enhance the natural system of family care by providing adequate and relevant formal services.

The key policy question relates to determining the most appropriate instrument of intervention and the most appropriate point of intervention to meet the various needs that emerge at various stages of the life-cycle. The dependencies of old age are chronic rather than transitional and may foreshadow continuing or increasing dependency. The dependencies are expected and accepted and by our study we hope to be able to provide more information on how these dependencies can best be dealt with in terms of the provision of support and services for family members and elderly dependent people.

In our society different needs are met by different support systems. The inter-relationship between statutory, commercial, voluntary and informal systems of care is not easily defined, nor is it in any way fixed. It is open for negotiation and rearrangement. To assume that the relationship can be redefined

on the expectation of greater informal care, more unpaid labour, and less statutory provision, is quite unrealistic. To assume that the so-called "Welfare State crisis" can be resolved by exhortations of greater family support and increased family care is to take the soft option in difficult times. A community which has benefitted from the endeavours of its population cannot in conscience abandon those requiring social care and argue that their needs are not sufficiently legitimate for the allocation of public resources. To date, social welfare provision has not responded well to rapid socio-technical and demographic changes. The community cannot default on its obligations to its citizens.