

Support and Services for People with Disabilities

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edited by

Sara Graham and Peter Whiteford

Proceedings of SWRC Conference, Sydney, 23 September 1988



Social Welfare Research Centre

THE UNIVERSITY OF NEW SOUTH WALES
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FOREWORD

This report is the proceedings of a special one day conference organised by the Social Welfare Research Centre and held in Sydney on September 23, 1988. The overall theme of the conference, 'Support and Services for People with Disabilities' is important, both in terms of current policy debates in Australia, as well as in relation to the proposed future research agenda of the Social Welfare Research Centre.

The Centre was particularly pleased that the opening address was given by David Richmond, Chairman of the Disability Advisory Council of New South Wales, who spoke about past-trends and emerging issues in disability services. Among the significant changes that have occurred in services and policies for people with disabilities over the past decade, he emphasised improvements in access to general community services, the movement towards a community based model of service provision, and the development of stronger advocacy for people with disabilities.

David Richmond mentioned that one of the important symbols of change was the gradual implementation of many of the recommendations of the 1983 Richmond Report, **Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled**. The transition from institutions to community care was also the theme of the papers by Sara Graham and Helen Molony. Sara Graham reviewed recent British research and Helen Molony presented the results of a New South Wales study of the effects of relocating people from institutional care to care in the community. Both studies were cautious in their conclusions, yet positive about the benefits of the transition to community care.

Further approaches to these issues were presented in the papers by Garth Nowland-Foreman and by Anna Howe. Garth Nowland-Foreman's paper discussed the assumptions and effects of community care as they impacted on the families who provided the care. This paper looked in particular at the performance of the Home and Community Care (HACC) Program from the perspective of carers. Anna Howe's paper was also given from the point of view of concern with evaluating the impact of government programs. She particularly emphasised that the apparent rate of change in service development depended upon the time frame adopted and the circumstances of the person making the evaluation. Her paper discussed a number of ways to improve policy-oriented research, in order to contribute to the effectiveness of assessments of the HACC Program.

Perhaps the most notable feature of the Conference was the variety of perspectives brought to bear on these issues, both by those who gave papers and from the audience. The variety of these views should be expected. The concern that was held to be most important was the necessity of focusing on the consumer's needs as perceived by themselves. This point made by David Richmond at the beginning of the day was emphasised by Jane Woodruff in her overview of the conference and came up many times in the discussion. Jane Woodruff also mentioned the desirability of conducting research that was not solely directed towards the interests of government policy, a point also made by Sara Graham in the conclusion to her paper when discussing the research agenda on community support services currently being developed at the Social Welfare Research Centre.

Finally, I would like to thank Peter Whiteford and Jennifer Young who organised the Conference, Jennifer Doyle and Toni Payne for preparing the Figures, and Jacklyn Comer for typing the report.

Peter Saunders
Director
Social Welfare Research Centre

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WELCOME - INTRODUCTORY REMARKS

Peter Saunders
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I should like to welcome both audience and speakers to this Conference. I am particularly pleased that it has attracted such a wide range of people and organisations.

In the audience we have people from user groups representing people with particular disabilities; we also have people with a responsibility for the planning, organisation and delivery of services of different sorts - for example, housing, transport, libraries, respite care; we have a range of professionals, for example, social workers, psychologists and occupational therapists, who work in a variety of settings, both in the community and in hospitals and we have representatives of Local, State and Commonwealth Governments whose concern is policy development and implementation. Last but not least, representatives of the research world, including a number of my colleagues from the Centre, are present here today.

The papers that have been prepared for this Conference similarly reflect a wide range of issues and interests. Some, such as David Richmond's and Anna Howe's will provide overviews of service and policy developments. Our discussant, Jane Woodruff, will focus on the key policy issues as they relate to people with disabilities. Some papers will be looking at particular disability groups; other will look across the spectrum of disabilities. The papers also look at the needs of people who may live in a variety of settings. Current policies for people with disabilities favour community living. The papers we shall be hearing address issues concerned both with the transition from institutional to community living and with those people and their families who already live in the community, as well as the interrelationship between 'informal' family care and Government programs, such as the Home and Community Care Program (HACC).

This conference has a New South Wales bias and most of the people here today do indeed come from New South Wales. However, on the assumption that the cross-fertilisation of ideas and the comparison of experiences can help to highlight one's own problems we have deliberately tried to look more widely than this State. Whilst Anna Howe will no doubt be able to tell us about the situation in Victoria, Sara Graham's paper describes research findings from the United Kingdom, which we believe are relevant to our own deinstitutionalisation policies.

This Conference is timely both from the point of view of the Social Welfare Research Centre and from my own personal viewpoint. As far as the Centre is concerned we are about to embark on a new program of research on community care and community services for people with disabilities, including frail elderly people. One of the Centre's main aims is to undertake policy relevant research and we see this Conference as providing an excellent opportunity to highlight issues of current policy concern and to draw together policy and research interests. Sara Graham is responsible for developing this new research program. She will naturally aim to make her program as relevant as she possibly can to the most pressing concerns of people with disabilities and their carers and she will be eager to hear about these from you. We have left a lot of time for discussion and for you to air your views. We are aware that our Conference has inevitably left out some important aspects of policy; for example, it is focusing on services rather than on cash benefits. We hope that people will not be inhibited from drawing attention to issues which are not covered in the formal papers.

As I mentioned earlier I myself have a particular interest in what will be said today. As the Chairman of the Working Group of Commonwealth and State officials reviewing the operation of the HACC Agreements, I have been closely concerned with issues associated with the service needs of people with disabilities. As part of the task of this Review, I have just completed a round of visits to all States and Territories to discuss with the HACC Advisory Committees their role in the program. I have also had the opportunity to meet with HACC service providers, community organisations and service users to talk with them about their experiences with the HACC program. I must say that I have emerged from this process with a very positive view of what HACC is currently achieving, both in terms of the range of services provided and of the innovative approaches being taken to service provision in many instances. Many of these are HACC services designed to meet the needs of

people with disabilities and their carers. I have also been most impressed with the degree of commitment to the basic goals and philosophy of HACC, as well as with the professionalism and dedication of many of those providing HACC services.

It would, of course, be amiss of me not to draw attention to the concerns many people have about the HACC program. Over the last few months I have, on many occasions, had these drawn to my attention. By its nature, HACC is a program that was bound to be controversial and its implementation difficult, encompassing as it does issues of Commonwealth-State relations in a context of trying to attain an appropriate balance between the concerns of service providers and the rights of clients. A fundamental objective of HACC is to focus services provided in the community on the needs of clients, and thereby to raise the quality of life of those in the HACC target group who wish - as the vast majority of them do - to remain living in the community. The achievement of this objective will not occur overnight and, while progress towards this end is already evident, there remains much to be done.

The HACC Review Working Group has, not surprisingly in view of its terms of reference, focused much of its attention on improving the administration of the program. I believe that the Group has made considerable progress on this, more indeed than I suspect some members thought possible when we began our tasks earlier this year. Our recommendations for streamlining the administration of the program, endorsed by HACC Ministers some months ago, have established better administrative arrangements and thereby provided a more solid foundation from which the program can develop. Equally significant in my view is that the work of the Group has made its members aware that they all face similar problems with the program, and the Review process itself has helped to create an environment of greater trust and shared commitment between the Commonwealth and the States, a necessary condition for the success of any jointly funded program like HACC.

We are currently working on the second stage of the Review, focusing on such issues as the no-growth restrictions, relationships between HACC and Medicare, more general linkages with other programs (e.g. Residential Programs and Disability Services Programs), the impact of other Commonwealth and State policies on HACC and the basis for a future review of services provided under HACC. Community views on these issues have been sought and will feed into the Group's deliberations over the coming months. It would be premature for me to say more at this stage, except to indicate that the Review is giving particular consideration to the ways in which HACC is currently meeting the needs of younger people with disabilities and how improvements might be made in this area. In the light of this, I will listen with great interest to the papers to be presented today, and to the discussion from the floor that they will generate.

TRENDS IN DISABILITY SERVICES IN NEW SOUTH WALES

David Richmond
Chairman
Disability Council of New South Wales

1. INTRODUCTION

The last decade has seen a significant increase in both the level of resources and the attention paid at political and administrative levels to services for people with disabilities.

There have been three broad trends as part of this process:

- * Improvements in generic community services by improving access to and utilisation of services by people with disabilities.
- * A movement towards a community based model in provision of specialised services (e.g. provision of community based housing as an alternative to hospital care).
- * Stronger group and individual advocacy for people with disabilities.

Changes at both Commonwealth and the State level have been symbolised by such issues as the New Directions document and the consequent Disability Services legislation, the introduction of the Home and Community Care program, the greater availability of Technical and Further Education services to people with disabilities, and far greater emphasis on a movement towards integration of children into the regular school environment.

An important symbol of change has been the translation into concrete services of many of the proposals of the Richmond Report in relation to people with an intellectual disability and those with a psychiatric disability. The implementation of the Disability Housing program and the recognition of the rights of people with disabilities to access to mainstream public housing programs are also important achievements.

The most significant recent achievement has been the Guardianship legislation and one of the most important issues over the next two years will be to ensure that the principles contained in the Guardianship legislation become a reality.

When we talk about disability services there is an inclination to focus on the 'welfare' sector. However, some of the most important changes in recent years have come from outside this sector and may in the long term indeed be more important than those in the welfare sector.

Two significant examples in New South Wales are the expansion of the subsidised taxi scheme for people with disabilities, which in spite of some of its administrative problems has enhanced the quality of life of many people, and the introduction of State Environmental Planning Policy No. 9. This policy allows group homes to be established in the normal residential environment without the necessity to obtain the approval of local government authorities. Without its introduction, almost no progress would have been made in moving people from institutional to community based accommodation.

2. CURRENT PHILOSOPHIES

To speculate on future directions in New South Wales it is useful to identify some of the philosophies which drive the current State Government. The Minister for Family and Community Services, Virginia Chadwick, at an Australian Council for Rehabilitation of the Disabled (New South Wales) meeting in August 1988, indicated that the Government accepts:

that access to, and the provision of, support services is an essential foundation for the principles that people with disabilities have the right to:

- . live in, and be part of, the community;*
- . make the decisions that affect their lives;*
- . realise their maximum capacity for growth and development; and*
- . be protected from exploitation and discrimination.*

In relation to the Government's overall budget strategy, there is significant emphasis on containing public expenditure, reducing public sector borrowing requirements, streamlining of public sector operations and generally adopting a more business-like approach to government. The Premier and Treasurer, Nick Greiner in his recent Budget Speech, indicated a commitment to:

delivering better services to the truly disadvantaged in our society, and delivering those services in a way that actually improves their conditions, rather than only appearing so to do.

There is also a commitment to encouraging and enhancing voluntary effort by people as individuals and in groups to solve their own problems. These policies have implications for people with disabilities and it is important for advocates of the needs of people with disabilities to understand these issues to turn them into opportunities rather than threats.

3. FUTURE ISSUES

In discussing future issues and likely directions I have chosen arbitrarily to classify a number of systems as 'closed', 'open' and 'support'.

a) Closed Systems

By a closed system I mean one which is highly self sufficient, and in particular the very large areas of health and education. In these areas I believe that the crucial issue will be determining where the balance lies between conventional forms of service provision (e.g. hospital services, special schools etc.) and community based services (e.g. regular schools, home care services, group homes, etc.).

The impending transfer of services for developmentally disabled people from the Health Department to the Department of Family and Community Services will mean that philosophically the emphasis will be on community care. However, this has to be balanced against a political commitment to maintain and enhance some of the traditional specialised services.

The imperative is to protect the gains that have been made in these areas by maintaining a level of advocacy which ensures that consumers are heard.

b) Open Systems

I am here referring to systems (e.g. transport, employment, etc.) which are more directly influenced by the private market place than are the systems mentioned above. There are two important Government initiatives which will have an impact on services for people with disabilities. The first is the movement towards 'corporatisation' of Government trading undertakings. Simply put, this means placing enterprises like the State Rail Authority, for example, on a business-like footing. One of the implications for people with disabilities is that subsidy

arrangements in respect of issues such as concession fares will become more clearly identified and monitored. They will therefore be under more scrutiny and their basic justification and effectiveness should be sound in order to maintain adequate funding.

The other is the introduction of Freedom of Information Legislation. This has the potential to empower consumers and is of particular importance to many people with disabilities, who spend a disproportionate amount of time negotiating with government agencies often without access to information which would assist both them and the agency in resolving issues.

In these 'open systems' generally, and particularly in relation to transport and employment, I believe that we have to look for more 'market based' solutions. Activities which rely or appear to rely mainly on the private market are often valued by society as a whole more highly than those which appear to rely totally on government.

The success of 'job search' type enterprises funded by the Commonwealth Demonstration program shows how the private market can be utilised to advantage. There is also I believe potential to use the funds currently provided for the taxi scheme in a more creative manner to improve services from the taxi industry.

Society places a high premium on employment and the ultimate total acceptance of people with disabilities will depend to a large extent on their success in gaining access to the employment market.

One of the difficulties is that the employment market is dynamic and many of the schemes developed by governments are based on arrangements which do not reflect market conditions. For example, something like 50 per cent of the jobs created in the last decade have been part-time, yet most employment creation schemes are predicated on the notion of full-time employment.

Both the market and society value part-time employment. It is respectable and it pays. It is also a form of employment which meets the needs of many people.

Recognising the importance of part-time work in no way indicates that people aren't entitled to full-time work but it does suggest a more flexible approach for many.

Closely related to the issue of employment is the matter of social security and income support arrangements which have significant disincentive effects built into them. Currently it is difficult to be able to have satisfactory part-time employment and still receive income support because the rules tend to encourage a person to be either a recipient of social security or in employment.

c) Support services

All individuals need physical and social support services irrespective of their levels of functioning or their income or wealth. Some people need more support than others and others need different types of support.

An important aspect of personal support is the encouragement of assistance to individuals through the provision of much greater emphasis on advocacy. Programs such as Self Advocacy, Citizen Advocacy and other activities which support, through a voluntary friendship network, an individual's capacity to operate as a member of the community are essential. These must be enhanced and expanded, drawing on community and business support as well as government assistance.

The whole question of adequacy of infrastructure support services whether for personal or home care assistance, respite care, provision of aids and appliances, access to community transport, or adequacy of compensation or rehabilitation arrangements in relation to accident victims is a major issue for the next decade or so. Respite care for example, is a key element in maintaining people in their community to support those who provide care within their own households for people with disabilities. It is an issue which goes hand in hand with the general ageing of the population and can have significant resource implications for government.

On the other hand it presents great opportunities for improved co-ordination of delivery of services at the local level. In spite of individual examples to the contrary, significant support services encompassed under rehabilitation programs, HACC, Home Care, PADP, respite care etc. administered by a variety of Commonwealth, State and Local Government and private agencies still lack focus on the consumers' needs. The HACC program, I believe, should be utilised as a vehicle which 'cements' together existing support services at a local level.

These issues can only be addressed at a local level by allowing the managers of these separate services some real management and budget autonomy to negotiate with their counterparts and consumers to identify needs on an integrated basis and then implement strategies co-operatively to meet these needs. Such an approach requires the definition of State-wide parameters as to broad policy directions, overall budget allocations on a program basis and effective accountability mechanisms to both the local community and (in the case of government services) to Ministers and Parliament.

4. COMMONWEALTH GOVERNMENT SERVICES

Aside from the important role of the HACC program and other specific direct services (e.g. disability services funding, rehabilitation services) in improving support services, the two areas of Commonwealth involvement which are most critical to the future are employment and income support policies.

The Commonwealth's role in the employment area involves not only the funding of specific employment programs for people with disabilities under the Disability Services legislation, but also its direct involvement in the labour market through the Commonwealth Employment Service and its policy role in the whole area of education and employment.

The other critical area for people with disabilities is the adequacy of income support payments through the social security system. The recently completed Social Security Review Issues Paper does contain proposals for improved income support arrangements for people with disabilities. Particular issues which require review are the adequacy of payments and flexibility of arrangements to enable people to make the transition from income security recipient to paid employee or to continue with dignity to be both. For many people the initial establishment costs of employment are relatively high (provision of personal equipment, etc.) and force them to remain on income support at a significant and perhaps unnecessary cost to the community, when an up front establishment payment might enable them to take up employment.

5. FUTURE FOCUS

At the political level, strong and united group advocacy is essential.

Improvements in the quality of life for people with disabilities depend on our capacity to ensure that we focus on the consumers' needs and that the strategies and mechanisms devised to meet these needs are not in themselves devaluing those they serve. This requires an approach which stresses 'normalisation' and 'localisation' and solutions which are 'market based' and do not rely entirely on traditional welfare approaches.

THE TRANSITION OF PEOPLE WITH DEVELOPMENTAL DISABILITIES TO COMMUNITY CARE

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The material presented in this paper is based on research funded by the then Department of Health and Social Security (DHSS) in the United Kingdom. I became familiar with this material through my work with the DHSS where, for some years, I was responsible for the management of its research program in the area of developmental disability or, as it continues to be called in Britain, 'mental handicap'. In order to provide a context for the points I would like to make today, I think that I should first explain that there is a quite deliberate and direct connection between the Department's immediate policy concerns and the research that it commissions. A primary requirement of the research that the Department commissions is that it should be relevant to current policy issues. Departmentally sponsored research activity is largely concerned with monitoring and evaluating policies and initiatives associated with these policies. For this reason, the research undertaken under government auspices is an extremely good barometer of current policy pre-occupations.

In this paper I want to draw on my knowledge of this British research to illustrate some of the key policy issues which have emerged there in recent years. I have also had the advantage of being able to refer to a paper by Jenny Griffin, my successor at the DHSS, which covers the very latest work in this field. Though I don't attempt to point to possible Australian applications, you might see some relevance to the local scene in what this research has brought to light. The themes are certainly topical.

Policies for people with developmental disabilities were originally spelled out in the 1971 Government White Paper **Better Services for the Mentally Handicapped** (DHSS, 1971). The broad aims as the White Paper summed them up were to develop health and social services in each locality and to achieve a major shift from institutional to a wide range of community care according to individual needs. To achieve this effectively, it is recognized as essential that there should be joint planning, involving all statutory authorities, notably health, social services and education, together with the private and voluntary sectors. It has also been accepted that shifting the responsibility for care from large hospitals to more locally based services will mean shifting resources, including hospital-based staff, to provide that care.

The current broad policy issues and hence research interests are firstly: how can resources most effectively be deployed to achieve the shift from institutional to community care? Secondly: what kinds of services should be provided? Thirdly: what will be the cost of providing care of the high quality that is required?

More specifically, policy makers are interested in how to co-ordinate and deliver support services in the community. They are also concerned with the social integration of developmentally disabled people in the community. Although the Government has accepted in principle the model of caring for people in small residential units, as far as possible in ordinary housing, it has reservations about the suitability of this model for some of the most severely developmentally disabled adults. It encourages the run-down of large hospitals for people with developmental disabilities. It has emphasised that care in a health setting should be limited to people with clear medical and nursing needs, and it has recognised that such care can often be provided in small, homely settings. It is nevertheless concerned to assess the suitability of this model, particularly for the most severely and profoundly disabled adults.

Research findings and the experience of some professionals have tended to reinforce the Government's view that some of the most difficult issues arise in implementing the policy of community care for people with additional problems, such as multiple handicaps, serious behaviour disturbance, or communication problems and associated mental illness. It is therefore in the area of special needs that a good deal of government-sponsored research is currently focused. The findings of this research are not altogether unanimous, but I think they point in sufficiently similar directions to be of practical help to professionals and service planners and providers.

What seems to be clear is that developmentally disabled people with special needs and additional problems can live, be looked after and develop their potential outside of hospitals. On the other hand, it is not at all clear

precisely what form provision for this type of client should take. But whatever form it does take, it is obvious that if the care is to be beneficial and of high quality, it is likely to be labour-intensive and hence expensive. Thus far, there is no evidence to suggest that high quality care in the community for the most severely disabled people is going to be any less expensive than hospital care, although it may be so for those who are less dependent (Wright, 1987).

I would like to describe some recent research in Britain which examines the progress of deinstitutionalisation and community care since the 1971 White Paper, and attempts to assess the extent to which the goals of that policy have been achieved. I shall be drawing on the findings of four research groups funded by the Department of Health and Social Security. Full accounts of some of this work have yet to be published.

Dr Lorna Wing, whose research base is the Medical Research Council Social Psychiatry Unit at the Maudsley Hospital in South London, has since 1980 been monitoring certain aspects of the gradual closure of one of Britain's largest mental handicap hospitals - Darenth Park Hospital in Kent, which is scheduled to close completely this year. The primary purpose of her research has been to assess the effects on residents of moving to a new home in the community. Dr Wing has paid special attention to the relationship between residents' patterns of impairment and their reactions to different living arrangements (Wing, 1988).

The second study is being undertaken by Howard Glennerster and Nancy Korman of the Department of Social Administration at the London School of Economics. This looks at organisational and administrative problems also associated with the closure of Darenth Park Hospital. Using a methodology, which the researchers have called 'administrative anthropology', they have monitored the process of joint planning between health and local authorities and the provision of alternative accommodation and day care services for the former residents. The research has also been examining the management of the hospital at a time when it is losing resources to new local services, but still needs to maintain its own services for the remaining residents (Korman and Glennerster, 1985).

The third study I shall be considering was undertaken by Dr Norma Raynes whilst she was a member of the Hester Adrian Research Centre at Manchester University. The objective of her project, which ran from 1982 for some three and a half years, was to follow up 448 developmentally disabled people whom she, Jack Tizard and Roy King had first assessed in 1967 and 1968. At that time the subjects of her research were children and lived in three types of residential facility - hospital, local authority home or voluntary home. None lived in the parental home. Dr Raynes was concerned to find out what had happened to these people, with regard firstly to their adaptive and maladaptive behaviours, and secondly to their current place of residence and their opportunities for contact with the wider community (Sumpton and Raynes, 1987a, 1987b).

The fourth project was conducted by Dr David Felce whilst he was a member of the Health Care Evaluation Research Team at Southampton University. The aim of Dr Felce's project was to help to set up and evaluate ordinary housing schemes for severely and profoundly disabled adults. The main aims of the project were, first, to develop a model of residential care using ordinary housing, and second, to develop staff procedures directed towards establishing a high level and variety of purposeful activity by residents. This was to include promotion of continued learning and behavioural development and encouraging the involvement of residents in the ordinary life of the wider community. Dr Felce conducted a number of experimental and evaluative studies. These examined the behaviour of severely and profoundly disabled adults in their interaction with staff and in relation to other aspects of their environment (Felce, 1988).

With very different perspectives, and employing quite different methodologies, these four studies have examined the implementation of care-in-the-community policies. What have we learned from their work?

Basically two sets of issues have been addressed. There are questions about the broader processes of planning and administration, and there are questions about what happens to the people in whose interests this activity goes on. Naturally the two concerns intersect, but they are approached from different directions. One important lesson has been that the process of relocating hospital residents in the community must be carefully planned and adequately resourced. It cannot be done on the cheap. All the activities, capacities and wishes of each individual must be carefully considered before the move from hospital, not simply the question of where he or she is now going to sleep. A great deal of co-operation and commitment is required from all concerned.

Both Dr Raynes' and Dr Wing's research throws light on some of the associated problems. When Dr Raynes followed up the children she first assessed in the Sixties she found, ten years after the publication of the 1971 White Paper, that only 22 per cent of those who were living in hospital when she first saw them were now living outside. Fifty per cent of her hospital sample were still living in the same hospital. Dr Raynes' findings led her to suggest that while this relatively sluggish movement may change, following the proposed closures of the really big hospitals, we should remain alert to the possibility that many movements may simply be transfers between hospitals.

Dr Wing's findings reveal a similar pattern. Four years after she began her research, 204 of the 900 Darenth Park hospital residents had moved out. But 181 of these had moved to another hospital with over 200 beds. Only 23 people had moved to other health, local authority, voluntary or private facilities in the community.

Many of the alternative units planned had not yet been built and many of the placements of residents had necessarily been entirely *ad hoc*, based simply on the availability of places elsewhere. A year later, the position had improved somewhat, but still left a good deal to be desired.

Dr Wing used a variety of measures to assess the effect of the move on the behaviour, skills and lifestyle of the residents. In general there was little evidence of change. With regard to self-help skills, communication, continence, personal independence, visits outside the living unit, number of personal possessions, participation in daily decisions, educational activities and 'appropriate occupation during free periods' there was no significant improvement after the move. All movers had more personal privacy than previously, but there was less in the way of regular organised occupation. There was a little more family visiting.

More use was made of community-based medical and personal services. But there was a good deal of variation on all of these measures. Those people who were the most severely socially impaired scored very badly, both before and after the move. But there was also considerable variation according to the type of placement to which people had moved. Those in private hostels scored low on measures of lifestyle. Residents in small houses showed the greatest signs of improvement with regard to personal independence in the domestic setting. Outside the home, however, there was in general no increase in their independence. There was also a decrease in levels of access to education and active occupation. Those in hospital wards scored low on most of the lifestyle measures but they and the hostel residents fared best on education and occupation.

This research continues. It will chart the progress of the more recently moved residents of Darenth Park, more of whom seem likely to find accommodation in new, smaller and better-planned units.

Glennerster and Korman's research on the organisational aspects of the closure of Darenth Park raises complex financial and organisational issues, and a range of problems which have arisen because separate authorities control different resources, all at a time when ideas about appropriate services for disabled people are changing. Their study provides us with a number of lessons, and although services here are organised very differently from those in the United Kingdom, I think that at least some of these lessons may be relevant to the Australian context.

It became apparent that a hospital closure is a much more complex, costly and technically difficult task than had at first been supposed. It requires the regular involvement of senior staff to ensure that the many frustrating difficulties and multiple agency agreements involved do not cause the project to lose momentum. At Darenth Park, a mental health co-ordinator was appointed to maintain links with each district to which residents were to be moved to ensure that plans were both made and implemented, to keep all parties informed and to iron out difficulties as they occurred. But this appointment was made only four years after the run-down had begun. The absence of a co-ordinator was, in the researchers' view, one reason why planning time was not effectively used at the start of the project. They concluded that additional administrative support in such a major project as a hospital closure is needed from the very beginning.

Whilst the slow progress of deinstitutionalisation has been one problem, the selective character of the process is another. Up to the point at which Dr Wing reported her interim findings in 1984, not one severely disabled person with a social impairment had left Darenth Park for a residential placement in the community. The only such people to have moved had gone to the other, somewhat smaller hospital to which I referred earlier. One of the objectives of Dr Wing's research was to examine the relationship between the individual's pattern of impairment and his or her reaction to a new type of environment. The project should have provided an excellent

opportunity to do this. Regrettably, it was unable to provide useful information on the most difficult-to-place residents precisely because of the failure to relocate them in non-hospital settings.

It is not surprising to find this situation also reflected in Dr Raynes' research. Her follow-up revealed that the hospitals included in her study contained a far higher proportion of people with poorer capacities and more difficult behaviours than did community facilities.

Wing concluded from her study that plans to close hospitals should include, from the beginning, arrangements for coping with the problems and needs of the various multiply disabled and behaviourally disturbed groups, including special facilities for their occupational and leisure activities, as well as their residential care. Her research revealed a sad shortfall in all these areas.

This recommendation is echoed by Glennerster and Korman. Their study of the closure of Darenth Park led them to conclude that hospital managers need to ensure that districts accept residents of all levels of dependency, in generally balanced proportions. Districts just developing new services are otherwise likely to begin by providing facilities for the more able people. The hospital will then be left with a more severely disabled group to care for, at a time when resources are coming under increasing pressure. Nursing morale, particularly, may suffer in these circumstances. It may begin to seem that the hospital will never actually close, but merely dwindle in numbers until it reaches an irreducible minimum population of those 'difficult to place'. Furthermore, staffing problems may well be exacerbated because the most forward looking staff are likely to be drawn away by the new units which are being set up elsewhere as hospital closure proceeds.

Experience gained during the closure of Darenth Park suggests that the effort to develop services outside the hospital, essential though it is, should not be allowed to divert all attention from the hospital itself. It remains necessary to provide an acceptable level of care for the contracting hospital population until closure is complete. The abiding problem at Darenth Park was to maintain a balance between the avoidance of non-essential expenditure on a structure with a limited future life, and the preservation of a pleasant, efficient living and working environment for residents and staff.

The research of Glennerster and Korman also points to the importance of staffing questions. It makes clear that several years elapsed before the managers of hospital and community services were able to collaborate effectively in working out ways in which experienced staff could be retained, where needed, by the hospital, at the same time as allowing some of them to contribute their skills to the development of new services in the community. A combination of job protection policies, retraining opportunities and early notification of vacancies in new services went some distance towards alleviating the disruption of employment and waste of trained personnel otherwise threatened. Many staff were nonetheless unable or unwilling to transfer to services in the districts receiving former residents. Certain frictions and inefficiencies clearly remain. How far they are unavoidable is still unclear.

The research showed that the costs of closure were significant. Additional maintenance, training and staffing costs were all considerable. The average cost per resident also increased in any case because of the increasing average age and dependency of those remaining in hospital as closure progressed.

This research also continues. An account of the final stages of the closure has yet to appear.

Wing's research highlights, among controversial issues associated with the planning of services, questions about what constitutes the most appropriate type of residential facility, and what professional inputs are needed for the most severely and profoundly disabled people. Dr Wing's view is that there are people who would derive no benefit and may even experience harm if relocated in the general community. She feels that there is a case for providing these people with a more sheltered living environment, perhaps in the form of a cluster of small, family sized living units constituting a sort of village.

David Felce's research is illuminating here. He helped to set up and evaluate ordinary community housing for two households, each of eight people, of whom several were severely disabled and some of whom also had social impairments. His research therefore represents a useful test of the feasibility of care in the community for people with these problems. Dr Felce concludes that care of superior quality can be provided in community settings, and

his view is that the numbers of people for whom such provision cannot be made 'must be extremely tiny' if the model of care he and the local health authority set up is replicated faithfully.

The objective of the scheme was to provide involvement in the community, sustained family relationships, opportunity for continuing development, and meaningful occupation as an alternative to disruptive behaviour. The location of the houses, near kin and town centre, was considered to be an important ingredient, as was their small size and well-finished appearance. Two or three staff were on duty each day, having full autonomy with regard to catering, shopping, budgeting and all other aspects of domestic management.

An important aspect of this approach is its emphasis on rigorous adherence to staff procedures which involve high levels of interaction with residents as well as opportunities for a variety of appropriate resident activities. Weekly routines and daily planning of staff duties, including the allocation of responsibility for particular residents, are all highly organised, with a view to helping and supporting residents as they learn social and domestic skills. Daily records of their activities and achievements are kept. This careful, continuing attention to detail is clearly essential for the successful delivery of the high quality care which Dr Felce has shown to be possible.

By comparison with a control group, the residents of these small homes gave much more evidence of successful social integration. For about half their time residents were involved in some social interaction, personal care, or household or leisure activity. There were more family contacts and visits to community facilities than usual in institutions, and more supportive staff attention. Residents were able much more frequently to work with staff in very small groups. They showed greater developmental progress than institutional residents or those living with their parents.

Felce acknowledges that even under these conditions, however, certain types of behaviour are not eliminated. He found that repetitive and self-stimulatory behaviours tended to continue despite careful attention to the social environment in these small homes. This leads him to conclude that one cannot attribute behaviour of this kind simply to the poverty of the hospital environment, nor expect such behaviours ever to be entirely eliminated.

There is a significant contrast between the approaches and the conclusions of Dr Felce and Dr Wing. Dr Felce, a social scientist and a committed reformer, is concerned to demonstrate that care in the community, in ordinary housing, is a realistic option, even in the case of very severely disabled people, though only if the most systematic, energetic and dedicated efforts are made, along the lines he describes. Dr Wing, a clinician with long experience, although not an advocate of institutional care, is more impressed by the intractability of some of the more severe states of disability, and is inclined to question whether it is right to expose people affected in this way to the constraints imposed by living in the community. This is not simply a difference of opinion about the facts of the case, clearly. It should alert us to the importance of inevitable differences in interests and value orientation. It is important to emphasise, however, that none of the research workers quoted in this paper are advocates of the traditional form of institutional care.

Although there may be disagreements about where care should be provided and even about the nature of the care required by some groups of people, I think there can be little dispute as to the importance of providing opportunities for each individual to lead as full a life as possible in an environment which nurtures and helps to develop his or her potentialities. Dr Felce's research has been most encouraging where it bears on staff-client interaction and client engagement in purposeful activity. His results also offer some encouragement as to the possibility of maintaining these improvements outside the research situation.

It is in this context that I have also found Dr Rayne's research valuable because it tells us a great deal about the reality of community care as it affects the daily lives of disabled people. Her findings are both disappointing and salutary. She found, for example that only 4.5 per cent of her sample population were in open employment. As many as 82 per cent were in training and the remainder, about 13 per cent, were unoccupied during the day. People who lived in their parental homes and those who lived in hospitals were the most likely to be unoccupied. One disappointing finding was that none of the people living in a local authority hostel were in open employment. Overall, Raynes' research confirms other evidence that the opportunities in open employment available to developmentally disabled people are extremely limited.

What does research tell us about other aspects of community living? In her Darent Park research, Wing compared the organisation and management practices of hospital and non-hospital units. She found that non-

hospital units in general had higher ratings for staff autonomy and physical appearance. Raynes, for her part, using a number of measures, found quite considerable disparities in the quality of care provided in residential settings. Where contact with the community was concerned she found that the use of public facilities such as shops, buses and pubs was strongly influenced by the type of residence in which people lived. Low level of contact with the community was very strongly associated with living in a hospital. It is interesting that people living at home with their families were more like hospital residents in this respect than hostel residents. However, despite the better opportunities and higher levels of contact with the community amongst those living in non-hospital settings, the actual level of contact of members of her sample still seems lower than might be hoped, even in hostels. This suggests that merely providing opportunities for contact does not ensure that community resources will be used. I think that we must look for an explanation of these findings in such factors as the practices and commitment of staff and management, as well as the attitudes of the wider community.

Despite these disappointingly low levels of contact, Raynes' study does give some grounds for optimism. As we would expect, differences in the extent to which people are permitted to make decisions about their daily lives are most strongly related to observed differences in their levels of ability, whatever the type of residential facility in which they live. On the other hand, her data suggest that the orientation of care practices, that is, whether people's daily lives are managed in an institutional or resident-oriented way, depends more upon the type of residential facility in which people live than upon their level of disability.

Raynes felt able to conclude from her research that the differences in the environments she studied were not mainly attributable to the characteristics of the residents. There are not distinguishable 'hospital-type' and 'social service-type' residents. Although people's handicaps may set limits to the extent to which they can use opportunities, within these limits, the use they do make of the available opportunities depends significantly on management practices.

It will be evident from this account that the research effort funded by the British Government leans heavily in the direction of problems associated with institutional care and the search for publicly-funded alternatives. The relevant problems are in the main those of government. How to run down a hospital without prejudice to the patients? How to provide alternative care from public funds at reasonable cost? What to do about the planning, co-ordination and delivery of the services involved? The problems are certainly real, but they are not necessarily the only ones. The amount and nature of the research commissioned is a fair indication of the scale of government resources involved. But there are other parties involved in the care of people with disabilities, who are not supported from public funds, or any funds but their own. Policies of care in the community depend very heavily on the availability of such people, but this is a fact of which the preoccupations of government-funded research, certainly at the time that I was associated with it, gave somewhat less indication.

I am increasingly conscious of the contrast between the tightly-controlled government-funded research which I helped to manage for the DHSS and the kind of research program which I have been devising here. Both are paid for by the state, it is true. Both are concerned with questions which have implications for social policy. Both emerge in contexts in which restraint of public expenditure is held to be imperative. In both cases, the context has also been shaped significantly by a policy of moving people with disabilities away from or keeping them away from institutional care. But it is clear in the one case that research priorities are entirely those of the government as manager and liquidator of the old-style institutions, faced with the necessity of finding alternatives. In the case of our research on care for people with disabilities who live at home, I hope we may come closer to answering questions which reflect a little more closely some of the priorities of dependent people themselves, as well as those of the people who care for them. I also hope that the results may still have their relevance for government.

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DEINSTITUTIONALISATION OF PEOPLE WITH DEVELOPMENTAL DISABILITIES: A NEW SOUTH WALES EVALUATION

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1. INTRODUCTION AND BACKGROUND

It is my intention to narrow the focus of the topic of deinstitutionalisation of the developmentally disabled and to put it in a local context by reporting on a study which evaluated the effects of relocating people from State Hospitals in New South Wales into group homes in the community as a result of Richmond Report (Richmond, 1983). Australia has been a relative late-comer to the field of formal deinstitutionalisation of people with developmental disabilities by comparison with Europe and the United States. In New South Wales informal discharges of people with developmental disability from hospital into the community has been occurring for at least 15 years. Since the 1970s a number of Australian States have held public enquiries and produced government reports on services for developmentally disabled people, most of which recommended relocation into the community - Victoria, South Australia and Tasmania are cases in point. In New South Wales the first formal government-sponsored move to relocate intellectually disabled people from institutions came as a result of the 1983 Richmond Report. This report recommended deinstitutionalisation even of the most severely affected, but neglected to build in an evaluation component. The move of people with developmental disability into the community together with the availability of a Prince Henry Hospital centenary research fund grant gave the opportunity for this study and allowed the monitoring of clients placed in houses in our local Area Health service. At the time of commencement of our research no equivalent Australian study had been published, although by now a number of reports are available including that of the closure of St Nicholas' Hospital in Melbourne (1988).

2. AIMS

The study had three aims:

- (i) To investigate changes in the adaptive functioning of severely developmentally disabled persons following relocation from institution to community and to compare them with peers who remained in institutions.
- (ii) To examine what characteristics of the residents and living environments (age, IQ, length of stay, physical and social features of residence, staff management style and care practices, staff attitudes and training, and family perceptions of services) were most strongly related to these changes.
- (iii) To examine directly the activities of residents in order to determine the extent of their appropriate and inappropriate behaviours and staff/resident interactions.

In this paper I will report on some of the findings relating to the first two aims.

3. METHOD

Subjects were obtained by screening a pool of developmentally disabled people in a local 160 bed State hospital. All wards and on site halfway hostels (three) were screened for subjects meeting the criteria of being over 15 years of age, mild, moderate or severely intellectually disabled, ambulant and with no significant sensory impairments or serious behaviour disorders. Fifty seven (57) subjects - 31 males and 26 females, were identified as meeting the criteria. Their age range was 18 to 69 (mean 41 years), years of institutionalisation 2 to 55 years (median 14). 'Movers' consisted of two groups - (a) all residents from 3 hostels (n = 13 and a random selection

from 6 wards (n = 13) placed in group homes during 1984-85. Thirty one (31) subjects meeting the same criteria who stayed in the hospital - 'stayers' served as the comparison group. All were tested before the move and 11 to 12 months afterwards. At pre-testing it was not known which residents would be moved to the community. The study was a pre-post non-equivalent control group design similar to that used by Conroy, Efthimiou and Lemanowicz (1982).

4. MEASURES

A number of instruments were utilised and some were specially devised for the purpose.

1. The Vineland Adaptive Behaviour Scale (Sparrow et al., 1984) which is an indirect (i.e. information is obtained from a respondent who is familiar with the subjects) measure of social and personal skills, was used to assess changes in each resident's adaptive functioning in a number of areas - communication (receptive, expressive and written language), daily living skills (self care, domestic and community living), socialisation (interpersonal relations, use of leisure time, coping skills) and also provides an index of maladaptive behaviour.
2. Cognitive functioning of subjects was tested on the Peabody Picture Vocabulary Test (Dunn, 1959) and Raven's Coloured Progressive Matrices (Raven, 1962). Neither test relies on language proficiency.
3. An environmental check list to examine the physical, social and organisational features of wards, hostels and group homes.
4. A staff management practices questionnaire looked at the organisation and management of the units.
5. A staff needs assessment questionnaire assessed staff attitudes to clients and their preparation and training for residential care work.
6. A parent and family attitude questionnaire attempted to investigate how they felt about residential services.
7. An adaptation of the Client Behaviour Measure (Porterfield, Evans and Blunden 1981) was used to carry out direct observations on clients and staff (35 matched subjects, 18 from group homes, 17 from wards).

5. RESULTS

In presenting these results I would like to focus initially on the differences observed between the institution wards and the group homes with regard to physical features, staff levels, staff management and care practices and staff training needs and attitudes of staff.

First, the environmental aspects. The focus was on the degree to which residential environments had been 'normalised'. The findings predictably showed that by comparison with community houses, wards had more locked doors, dormitories and uniform colour schemes with less individualised furniture and fittings; residents sat in the same places at meal times, had no influence on the menu and less ability to prepare food or help themselves to food between meals. All staff in houses ate with residents compared with one third in wards. Staff/resident ratios were higher in group homes (1:2.5 c/f 1:6-7) and 12 hour shifts were common in wards. There was less privacy in recreational and bathroom areas in wards. Most group houses were near day programs and community leisure facilities.

Second, staff management practices. The most important findings noted were the tendency for staff in group homes to have more delegated authority and responsibility to make decisions about daily routines e.g. rosters; day evening, weekend, and holiday activities; and purchasing; for group homes to have less 'block' organisation of activities of daily living; more use of local facilities by residents in group homes; slightly more access to structured training programs in homes; and more residents of group homes carried out domestic chores.

Third, staff needs and training. Staff in institutions perceived their medical training and knowledge to be more adequate than staff in group homes, but the latter felt they had been significantly better prepared to integrate clients into the community. Staff in group homes were in general more satisfied with their work conditions, management and supervision, staffing levels, and the competence of other staff than their peers in institutions. Institution staff saw people with developmental disability as more 'deviant' members of society.

Next, the results obtained on adaptive functioning as measured on the Vineland Adaptive Behaviour scale (Sparrow et al., 1984). There was a statistically significant increase in the level of total adaptive functioning following the relocation of residents from hostels and wards to community group homes. In particular, statistically significant differences were found between the pre- and post-test scores in the composite adaptive behaviour of the two relocation groups with improvement in the level of adaptive functioning of those placed in community houses. There was no change in overall functioning of those remaining in institutions (see Figure 1).

There were statistically significant increases in daily living skills, self care, and domestic, community, and coping skills of those placed in the community. There was no change in the areas of communication skills, interpersonal relations or leisure skills between the two groups (see Figures 2 and 3). There were no significant differences between groups in maladaptive behaviours although some clients showed evidence of a 'Relocation Syndrome' (Kasl, 1972) - a recognised transient phenomenon with withdrawal, regression, anxiety and aggression.

6. FAMILY REACTIONS

Only 20 responses to questionnaires (11 from institutions, 9 community) were returned out of the 57 sent. Most relatives preferred their family members' present placement. Of interest however, were answers to questions concerning where family members wanted their disabled relative to be living in twelve months time. All respondents with relatives in group homes affirmed that they wanted them to remain in this setting. By contrast 5 of the 11 respondents with relatives in institutions were uncertain.

7. CONCLUSION

This concludes the presentation of results of our study, which are in line with research across the world. A period of 11 months is too short to establish whether the improvement in relocated subjects will continue to be permanent and further assessment is planned. If funds are available the subjects will be followed up at 2 1/2 years after placement.

The study does not attempt to find reasons for the changes, although the factors most related to the changes have been established. I would like to finish by quoting some of the conclusions published in the **American Psychologist**, arrived at by Landesman and Butterfield (1987) following their extensive review of deinstitutionalisation studies. The following conclusions are of relevance to planners and policy makers in New South Wales:

1. The most severely and profoundly disabled persons, even those with additional problems, can progress in settings other than large institutions.
2. Improving institutions has less effect than a move to community houses.
3. The fears of parents and communities diminish over time.

We hope these conclusions and the results of our study will be taken into account in the future planning of services for people with developmental disabilities in this State.

FIGURE 1: CHANGE IN ADAPTIVE BEHAVIOUR FOLLOWING RELOCATION TO THE COMMUNITY

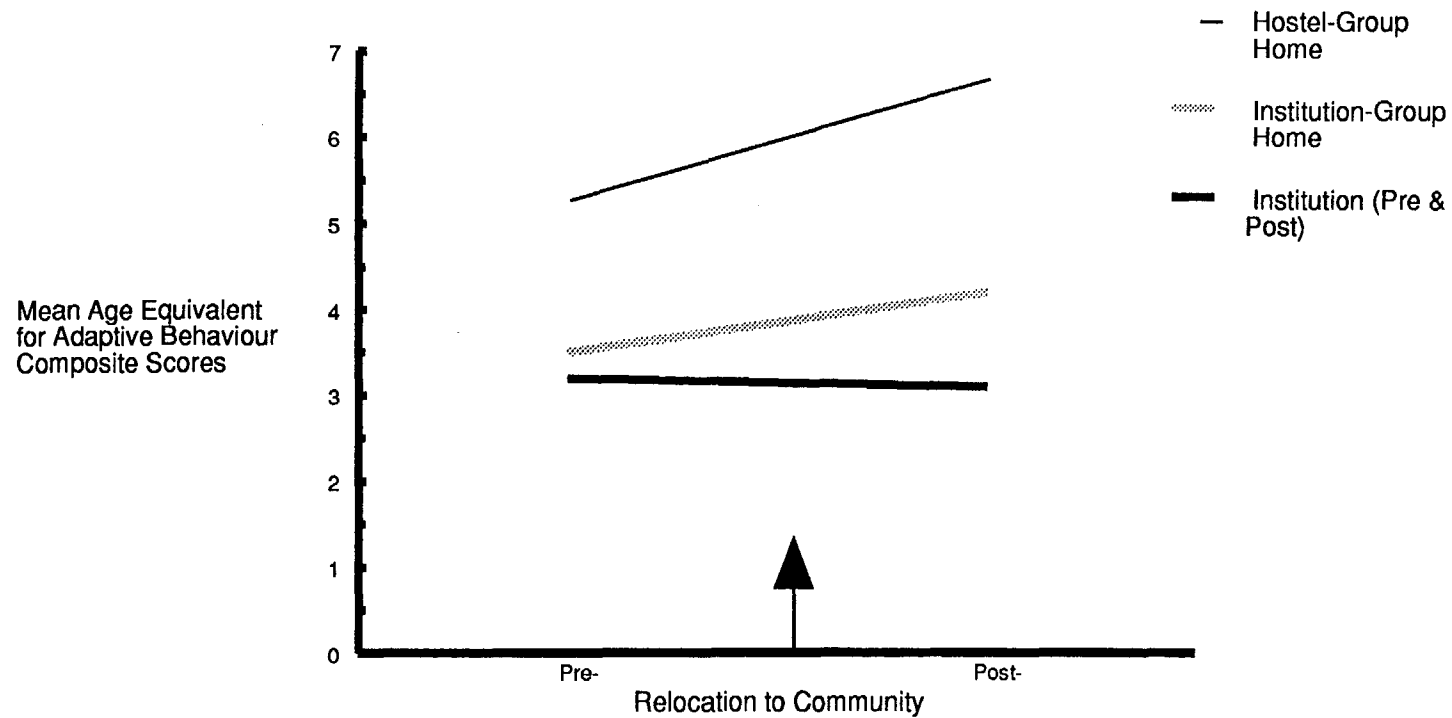


FIGURE 2: DEGREE OF SOCIAL MATURITY AND INDEPENDENCE

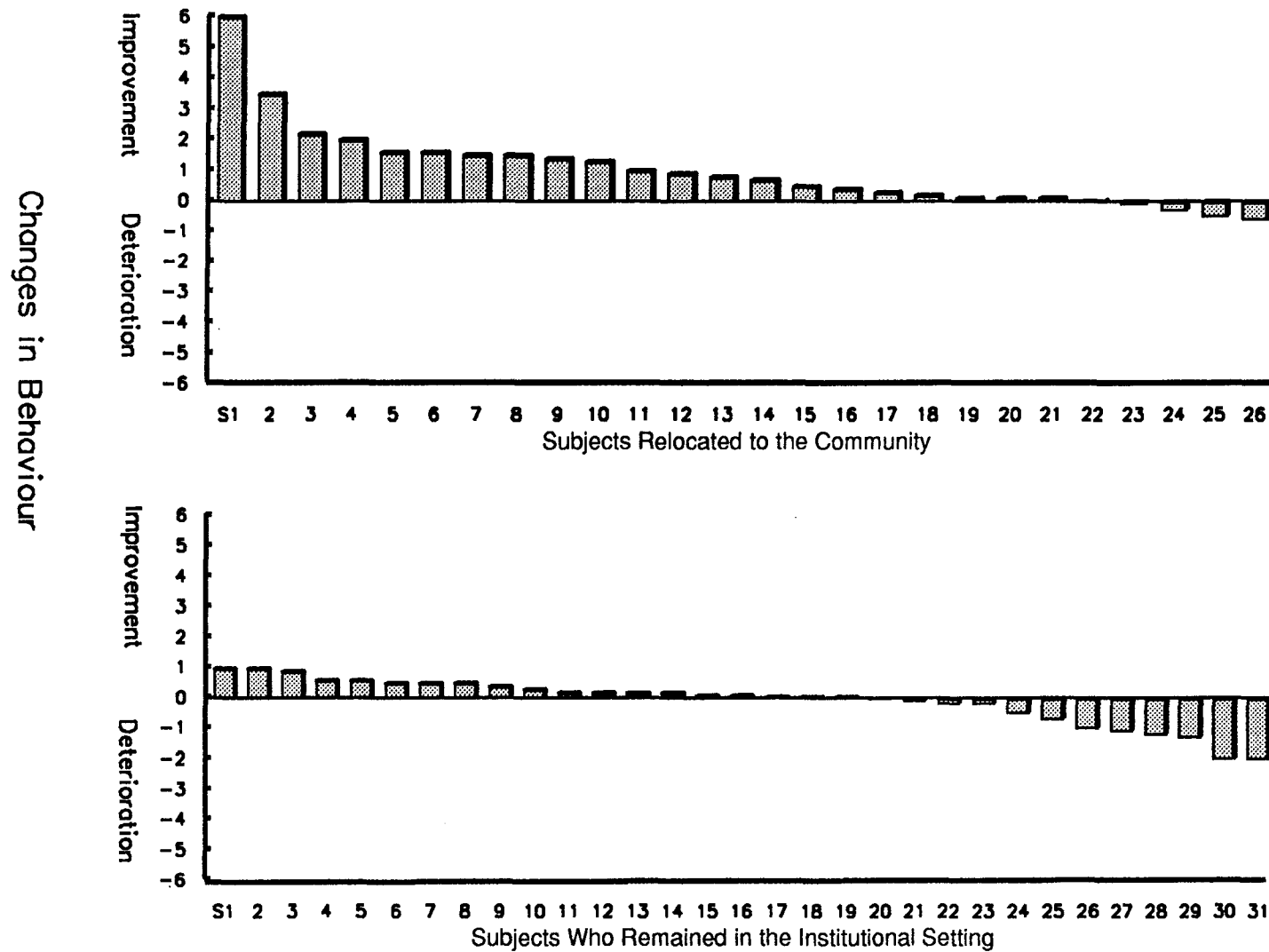
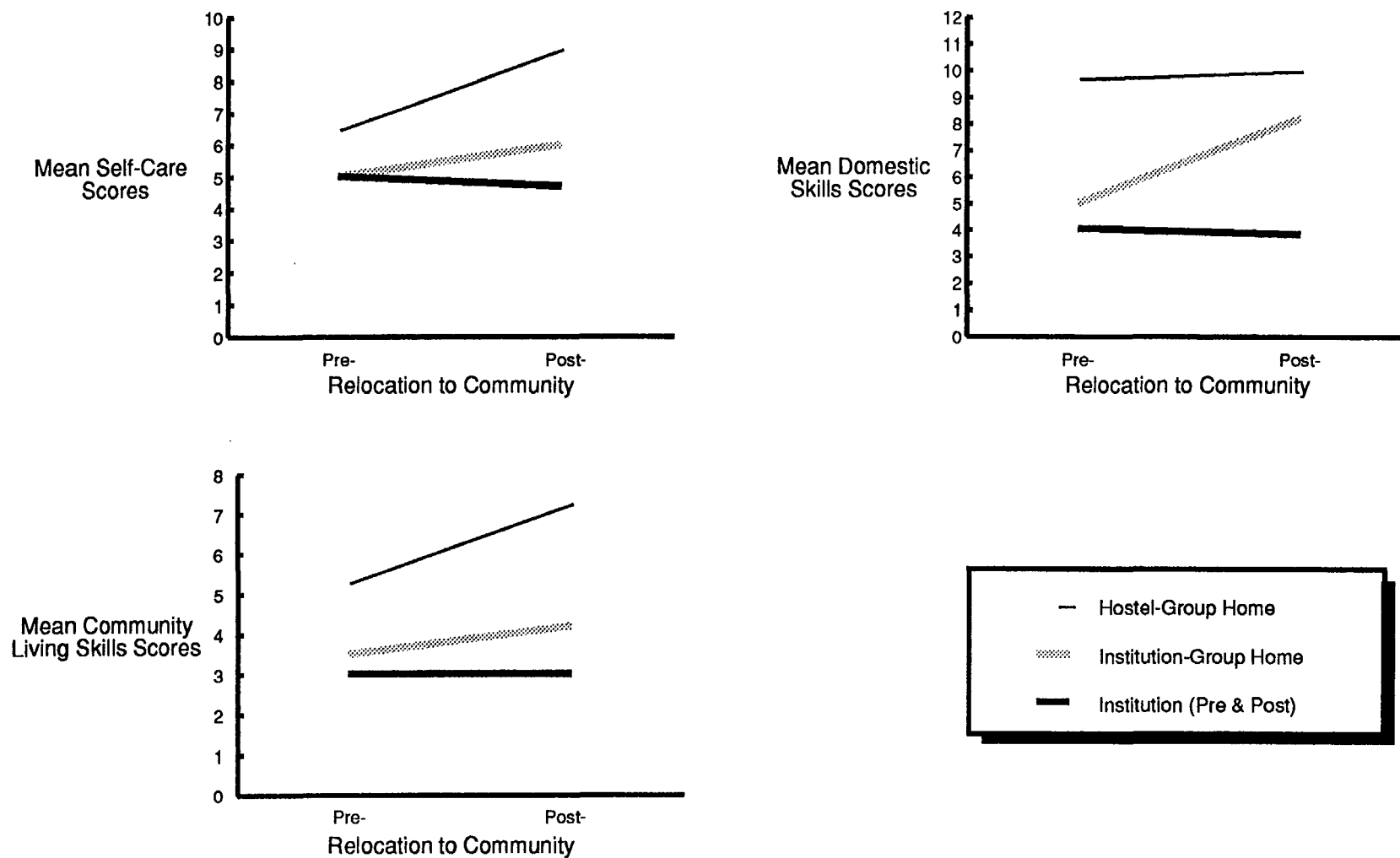


FIGURE 3: CHANGES IN DAILY LIVING SKILLS FOLLOWING RELOCATION TO THE COMMUNITY



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FAMILIES AND COMMUNITY CARE *

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FAMILIES AND COMMUNITY CARE

This paper deals with those families or other household members providing practical care and attention (usually on a day-to-day basis) for people with a functional disability (usually of a moderate or severe level in the area of self-care) in the same private household¹. Therefore, it does not deal with all families or all people with disabilities. Examples are primarily drawn from the situation applying in New South Wales.

An Historical Perspective

In the recent debate in the United Kingdom, one observer noted that 'community care' means different things to different people:

To the politician, 'community care' is a useful piece of rhetoric; to the civil servant, it is a cheap alternative to institutional care which can be passed to the local authorities for action - or inaction; to the visionary, it is a dream of the new society in which people really care; to social service departments, it is a nightmare of heightened public expectations and inadequate resources to meet them. We are only just beginning to find out what it means to the old, the chronic sick and the handicapped. (Jones, Brown and Bradshaw, 1978, p. 114)

Interestingly, the question which is often omitted is, what does community care mean for families?

Debate about the role of families in the care of frail elderly and other people with disabilities, however, is not a new issue. The Elizabethan Poor Law of 1601 set out to codify society's expectations of familial responsibilities at that time and provided that

..... the father, grand-father, mother, grand-mother and children of every poor, old, blind, lame, and the impotent person or other poor person not able to work, being of sufficient ability shall, at their own charges, relieve and maintain every such poor person according to the rate assessed by the Justice of the Peace. (cited in DeJong, 1982)

While New South Wales never quite had a Poor Law as such, the poor houses and asylums were quickly transported to the new colony. The destitute aged and infirm had been cared for in institutions since the opening of the Benevolent Society's Sydney Asylum in 1821. Run by a voluntary charity, but massively subsidised, was this Australia's first 'nursing home' just 33 years after European settlement?

In 1862, the Government assumed direct responsibility for the management of institutions for this purpose; with aged and infirm women being moved to Hyde Park Barracks (no longer required for convicts) and aged and infirm men separated and moved to the old Military Barracks, Parramatta, and the former Liverpool Hospital.

* Any views expressed in this paper are those of the author and not necessarily the views of the Department of Family and Community Services.

1. See definitions of functional disability in Australian Bureau of Statistics, **Handicapped Persons Australia, 1981**, (Catalogue No. 4343.0).

These asylums were extended and others established, and so by 1900 some 5,068 aged and infirm were officially recorded as inmates of institutions (80% in government asylums) (Kewley, 1973).

Echoing Poor Law sentiment, the Inspector of Public Charities, in his annual reports of the time, bemoaned the growth of an attitude in the community that

...self restraint and provident habits are unnecessary - that to the Government they have a right to look for provision in sickness or old age - and that on it they may cast the responsibility of maintaining parents, children, or any other helpless members of their family whenever it becomes convenient and without reference to their ability to bear such burden. (Kewley, 1973, p. 16)

While large numbers of the aged and infirm continued to be cared for in institutions, the State Children's Relief Board had since 1881 been gradually reducing the number of neglected and destitute children in institutions through a 'boarding-out' system (many of whom were, by the turn of the century, actually 'boarded-out' with their own widowed or deserted mothers, following legislative change in 1896) (Kewley, 1973, p. 14).

One of the major protagonists in the movement for the introduction of old-age pensions in the colony was J. C. Neild, member for the district of Paddington in the New South Wales Legislative Assembly. On 16 June 1896, Neild proposed in Parliament a similar 'deinstitutionalisation' program for the aged and infirm:

... 'Old-age pensions or out door relief should, as far as possible, be substituted for the existing asylum system...' He explained that he did not envisage a scheme of general application, but simply that about one hundred of the 'best-charactered' inmates of the asylums should be selected and provided with outdoor relief, instead of being maintained in those institutions. This small experiment, he contended, would cost the Government nothing as it was planning to create a new asylum and spend approximately 7 shillings per person a week in indoor relief. (Kewley, 1973, pp 541-542)

The New South Wales Old-Age Pensions Bill when finally introduced in November 1900 was certainly much broader in intent and coverage than Neild's scheme of replacing care in asylums with the more 'enlightened' methods of outdoor relief he had seen in Europe. Nevertheless, it is worth noting that the scheme significantly overspent its expected budget in its first full year of operation and the asylums were never actually closed down - only their roles and their 'inmates' changed.

Moving ahead several decades, the Commonwealth Joint Parliamentary Committee on Social Security recommended in 1941 that the Minister for Social Services determine the most suitable means of caring for the age pensioners. As well as a scarcity of suitable accommodation for age pensioners generally, it was disturbed by the number it found accommodated in state institutions, most of which were drab places with dormitories or wards and communal dining rooms, and which often required the breaking of domestic ties (of husband and wife) as a condition of entry.

A decade later the same concerns were still noted:

There can be no more depressing sight than an old people's dormitory with bare floors and tidy rows of beds and small lockers, or common room full of men and women who look as though they are merely waiting to die. In our State institutions are inebriates, mental defectives, social misfits, people with senile dementia, people who are convalescent after a long illness and people whose only disability is the physical infirmity of old age. (Kewley, 1973, p. 312n)

One of the aims of the Commonwealth Aged Persons Homes Act introduced in 1954, was specifically to foster the companionship of husband and wife, so as at least to avoid the segregation of married couples which had occurred under previous forms of care. Nevertheless, Prime Minister Menzies had earlier articulated the assumption that accommodation for aged persons would particularly benefit those who had no other family to help them. Yet by 1957 when amending legislation was required, the then Minister for Social Services soberly observed that despite the massive building program there were still long waiting lists - attributable in part to

'... the modern tendency for young couples to build small houses or family units in which there was no room for elderly parents' (Kewley, 1973, p. 315).

Following a massive escalation of costs and numbers in nursing homes, there were threats in 1972 from the Private Hospitals' and Nursing Homes' Association that a large number of nursing homes would be forced to close down unless Government benefits were increased. In the 1972 Budget, Treasurer Snedden announced that the Commonwealth Government proposed to introduce '... new nursing homes, but also to assist aged infirm people who can be looked after in a home environment' (Kewley, 1973, pp 541-542).

In 1969-70, some \$47 million was already being spent on nursing home benefits. By 1979-80, the expenditure on nursing home and hostel subsidies (excluding capital grants) had grown to a staggering \$327 million.

The period 1969 to 1972 saw, for the first time in our history, the development of a range of government schemes specifically aimed at encouraging aged and infirm persons to remain in their own homes for as long as they were able. This 'comprehensive and co-ordinated program for home care' included:

- subsidies to the States for home care services, senior citizens centres and welfare officers (1969);
- subsidies to the States for paramedical services (1969);
- subsidies to organisations providing meals on wheels services (1970)
- domiciliary nursing care benefits (1972);
- increases in subsidies to organisations providing home nursing services (1972).

While all these schemes were slow to start, once established expenditures grew quite rapidly (from less than \$0.25 million in 1969-70 to almost \$40 million in 1979-80).

Despite the focus on 'care in their homes', surprisingly little emphasis was actually given to the role of family carers. The Home and Community Care (HACC) Act was introduced in 1985 and brought together most of the above schemes as well as providing for an expansion of funding for a wider range of support services. Only then did we have explicit legislative recognition of family and other carers as a legitimate target group for support in their own right.

A parallel approach developed in assistance for children with disabilities. The Commonwealth entered this field in 1968 with the announcement of a Handicapped Children's Benefit; however, this benefit was only available to charitable organisations operating residential handicapped persons homes.

Families looking for support in caring for a child at home had to wait until 1974 for the introduction of the Handicapped Child's Allowance. Ironically, until recently when a family normally caring for a child with a disability placed that child in short-term residential respite care, the family lost their entitlement to Handicapped Child's Allowance (now Child Disability Allowance), while the residential agency became eligible for the Handicapped Children's Benefit at about twice the daily rate.

The Current Context

The 1981 Handicapped Persons' Survey conducted by the Australian Bureau of Statistics (ABS) found that approximately 8.6 per cent of the population, or 1 264 600 Australians, were handicapped (by which it means people with one or more of a list of specified disabilities or impairments who as a result are limited in their ability to perform certain tasks of daily living, schooling or employment).

**TABLE 1: PERSONS WITH SELF-CARE HANDICAP:
SEVERITY BY TYPE OF RESIDENCE**

Severity of Handicap	Type of Residence		
	Households	Institutions	TOTAL
Mild	22 600	4 900	27 500
Moderate	220 900	6 600	227 500
Severe	204 800	84 400	289 200
	<hr/>	<hr/>	<hr/>
TOTAL	<u>448 300</u>	<u>95 900</u>	<u>544 200</u>

Source: Australian Bureau of Statistics, **Handicapped Persons Australia, 1981**, Catalogue No. 4343.0, Table 1.2.

Less than 9 per cent of these handicapped persons lives in institutions; 91.2 per cent were in ordinary private households. Even when we focus in on those people with difficulties in showering, bathing, dressing or eating a meal, we find that many more people continue to live in private households - even when the handicap or limitation is at a severe or moderate level.

Almost eight out of ten handicapped persons (77.2%) lived in families with other adult members who might provide help or assistance. However, 17,100 were handicapped lone parents caring for dependent children (1.6%), 3 800 were handicapped lone parents living with another handicapped relative as well as caring for dependent children (0.4%); and further 200,900 (18.8%) were handicapped persons living alone.

Further support for the significance of family relationships in community care is provided when we compare marital status of handicapped persons in private households (where 52.6% are married), with those in institutions (where 49.5% are widowed).

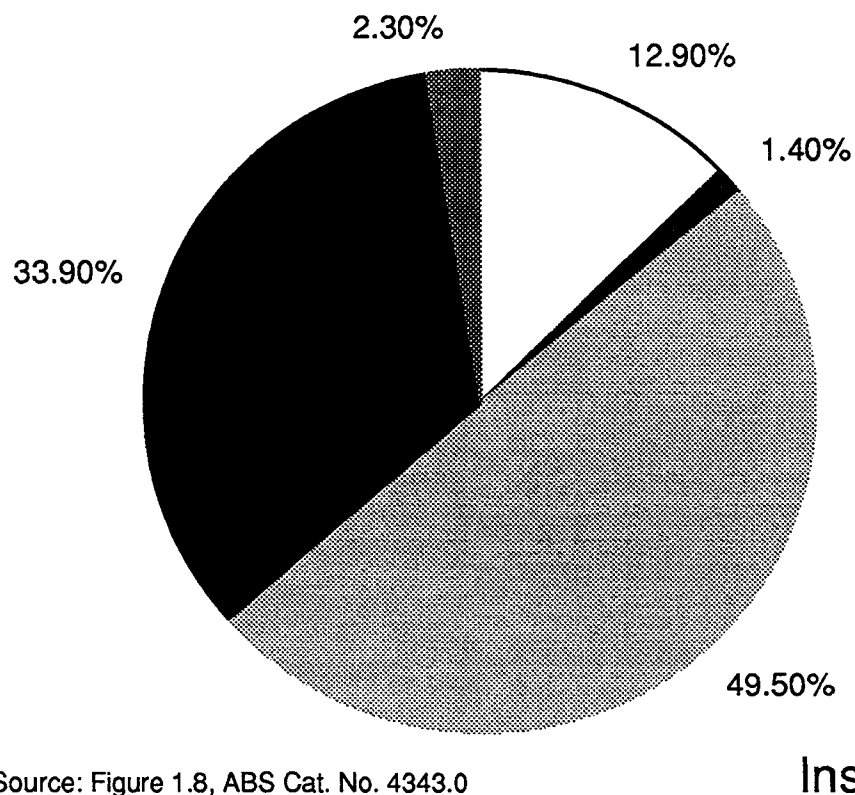
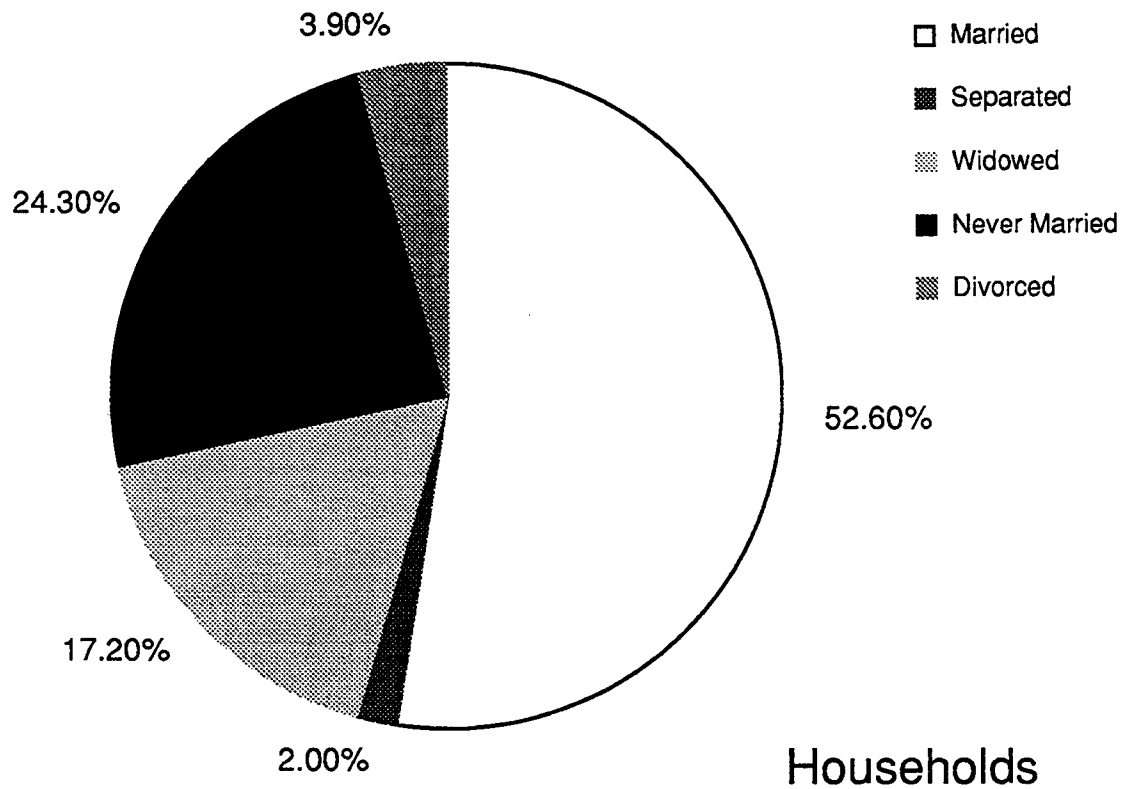
The ABS survey identified the most striking characteristic of people with handicaps as being their age profile. The percentage of people with handicaps, after remaining relatively constant in the younger age groups, rises very rapidly in the older age groups. So, for example, while 9.7 per cent of the population generally are aged 65 years and over, 36 per cent of persons with handicaps and 73 per cent of those in institutions, are aged 65 years and over. The comparisons are even more extreme when we look at those 75 years and over.

Australia is currently experiencing rapid population ageing. While the percentage of the population aged 65 years and over actually declined in the 1960s, it had increased to almost 10 per cent by 1981 and is expected to rise to just under 13 per cent by the year 2001 and over 16 per cent by 2021. The proportion aged 75 years and over will grow at an even faster rate (Kendig and McCallum, 1986).

At the same time as the potential demands for support are set to increase rapidly, numerous commentators have identified a reduction in the capacity of the traditional sources of family care:

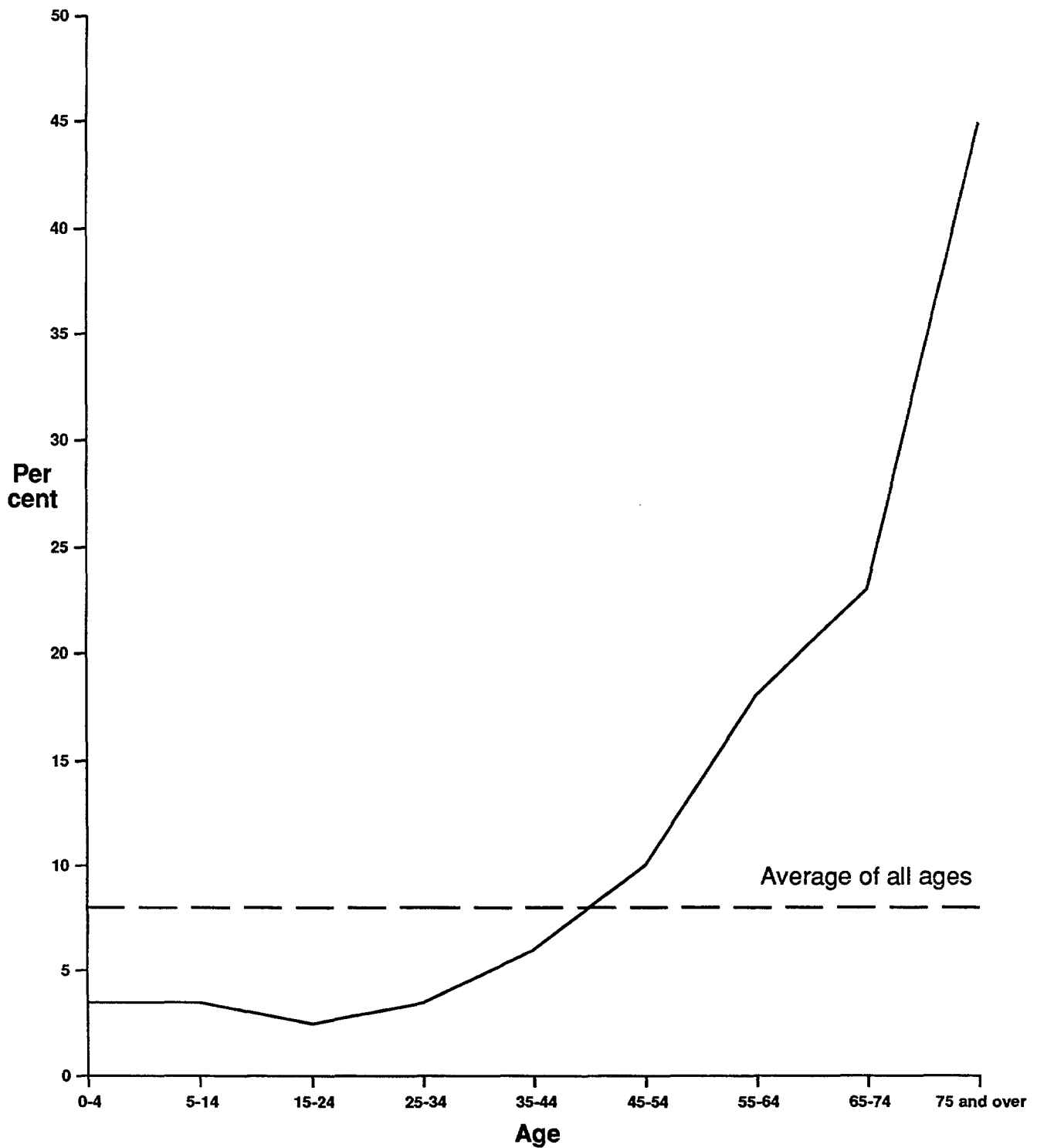
- smaller family size and childlessness will reduce resources available for family care (Kendig and McCallum, 1986, p.51);
- the increase in rates of divorce, separation and single parenthood mean that the important support of a spouse might not be there in old age - it also means less family resources to care for a dependent child (Kendig and McCallum, 1986, pp 19-20);

FIGURE 1: HANDICAPPED PERSONS: TYPE OF RESIDENCE BY MARITAL STATUS



Source: Figure 1.8, ABS Cat. No. 4343.0

FIGURE 2: HANDICAPPED PERSONS AS A PERCENTAGE OF TOTAL POPULATION BY AGE



Source: Figure 1.5, ABS Cat. No.4343.0

- the significant growth in the workforce participation rates of women (especially married women) directly reduces the traditional pool of carers (Kendig and McCallum, 1986, pp 14-15, 51);
- increasing urbanisation has been shown to be associated with decreasing opportunities for family care (Perlman and Giele, 1982);
- workforce and family mobility can also lead to families being separated across large distances (Kinnear and Graycar, 1982).

The relationship between the three principal parties (the person with a disability, the family and the society) have been described as an 'unstable triad' (Perlman and Giele, 1982, pp 12-13). Under this approach the key variables are assumed to be:

- the physical and emotional needs and demands that the person with a disability places upon the family;
- the material and non-material capacities of the families to meet these needs and simultaneously to fulfil other family functions; and
- the availability and use of community resources such as support services.

This is a useful approach for it emphasises that change in one part of the equation will require compensation and adjustment in the others. This is equally applicable to the complex and delicate balance at the household level, as it is at the societal level. When the resources of families are not equal to the task, and when they do not receive adequate support, the results can lead to inadequate care, or costly and unnecessary institutionalisation, or deterioration and even breakdown in the family itself.

Changes are quite clearly taking place in the shape, size and capacities of families. At the same time, society (particularly in the post-war years) has become more involved in the provision of publicly funded support programs (particularly residential care). Different views are taken on which is 'cause' and which 'effect'.

There is concern that the evolution and growth of the welfare state itself has 'crowded out' the role of families and reduced their willingness to provide social care (Moroney, 1982, p.190). Some may be surprised to find that this is not a new concern, and can even be found pre-dating the major expansion of public welfare services (Kewley, 1973, p. 21).

On the other hand, it is argued that the changes are largely evolutionary and reflect the changing nature of the family itself. That is, a weakened family necessitates an increased role of the state to 'fill the gap' (Kendig et al., 1983). However, this gives little regard to the way in which services have been organised. As we have seen, until fairly recently, services have primarily been designed to 'substitute' for families rather than 'support' them.

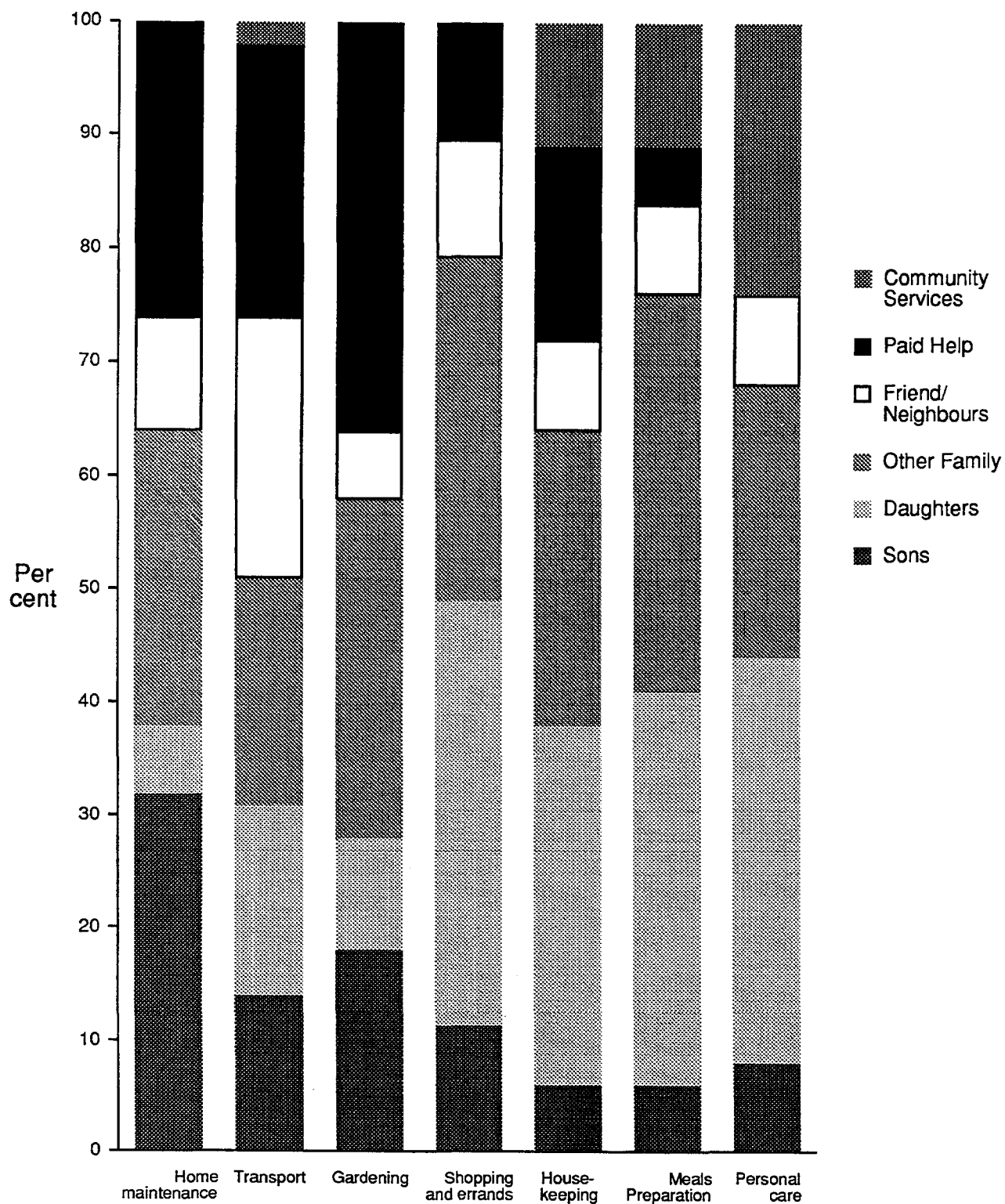
The result has been a forced dichotomy between society and families. While this has provided fuel for ideological debates on the family and the welfare state, it has tended to overlook the realities of family care and has not been able to devise a practical approach to family policy.

The Realities Of Care

All the evidence points to a vast amount of care still being provided by families in ordinary households. This is reflected in the results of the 1981 Handicapped Persons' survey outlined above concerning the place of residence, household composition and marital status of people with handicaps.

The Ageing and the Family project, for example, identified the preponderance of assistance with the essential tasks of daily living being provided by families for older people with handicaps (Kendig, 1986).

**FIGURE 3: HANDICAPPED AGED:
SOURCES OF ASSISTANCE**



Source: Figure 10.3, H.L.Kendig & J.McCallum, "Greying Australia: future impacts of population ageing", AGPS, 1986.

This research shows that spouses and daughters in particular usually provide the more intensive and regular day-to-day assistance. Only a very small proportion of assistance is provided from subsidised community services - for example, only about 7 per cent of older people were using meals on wheels, home help or community nurses and virtually no services were evident providing shopping, gardening, transport and home maintenance.

By way of aside, it is probably important to note that we can develop a distorted picture if we only concentrate on the dependencies of people with disabilities and see the family purely as a 'service system'. As one United States observer has warned:

The dependent individual then becomes a costly user of these [family] services, whether they are priced in terms of the usual wages in the community or of contribution that the dependent person makes to that primary group. The older woman who requires shopping assistance has just finished knitting a dress for her grand daughter; the dependent aunt for whom the bed pan has been emptied has for years been the 'significant other' for her retarded niece (a psychiatric service?); the wheel chair-bound father-in-law has just called in some of his chips and made arrangements with the local banker and lawyer to set up his son-in-law in business. The service equation looks only at the costs of what is provided; it does not take into account the contributions that are made by other members of a primary group on a reciprocal basis. It will be very important to get out of this trap, otherwise dependent people will be further devalued on the one hand, and become too expensive on the other. (Perlman, 1983)

Australian research confirms that older people, for example, are major contributors of not only emotional and social support, but also of practical assistance (such as child-minding and transport) (Kendig and McCallum, 1986, p. 41).

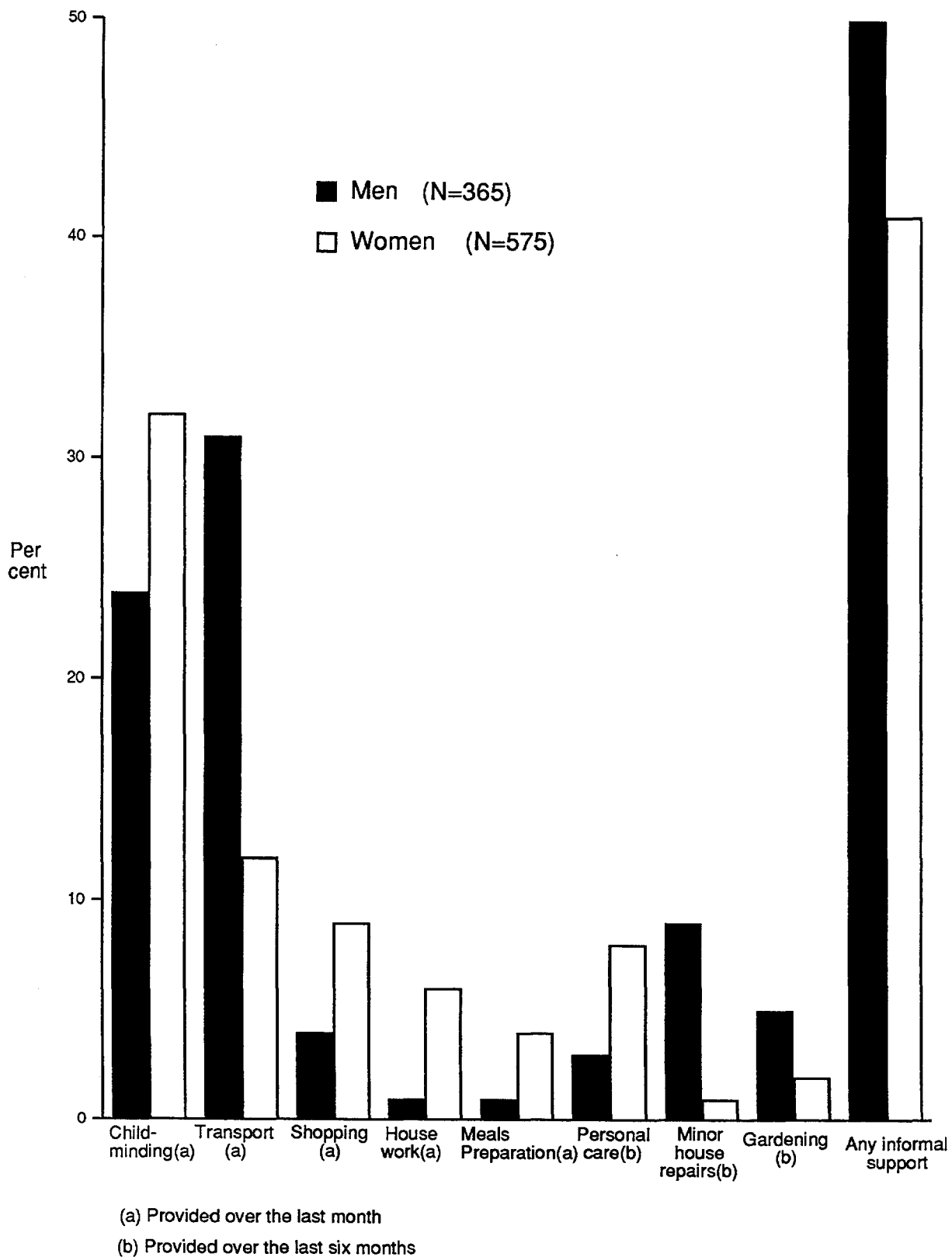
Similarly in terms of financial support or shared households, older people are much more likely to be providers than recipients. Furthermore around half of the people of retirement age are also involved in making their own contribution through voluntary community work (Kinnear and Graycar, 1982). This compares to the 7 per cent of elderly who are recipients of subsidised community services.

Nevertheless, as two recent small-scale local surveys by the Social Welfare Research Centre indicate, for those families caring for elderly or disabled members the responsibilities are often burdensome and take a heavy toll.

A 1982 survey of families caring for elderly people with disabilities (Kinnear and Graycar) found that the carers:

- had less time for recreation and leisure activities (79%);
- suffered a deterioration of work performance, when in paid employment (84%);
- had less time to complete housework and allied chores (52%);
- suffered from a deterioration in the relationship with their spouse (56%);
- were less able to relax and sleep at night (60%);
- were more apprehensive about their own growing older (51%);
- suffered a rapid deterioration in their relationship with brothers or sister (90%);
- experienced a decline in their general emotional well-being (50%).

Furthermore, this burden of care was usually born by one person in the family - in 95 per cent of cases a woman (half of whom had been required to give up paid work to take on this caring role). This caring role was usually lonely and carried out with little support from others:

FIGURE 4: CONTRIBUTION OF THE AGED

Source: Figure 4.3, H.L. Kendig & J. McCallum, "Greying Australia: future impacts of population ageing", AGPS, 1986.

Neither spouses nor children contributed significantly to care for the elderly relative. While many husbands were supportive of their wife's caring role, they felt it was her duty and provided little assistance. (Kinnear and Graycar, 1982, p. ii)

A 1980 to 1982 survey of families caring for children with disabilities similarly found that '...parents, but especially mothers, have enormous and almost unbreakable stresses on them if they attempt to care adequately for their severely handicapped young children' (Rees and Emerson, 1984, p. i).

Not only is care emotionally and physically draining, but it also presents families with significant financial costs. A number of studies have attempted to document the costs of disability, but what is particularly pertinent for this discussion is the comparative costs of community care in families and institutional care.

A comparative study by Tim Philips (1987) indicated that total costs were much the same, with community care marginally more expensive. Updated to 1988 values, these costs are just under \$250 per week. Many of the components, however, are hidden and Philips refers to them as the cost 'iceberg'. As Table 2 indicates, a significant proportion of the costs of care at home are borne by the family (43%) and the individual concerned; only 15 per cent relates to subsidised services and this is reduced further by fee recoupment. The total cost of nursing home care appears to be significantly under-estimated in these calculations but in any case is much more heavily subsidised. Thus the individual and (particularly) the family carer 'pay' significantly more for care at home.

**TABLE 2: COMPARATIVE COSTS PER WEEK
(UPDATED TO 1988 VALUES)**

Nursing Home Average (<u>Ordinary Care Level</u>)	Home Care Average (<u>Home Nursing Clients</u>)
\$241.50	\$246.00
Includes:	
Food Accommodation Nursing Personal Care Recreational Therapy, etc.	Living Costs - 24 per cent Housing Costs - 16 per cent Formal Care - 15 per cent Informal Care - 43 per cent (includes estimated value of carers time) Transport - 1 per cent
Sample n = 37 Nursing Homes	Sample n = 39 Clients of Home Nursing Service

Source: Philips, 1987, p. 332. Updated to 1988 values by movements in the Consumer Price Index.

Yet despite these pressures, strains and costs, families are continuing to provide the vast bulk of care for people with disabilities - there is no large scale 'dumping' of responsibility:

Despite the problems associated with care, the carers as reported above overwhelmingly rejected that alternative living arrangements may have been possible when the question of care first arose. When faced with what conceivably may have been an alternative to home

care, most families really never perceived themselves as having a real option. To them, there was a clear cut duty or obligation to care, whether it was because it presented an opportunity 'to repay my mother for her past help' or because 'families ought to look after their parents'. This sense of duty or obligation was also reflected in their reluctance to consider the hypothetically posed question that there may come a time when nursing home care was the most practical, sensible and workable solution.

Almost two-thirds (65%) responded to this question by admitting some possibility of nursing home care existed but only when the elderly relative became so physically dependent that the care required was beyond their means especially if the elderly person became confused, incontinent and generally unaware of their surroundings. However, they rarely felt that their relative would last to this stage. The other 35 per cent were adamant that 'as long as I am alive, my mother will never be placed in a nursing home'. (Kinnear and Graycar, 1982, p. 40)

Even the long waiting lists of parents who said they wanted residential care for their young disabled children, was largely composed of families who wanted to '... quickly take out some form of insurance to protect themselves against the prospect of being unable to cope at some point in the future. In most cases the business of seeking permanent residential care for their child did not prove subsequently to be a major concern of the parents' (Rees and Emerson, 1984, p. 4).

In summary, families do not want to give up, but they do want support. The support required is essentially practical and non-professional. It includes social support, personal care, transport and financial aid, and house maintenance care (Perlman, 1983, pp 155-156). Services are required which support families (and particularly women) in carrying out their caring role where this is their choice.

Families' requirements of professionals are equally modest. They want people who are sympathetic and understanding of their feelings, helpful in answering questions and providing information, and able to refer them to other services and resources they might need (Rees and Emerson, 1984, p.20).

The Performance of HACC

The Home and Community Care Program was introduced in 1985-86 and is now the major government funding scheme for community care services. It has attempted to address many of these issues:

(i) The extent, range and scope of support services have been significantly expanded in the last two years:

- a doubling of program expenditure (from just over \$57 million in 1985-86 to almost \$104 million in 1987-88) has resulted in 400 new or expanded services being funded across New South Wales;
- new service types have been established to provide a wider range of practical supports, including shopping, transport, home maintenance and modification services.

(ii) A particular priority has been given to the development of a broad spectrum of respite services:

- approximately 16 000 hours of in-home relief is now provided every 4 weeks by the Home Care Service of New South Wales with HACC funding;
- in addition, around 100 new and expanded respite services have been approved since the program's inception (these include day care, host family and peer support schemes).

(iii) Specialist services have been funded to provide extra back-up and support with respect to dementia and continence problems:

- these are two areas which appear to be particularly burdensome for carers (Rossiter et al., 1984, p. 95).

(iv) Aboriginal and migrant families, who have in the past all too often missed out on assistance, have been particularly targeted for assistance:

- established agencies such as Home Care are continuing to assist an increasing proportion of such families;
- more than 80 new services (many of them day respite schemes), which are culturally and linguistically appropriate, have been set up.

An important experiment was also established last year with funding of eight pilot 'community options' projects in different areas of the State. By the employment of 'case brokers' and the allocation of a flexible pool of funds to purchase the needed services, these projects aim to test out a more sensitive and adaptive approach to organising support.

In its simplest form, the broker sits down with a person and asks her or him what support or assistance is needed which will make a difference in preventing premature or unnecessary institutional care. As well as helping to negotiate the required support from community services, the broker also assists in negotiating what care and support can feasibly be provided by the family members and friends. The family is deliberately a part of the system - not to impose additional burdens on them, but to recognise the important role it is probably already providing and to buttress it with any needed back-up support.

The philosophy of this approach highlights on the one hand the autonomy and responsibility of the client, and on the other hand the need to ensure that an individualised (tailor-made) package of support is available, one which fits around and supports the person with a disability and his or her family and social system.

The broker also fulfils an important role as a single point of contact, able to negotiate a complex service system - a friendly and informative person who is available as a back-up, should circumstances change.

While these developments suggest that government programs now may be much better structured to properly support families caring for people with disabilities, we are still a long way from a position where we can afford to be complacent.

Despite the generous and substantial increase in government subsidies, resources remain thinly allocated across an ambitiously wide span of services for a large and increasing target group. Combined expenditure on community care services by both State and Commonwealth Governments in New South Wales was still only one quarter of Commonwealth subsidies provided for nursing homes and hostels in 1987-88.

While HACC has been able to focus on basic maintenance services, there has not always been the same level of development of education, recreation, training and employment services - which are particularly important to younger people with disabilities.

While there have been some significant developments in workforce policies regarding recognition of child-caring roles (such as worked-based child care, maternity leave and special leave arrangements), there has not always been the same flexibility to allow carers to remain in the workforce where there is a family member with a disability.

The relationship between the income support system and community services has not been fully explored. Despite recommendations of national enquiries², successive Commonwealth Governments have avoided the introduction of a comprehensive attendant care allowance system (which would give considerable autonomy to people with disabilities and probably permit more flexible financial support for family carers).

Traditionally many of the services which were incorporated under the HACC program have responded to funding constraints by restricting coverage of their assistance to those with no family or social supports (NCOSS, 1981). This has perpetuated an 'all or nothing' approach, which in the past has failed to provide realistic support in partnership with family care.

In some areas there is evidence that professionals have actually unwittingly added to the stress and strain experienced by the family carers in the way in which community care has been provided (Rees and Emerson, 1984, p. 65).

The challenge that still remains is whether community care policies can move from the extremes of either ignoring families altogether or putting families so much on a pedestal that we equate lack of support with non-interference. We need flexible and adaptive policies which emphasise a shared responsibility, based on a realistic appreciation of the contribution families are making.

Moroney, who has written widely on families and social policy, summarises the issues with the following guide for policy in this area:

It would seem that in some situations families can provide better care and in others, the State would be the more appropriate caregiver. Given this, there should be a range of policies and specific policies may have multiple purposes. Policies might then be located on a continuum whose end points are extreme forms of substitution (the State becoming the family for the individual) and total lack of State involvement in family life. The needs of families and individuals vary in time and over time, and ideally the State would respond to those variations with policies that support families when they need support and substitute for families when they are incapable of meeting the needs of their members. Even this postulation is incomplete since it suggests a progression from no services to supportive services to substitute services, the last only when the family breaks down. In many cases a family may need some other social institution to temporarily assume the total caring function of a child or frail elderly parent but would reassume primary responsibility after the crisis has been dealt with. From this point of view, both functions (support and substitution) are necessary and neither can be offered as more important or desirable than the other. (Moroney, 1982, p. 210)

2. For example, Report from the House of Representatives Standing Committee on Expenditure, **In a Home or at Home: Accommodation and Home Care for the Aged** (AGPS, 1982) and A. Clarke & J. Faragher **Evaluation of the Attendant Care Pilot Project** (Department of Community Service, 1985).

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SHORT AND LONG TERM PERSPECTIVES IN POLICY DEVELOPMENT

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1. INTRODUCTION

The last few years, from 1985 to 1988, have seen unprecedented activity in the development of policy and programs for home and community care for the aged and disabled in Australia. Not since the introduction of the Community Health Program, the Australian Assistance Plan and other initiatives of the Whitlam Labor Government in the mid-1970s have there been such opportunities for growth and innovation in the community services field. This expanded activity has brought many new participants to the field across the range of senior policy analysts, service agency staff and direct care providers. Paradoxically, it is often these newcomers who most keenly feel frustrations over delays in decisions on funding and the slowness of implementation; some of those with a longer memory and experience are overwhelmed by so much change.

The extent of change apparent at any one time depends very much on the time scale over which it is seen - what seems like little change in the short term may be part of a much more marked change in the longer term. The aim of this paper is to outline a framework for integrating these short and long term perspectives on change that provides not only an understanding of the historical context of present developments, but also assists in planning future change.

2. THE COURSE OF PROGRAM IMPLEMENTATION IN HISTORIC CONTEXT

The course of program implementation can be depicted in three phases as set out in Figure 1: the initial phase of preparatory work but little apparent change, a take-off phase of sustained change, and consolidation in a final phase of stability. Each of these phases, lasting from three to five years, presents a different view of change in the short term, while a medium term perspective of program development is gained from the cycle of the three phases combined in an S-shaped curve.

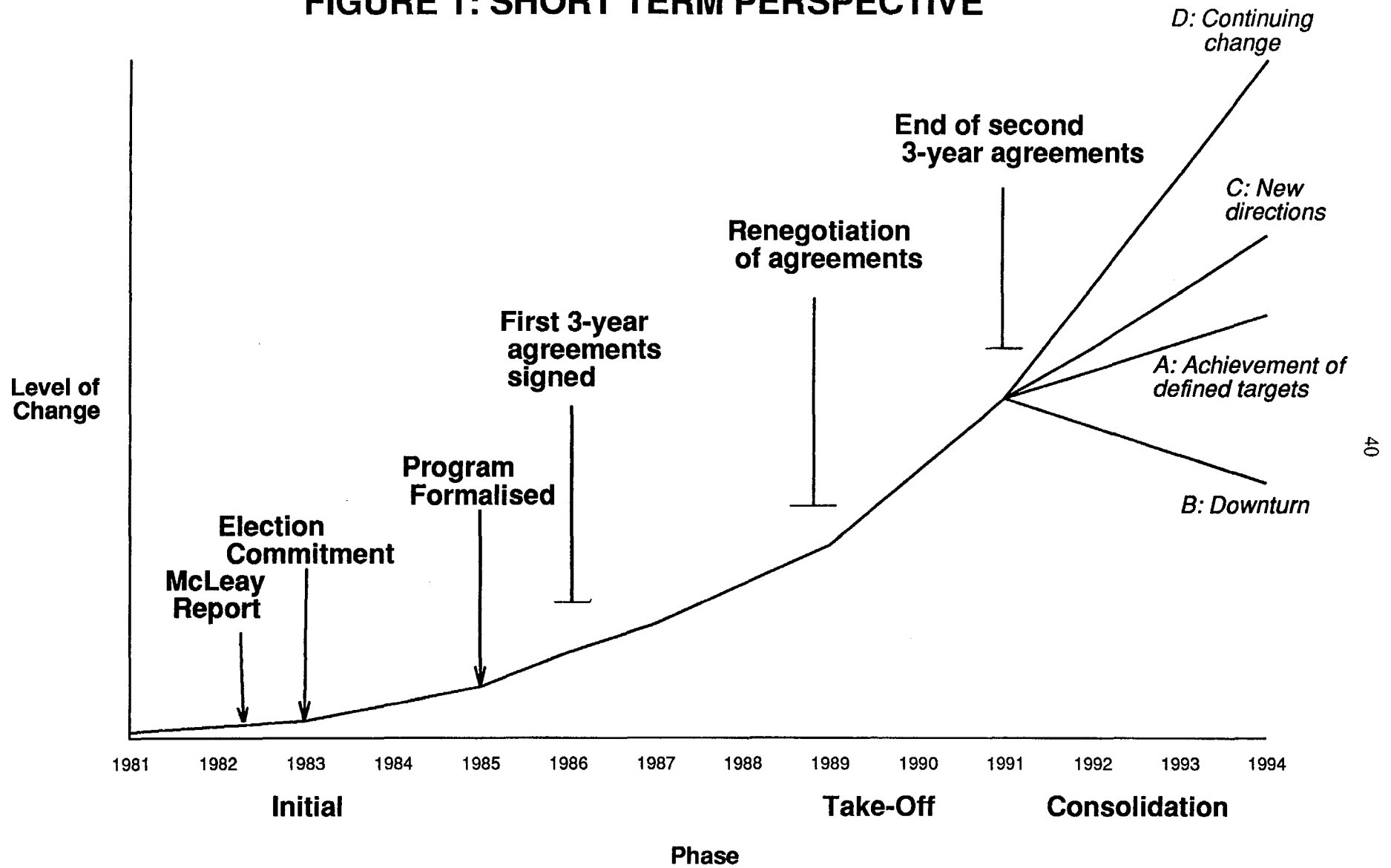
The Short Term Perspective

These three phases can be identified in the development of the Home and Community Care Program (HACC). As depicted in Figure 1, the span just over a decade from 1982 to the early 1990s, with the vertical axis providing a scale of change. Change on this scale is not gauged by funding or any other simple measure but by a more general 'level of activity', graded only in relative terms shown by the slope of the curve. The flat parts of the S curve represent periods of relatively little change at the beginning and end of the period compared to the middle section of significant change.

The initial phase in the implementation of HACC lasted from late 1982, when policy proposals were made in the Report of the House of Representatives Standing Committee on Expenditure Inquiry into Home Care and Accommodation for the Aged (McLeay, 1982), through the commitments made in the 1983 election, to the formal commencement of the program in 1985. Allocations to existing community care programs were increased in the 1983-84 and 1984-85 Budgets, initiating some modest growth in services although not producing major change in the nature of provision.

The beginning of the take-off phase is aligned with the signing of agreements between the Commonwealth and the States from mid-1985 through 1986. These agreements can be seen as a necessary but not sufficient,

FIGURE 1: SHORT TERM PERSPECTIVE



condition for take-off. With this mechanism in place for negotiating program implementation and for the allocation of funds, the potential existed for the level of service activity to increase and the stage was set for the purposeful restructuring of home and community care services to begin. The first three-year HACC agreements covered a continuation of the existing activities supported in the initial phase, some of which were declared 'no-growth' areas, and the support of a range of services that had not previously received Commonwealth funding.

The very rapid growth of HACC is indicated by the increases in funding and the number of service programs supported. Extensions were granted to 487 existing programs at the commencement of the HACC and an additional 1 178 new programs funded in two years; Commonwealth funding grew from a 1984-85 level of \$78 million to \$177 million in 1987-88, an increase of almost 130 per cent (Auditor General, 1988). Whatever the measure of change, the take-off phase can be said to have begun with the formal agreements, and it might be expected that the renegotiation of the agreements in mid-1988 will see the take-off phase advance with further growth and change in program activity.

The date at which the consolidation phase emerges will depend on the pace of these developments, but some significant outcomes might be expected in a further three to six years, so that the impact of the HACC strategy should be evident a decade after its introduction, by about 1992 to 1995.

The Long Term Perspective

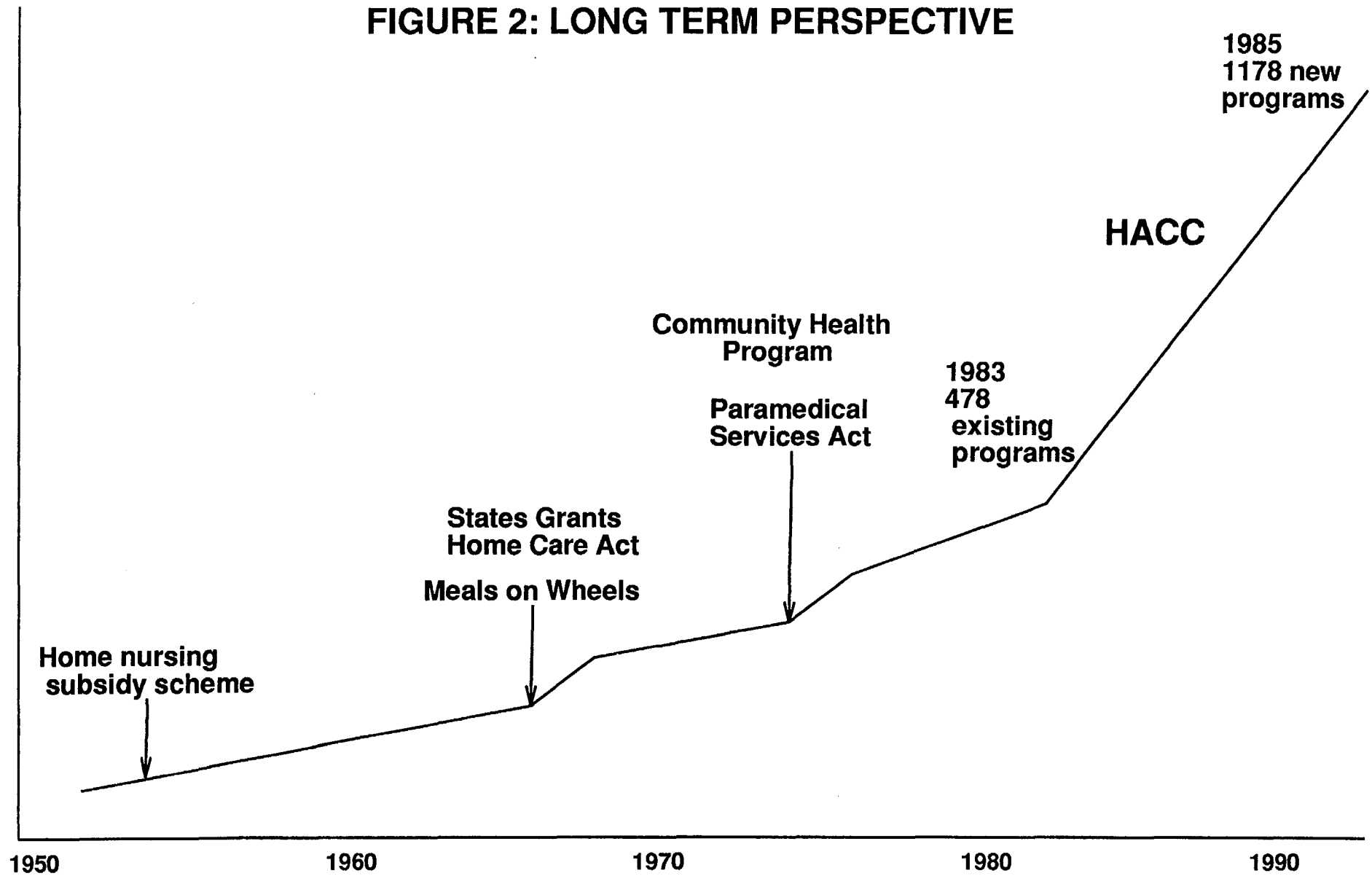
When the current Home and Community Care Program is placed in wider historic perspective, these three phases can be seen to constitute a cycle which has occurred twice previously in the development of community care programs in Australia in the post-war years. This longer time span, from 1950 to 1990, is set out in Figure 2.

Very briefly, the first cycle is characterised by a long initial phase, beginning with the development of domiciliary nursing, formalised in the Home Nursing Subsidy Scheme in 1954, with continuing elaboration of services by local and state governments over the ensuing fifteen years. A short take-off phase saw the implementation of the States Grants Home Care Act, providing Commonwealth support for home care services, and the Meals on Wheels Subsidy Scheme in the late 1960s. In the following consolidation phase, the spread of these services saw the establishment of a community care delivery system, albeit of a rudimentary kind in many areas.

The second cycle began with the climate of change that came with the election of the Labor Government in late 1972. Initiatives were formalised in the Community Health Program, the Paramedical Services States Grants Act and the Australian Assistance Plan, with a brief take-off period tapering off as funding was curtailed with the return to office of the Liberal-National Party Government in 1975. With the lapse of these program initiatives, the ensuing period cannot be properly labelled a consolidation phase, but nonetheless there was some diffusion of new services, such as geriatric assessment services and day hospitals, through State Government programs, and through Local Government and community groups developing other services such as day centres and self-help support groups.

These developments were made evident through the various Inquiries conducted over the years from the mid 1970s to the early 1980s, culminating in the House of Representatives Expenditure Committee Inquiry. The Committee's recommendations that the existing fragmented programs be integrated and expanded eventuated in the Home and Community Care Program. A subsequent statement of Commonwealth priorities for service development under HACC outlines the goals of the program (Commonwealth Department of Community Services, 1986). Achievement of these goals will mark the transition to the consolidation phase, with the end of this third cycle extending the long term perspective to some forty years.

FIGURE 2: LONG TERM PERSPECTIVE



The Medium Term Perspective

The period from the renegotiation of the initial HACC agreements in mid-1988 to the stabilisation of the program by the mid-1990s presents a medium term perspective in which it is appropriate to consider the level and nature of change required if the program goals are to be realised. The course of change expected over this time can be traced in Figure 1, with a number of different outcomes possible depending on the extent to which change proceeds in a purposeful manner.

A lessening in the rate of change in the consolidation phase does not mean that there will be no further development of the program, but that the emphasis will shift from creating new structures and services to elaboration within the new system. This stabilisation in the rate of change is shown by the flattening of the curve in Figure 1 (line A).

A tapering off in the level of change due to a reduction in support would result in curtailment of the development rather than consolidation, repeating the experience of the late 1970s. The consequent loss of momentum can be depicted as a downturn in the level of change (line B). Alternatively, a failure to consolidate advances could lead to a review of program goals and major redirection. Political change is clearly the most likely trigger to a fourth cycle of this kind, beginning with a short initial phase followed by renewed take-off, but with change in a different direction to the present HACC program (line C).

The final course that can be suggested is that change continues for the sake of change, over and above that found in a consolidation phase (line D). This outcome can be seen as a failure to achieve the program goals, with on-going change indicating a lack of clear direction. The likely consequences here are proliferation of uncoordinated services and *ad hoc* responses to short term expenditures. If these outcomes are to be avoided, some purposeful steps towards consolidation will be required; the renegotiation of the three year HACC agreements due around 1991 might be directed to this end.

Given the financial and service commitments made under the present agreements, and the experience in implementing HACC to date, two questions that can be asked for the medium term are:

- What are the outcomes that might reasonably be expected at the end of the second three year HACC agreements for the resources that will then be allocated to the program?
- How can progress towards achieving these targets be assessed?

An approach to answering these questions can be developed in the planning framework of setting goals, strategies and targets, as formulated by the World Health Organisation (WHO) in its plan for its Health For All by the Year 2000. Accepting that the goals of HACC have been stated, and that implementation is effecting a variety of strategies for service development, the following discussion focuses on the definition of targets whereby progress in the achievements of the program goals can be measured. The specification of targets which translate the broad program goals into service delivery outcomes has so far received little attention in HACC, but they can provide useful signposts that the program is moving on course and at a satisfactory pace.

Targets cast in a medium term perspective provide a bridge between the short term and long term perspectives on change. On one hand, they can assist in plotting a path to longer term change than otherwise may seem too distant, and on the other, set a horizon beyond the immediate short term. Definition of targets also assists in recognising the particular characteristics of change in each phase, and hence in the transition from one phase to the next.

The setting of medium term targets is particularly relevant as HACC moves into its take-off phase. This transition requires resolution of the main deliberations of the initial phase of HACC. The instigation of the review of the administrative arrangements of the program, with a view to simplifying them, is one indication of the need for such resolution if further development is not to be inhibited. The change to be brought about is a shift from the very detailed oversight of the program characteristic of the initial phase to a more streamlined processing as a means to facilitating the expansion of the program in the take-off phase.

The initial phase of HACC was also characterised by the gathering of data for planning purposes. The drawing together of a statistical account of the program, albeit a very basic one, constitutes a resolution of what was until then a very fragmented picture. The change that comes about here is the transformation of piecemeal and *ad hoc* data collections into a standardised information system for use in routine program monitoring, and the development of data bases for HACC is now advancing to this end. An account of key program dimensions at the point of take-off can thus provide baselines against which targets to be reached by the consolidation phase can be set. Unless these baselines are known, there will be little prospect of monitoring the implementation of HACC or recognising when outcome goals are achieved.

The exercise of defining resources targets at the take-off stage is useful not only for determining the level of funding required to cover a preferred level of service provision by a given date, but also to turn attention to what can be achieved with the resources that can reasonably be expected to be made available over the period. HACC has experienced rapid expansion of funding over the last three years, almost exceeding the capacity of the service system to absorb funds due to the bottlenecks in translating dollars into service provision. Such bottlenecks are manifest in the time taken for new community-based service organisations to become operational, and for the training of new categories of care providers and so on. In taking the 'lumpiness' of change into account, expenditure increases may need to be graduated to allow for 'gearing-up' rather than following a regular progression. Recognition of the limits of resources and the timing of their availability should also assist in setting priorities among the many competing claims made on them: too ready and too large commitments, too early, may pre-empt longer term priorities.

3. DEFINING TARGETS

The process of target definition proposed in the remaining part of this paper is adapted from a four fold approach to program evaluation developed by Harrington and others (1985). In their analysis of changes in the provision of long term care in the United States, they direct attention to four main dimensions of policies and programs: coverage, eligibility, recipients and access.

As well as considering each of these target areas separately, relationships between them can usefully be taken into account. For example, once the eligible population has been defined, the adequacy of coverage that can be achieved with a given level of funding can be assessed; similarly, comparison of the number and characteristics of actual recipients to total eligible populations may provide a means of identifying groups facing barriers of access to services and unmet need.

The definition of targets and assessment of their achievement requires attention to baselines, indicators and outcomes that can be related to the phases of program implementation. That is, we need to have baselines to know where we have started, indicators to know where we are going and outcomes to know when we have arrived. A primary concern for making the transition from the initial phase to the take-off phase is thus identifying baselines in each of the target areas so that progress can be measured in some way. In the take-off phase the emphasis is on indicators of change that can serve as sign-posts to ensure that the path of implementation is on course, or if off-course, to enable appropriate corrections to be made. The consolidation phase can be seen to be reached when the program outcomes match the targets.

Coverage

Coverage targets are concerned with the amount and distribution of service provision, with targets most readily set as level of expenditure and changes in these over time. HACC has envisaged increased expenditure on services, expansion of service use and a wider range of services, requiring coverage targets to be specified in terms of level of funding, uptake of services provided. Funding outcomes can then be expressed in a variety of ways: as aggregate levels of expenditure, rates of increase, shifts in allocations between types of services and the funding of new services.

The goal of changing the balance of services towards community care is most readily seen in the relative growth of expenditure on HACC compared to nursing home programs. Spending under HACC has increased by 200 per

cent in the five years to 1987-88, twice the rate of increase in expenditure on nursing home care. This trend is expected to continue over the decade to a level at which expenditure on community care will be in the order of one third of that going to residential care, compared to 10 per cent at present. Measures of this change in relative expenditures provide indicators of progress towards this target.

While most readily defined in expenditure terms, coverage targets, indicators and outcomes can also be stated with reference to service providers and users. Other relevant indicators of change in coverage could be the trend in disbursement of funds to new community agencies relative to longstanding providers; outcome targets could be set as numbers of agencies of different kinds to be funded under the program. Targets might also be set in terms of recruitment and training of the workforce involved in service delivery, with coverage measured as the number of new training places established in relation to staff seeking training.

Eligibility

To date, the HACC program has defined targets only in relation to broadly defined target populations, namely the frail and at risk aged (generally those aged 70 or more with moderate or severe disabilities) and their carers, the younger disabled and their carers, and 'other groups as agreed'. Particular mention is also made of migrant groups, Aborigines and the confused elderly. The inclusion of younger intellectually disabled people is perhaps the most dramatic change as services for these clients have traditionally been the responsibility of State Governments.

Definition of eligibility targets is concerned with the identification and characterisation of populations to whom services are to be directed. The target groups eligible for HACC services represent a considerable widening of groups beyond those previously served by the specific service programs that have been subsumed. Those programs were totally lacking in any stated eligibility criteria, and it was left to resource constraints to contain the uptake of services.

The first target in defining eligibility is some decisions on the kinds of criteria to be used, with initial arbitrary standards giving way to assessed need. An example of this progression is seen in the residential care field, where the arbitrary age criteria for receipt of the Personal Care Subsidy has been replaced by an assessment of dependency and care needs. The increased availability of appropriate assessment services then becomes the means to the more effective targeting of services through the take-off phase, with consolidation achieved when all entry to services is via such assessment. Progress towards this outcome target is then indicated as the ratio of assessed to non-assessed clients changes.

It should also be noted that clearer definition of eligibility can be a means of exclusion from services as much as giving entitlement to them. The drive to define target groups appears to have arisen in part from concerns that increased funding might open the way to widespread unwarranted service use unless some rationing device were adopted. The American experience certainly demonstrates that revision of eligibility criteria to impose more stringent tests can be a powerful tool for budgetary control in long term care programs.

Recipients

Recipient outcomes can most simply be addressed as the number of recipients in relation to the defined eligible population. While broad eligibility criteria may be preferred, either to avoid making decisions as to priorities for service allocation or to give the appearance of generosity notwithstanding limited resources, achievement of high target ratios will be more difficult and so serve as an incentive to define eligibility more concisely. Shortfalls between recipient and eligible populations can be taken as indicators of either inadequate coverage or of access barriers. The opposite, albeit less likely situation, of the number of recipients exceeding the size of the defined eligible population, may indicate either a misallocation of resources to non-eligibles, or inappropriate eligibility criteria relative to need.

For example, a target could be stated as an uptake rate among potential users. It is worth noting here that the take-off phase of HACC is set to coincide with the most rapid period of aged population growth, with some

moderation expected by the second half of the next decade; it is thus necessary that indicators demonstrate advances relative to trends in population growth over the implementation period.

As well as setting outcome targets in terms of numbers of recipients, the intensity of service receipt needs to be taken into account. The issue is of particular relevance to those who are at the margin of admission to residential care, as their maintenance in the community will depend on receiving an increasing intensity of service, for example, in the frequency of home service visits. The difficult issues that emerge in setting targets are whether intensity of receipt or coverage of target groups is to be maximised, and defining the trade-off between them.

The tension is clearly posed with the expansion of the target groups eligible for various HACC services. The stated goals include 'reaching all people, regardless of age who have a functional disability, and their carers', and 'preventing inappropriate or premature admission to residential care' (Commonwealth Department of Community Services, 1986). Whereas the former goal implies a much wider coverage of the various population groups, achievement of the latter goals requires a concentration of more services on a smaller number of clients.

Access

Access outcomes are essentially concerned with equity. The present patterns of use of community services are characterised by great variability between areas, but the extent to which this variability reflects variation in need is not well established (Howe, Newton and Sharwood, 1987). Outcome targets set simply as the reduction in variability of service provision may not achieve more equitable outcomes, and the development of needs identification formulae and their incorporation in programs as mechanisms for guiding resource distribution may be useful indications of progress towards more equitable outcomes.

Outcome targets may be quite readily set as equity between areas on the basis of population-based needs indicators to guide the redistribution of resources between areas. Identification of deficit areas in the initial planning phase of HACC should enable priorities to be set for the direction of resources that become available at the beginning of the take-off stage.

Identification of other barriers to access, such as cultural barriers, may reveal further need for the development of alternative types of services. In such cases, appropriate indicators of progress towards the target outcomes may be provided by measures such as the availability of information in community languages, the recruitment of ethnic staff and the participation of ethnic agencies in service delivery.

4. PERSPECTIVES ON CHANGE

Over and above the four specific dimensions for target setting outlined above, consideration of targets in the rate and pattern of overall change in HACC warrants some attention. One goal here is to establish realistic expectations about the achievable rate and scale of change. Rather than being an exercise in limiting possibilities, it may well be that expectations are too modest and conservative and that purposeful attention to every opportunity for change may open new, yet realisable, horizons. In particular, some attention to the cumulative effects of change over the medium to long term should suggest outcomes that might not be envisaged in a short term perspective.

Canvassing of expectations about change also calls into question the implicit values underlying preferred options; the necessity of choice between options requires that these implicit values should be made explicit. A period of reconciliation of differing expectations and values early in the implementation process, resulting in clearer definition of decision rules for subsequent resource allocation, may avoid later conflicts. HACC has promoted the entry of many new interest groups through its consultation process, with the consequence that many extant interests are being challenged.

Taking the Long Term Perspective - A Case Study

If there is any doubt about the value of viewing short term developments in a longer term perspective, a very different example can be given to illustrate the insights to be gained. The brief case study of past policy and program development that follows is intended to demonstrate at least three of these, namely:

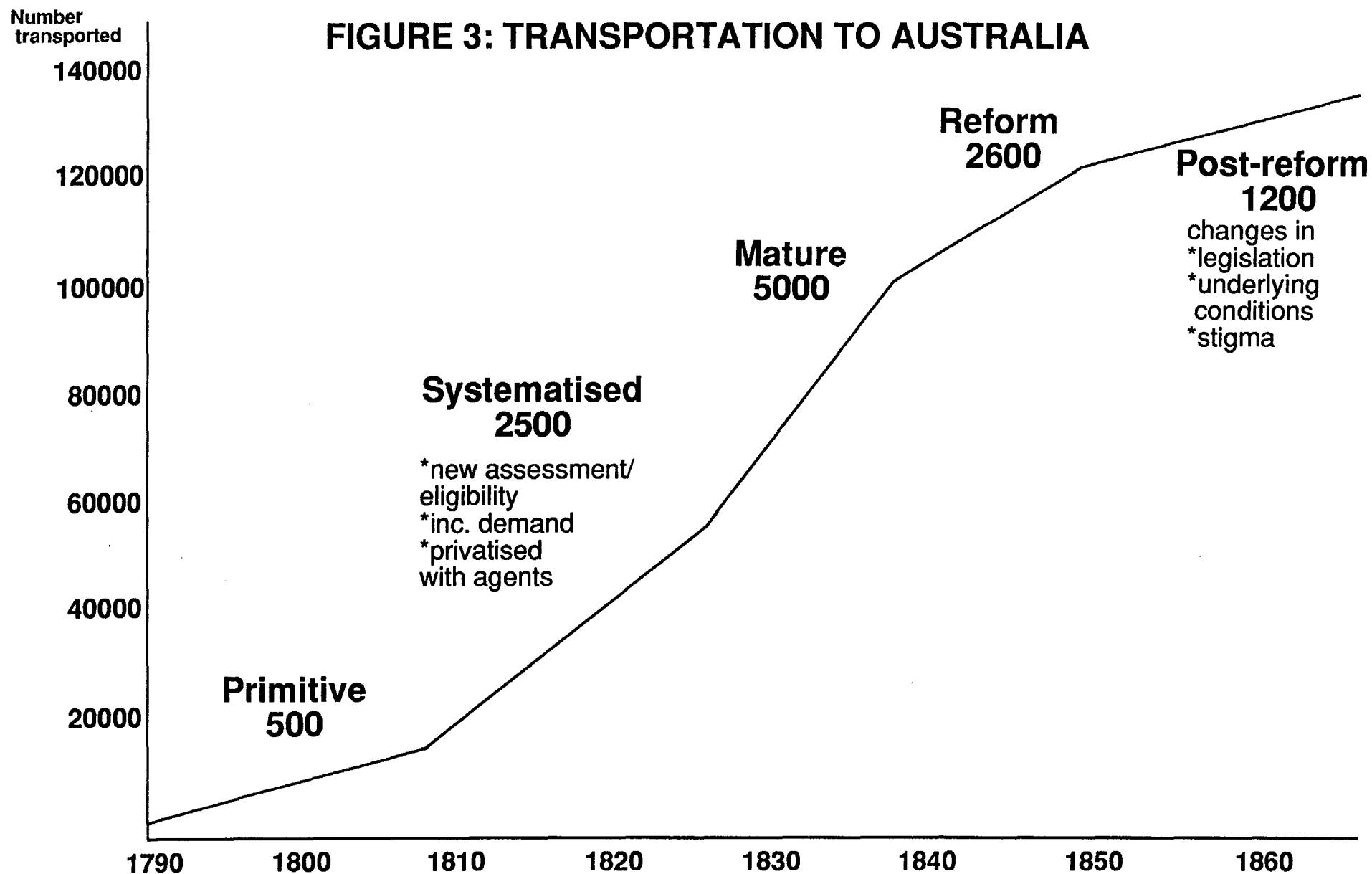
- that the extent of change that can occur even in the short term is more readily appreciated by viewing it in longer term;
- that policy is driven by changes in the way we define problems and the means we then devise to deal with them as much as by changes in the problems themselves; and
- how long we can go on considering these changes.

The program to which I refer ran for nearly 80 years, perhaps a record run in the human service sphere. It was fully funded by central government to begin, but was to be cost shared by the participating states as a transition to their taking on full financial responsibility. Quite distinct phases have been identified in the course of the program's implementation (Hughes, 1987). Three of these phases coincide with the cycle of initial, take-off and consolidation phases, with a final wind-down phase ending with the abandonment of the program.

In its initial phase, the program could best be described as primitive, being experimental and with formal guidelines, processing only a few hundred clients each year. By the end of the first twenty years, the program became more systematised: new eligibility criteria widened the target group, assessment services were streamlined, a degree of privatisation came about, with operation through agents, and there was increased demand for the program's services in the participating states. This take-off phase saw the number of individuals in the program reach about 2 500 per year. The program consolidated with the maturing of the administrative arrangements, and there were some 5 000 recipients a year over this phase. When the problems that initially gave rise to the program however became the subject of social debate, reforms came about through legislative and institutional changes; the acceptance of the program in the participating states also declined due to stigmatisation of the beneficiaries. Numbers fell to 2 600 then 1 200 a year, and over this final decade, the program faded away.

If the program cannot be recognised by this summary, the case study refers to transportation to the Australian colonies, the 'clients' being the convicts and the 'assessment services' the courts of Great Britain. It was reforms of the British criminal justice and penitentiary systems with the passing of the Prisons Acts of the 1830s that signalled the end of the system. In his detailed account of these phases in *The Fatal Shore* (1988, pp 161-162), Hughes observes that 'a graph of transportation to Australia would run fairly flat (though uphill) from 1788 to 1816, then climb more steeply, shoot to a peak in the mid 1830s and then flatten again'. The similarity between the shape of this graph as depicted in Figure 3, and that drawn for the HACC program in Figure 1 is readily apparent. Does this mean that, having just undertaken the Bicentennial evaluation of the transportation program, we are destined to do the same for HACC two hundred years hence - truly a long term perspective.

FIGURE 3: TRANSPORTATION TO AUSTRALIA



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OVERVIEW

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1. INTRODUCTION

In this overview I wish to address what I see as the main policy issues, contrasting current preoccupations with the real issues of significance to people with disabilities.

If there has been change, then that change has to be experienced by the consumers.

The New South Wales Government budget speech stated that at the end of its four year term the Government would be in a position to **significantly improve services to the truly disadvantaged**.

David Richmond raised the issue of **who should get the services** as part of the Government's agenda, i.e. who are the truly disadvantaged? I think it's fair to say that people with disabilities do currently fall into this category - the Minister for Family and Community Services has made public commitments to access and community living and the like on a number of occasions.

However, there is another question that should be on the agenda, particularly on the agenda of people with disabilities, their families and carers. This is who decides what to provide.

2. CURRENT POLICY PREOCCUPATIONS

It seems to me that there have been three policy preoccupations in the area of disability, all of which reflect, to some extent, **segregation**.

i) Institutionalisation/Deinstitutionalisation

This debate is misguided and is not really about the deinstitutionalisation only of people with disabilities. Most have never been institutionalised and never will be. We have discussed **ad nauseam** the maintenance or otherwise of schedule V hospitals when there are actually no admissions to these hospitals and populations have declined. In the Home and Community Care Program, the aim is to prevent premature institutionalisation - anyone who works at the grassroots level knows there are no places available anyway.

ii) Integration

Why do we talk about integration as an option for a child that has lived at home, attended a regular pre-school and wants to go to a regular school? This child has never been segregated, what is sought isn't integration; it's education! Currently we are having a Review of Integration because the Minister is concerned about its cost-effectiveness and its impact on the child - do we ask these questions about children without disabilities? Why treat five year old children differently?

(iii) Services for People with Disabilities

Why do we regard these as if they are somehow different from the services other people want and use: e.g. housekeepers for me, Home Care for the person with a disability; vacation care for my child, respite care for the child with a disability. The provision of special services is fine if the outcome is the provision of the required services, but not if it results in assessment and little or no service, because the person is too disabled or too old.

Why don't we do research about why generic services are not accessible (e.g. transport) rather than assessing continuously the needs of people with disabilities for suitability to use specialised services?

These preoccupations are depersonalising, distract from people with disabilities **as people**. It also tends to focus research on the economic demands of the State.

Why? I wish I knew. However, a couple of reasons may be ignorance and the inability to recognise people with disabilities as 'real' people. One is subjected to all sorts of political platitudes that are, largely, the result of ignorance:

'Don't raise unreasonable expectations.'

'Special education is a bottomless pit.'

'They're never satisfied.'

The people who say these things may never have met a person with a disability, particularly if their office is inaccessible!

What then do I see as the real issues?

3. EMPOWERMENT OF PEOPLE WITH DISABILITIES AND THEIR FAMILIES

Empowerment requires:

i) Education

This should not be a discussion about integration or segregation. It is about quality. Quality education assumes that people will work, rather than that they will not.

ii) Moving Away From a Welfare Context

Welfare encourages dependency through providing services, including assessment, in settings that suggest people have to be helped. Workers act as gatekeepers, restricting access to information and choices. A good example is the provision of employment services, e.g. supported employment through the Department of Community Services and Health (DCSH) rather than through the Department of Employment, Education and Training (DEET). The outcome is that employment of people with disabilities is not taken seriously; it is seen as a way of filling time rather than earning income.

iii) Income Security

This needs to be both flexible and adequate. Its importance was pointed out by David Richmond on his comment on the Social Security Review Issues Paper No. 5.

iv) Access

This should really be first. In this I would include advocacy, as access to information and services, specialised or generic, is as important as physical access. However to illustrate: a new New South Wales Government program which includes both a service and a physical base does not see physical access (i.e. wheelchair accessibility) as a priority. I ask you, do we have a discussion about whether doors are a priority?!

If we agree, and presumably everyone at this seminar does agree, or they wouldn't have lasted the day, that people with disabilities are:

- a) people first
- b) want the same things as everyone else, and
- c) want to be able to make choices,

then, to be able to choose you need real options, information, the skills to make choices, cash and the opportunity to take some risks.

These are the 'real' policy questions.

DISCUSSION AND OPEN FORUM

A wide range of issues was raised during the discussion periods after papers and at the open forum at the end of the day.

One of the major concerns expressed was prompted by Sara Graham's and Helen Molony's papers on deinstitutionalisation. Some in the audience felt that the perspectives used placed too much emphasis on institutions and implicitly devalued people with disabilities. There was a plea for recognition that in all circumstances an institution is a completely inappropriate place for anyone to live. A number of speakers wished to emphasise the importance of recognising that people with disabilities are individuals first, who want to be able to make the same choices as any other person in the community.

A further issue raised related to the role and purpose of research on disability, particularly that sponsored by government. Some members of the audience who had been involved in small scale research for governments felt that there was a very low level of interest in actual research findings and were therefore sceptical about the value of conducting the research in the first place. Others felt that research could essentially be used as a kind of management tool or as a means of defining the issues in a manner suited to the interests of government. It was also argued that governments would shelve or ignore research which they did not find agreed with their own pre-existing conclusions, or may attempt to repress such research. In contrast, other members of the audience who had been involved within government in evaluating and analysing the results of a range of research argued that these activities did make a contribution to planning and delivery of appropriate policies and services, even if this was not always immediately apparent. A related issue that was raised was the concern that research should be carried out with the interests of people with disabilities themselves as the first priority.

In addition to these two main themes, there was a very wide range of specific issues raised. The inadequacies of service provision for people from non-English speaking backgrounds was raised as a concern, as was the fact that the Conference had not dealt with ethnic issues and disability in its program. Other particular issues raised were the inflexibility of transport services for people with disabilities. Particular concern was expressed with the decision to dismantle the New South Wales Department of Housing's special unit for housing for people with disabilities.