# Social Policy and Personal Life: Changes in State, Family and Community in the Support of Informal Care

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Social Policy Research Centre

# SOCIAL POLICY AND PERSONAL LIFE: CHANGES IN STATE, FAMILY AND COMMUNITY IN THE SUPPORT OF INFORMAL CARE

by Sheila Shaver and Michael Fine

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# Abstract

Recent developments in the provision of ongoing care have served to highlight the significance of informal caregiving for social policy, making private households the preferred site for the exercise of public responsibility for many of the most vulnerable and dependent citizens. We discuss two contemporary developments challenging policies which support informal caregiving. One is the post-industrial transformation of employment, which while supporting continued growth in female labour force participation is also reshaping the hours of work and stability of employment of women and men. A second concerns demands for policies which are responsive to social difference and distinctive values of care in communities of shared sexual, ethnic and religious identity. With these developments in mind, the paper explores the options for policy and briefly considers how these options might be implemented. Three approaches are canvassed: the enforcement of family responsibility through the withdrawal of public assistance; the relief of caregiving responsibilities by provision of alternative forms of support; and the development of a 'shared care' approach, based on a 'partnership' between the state, community and family. The paper suggests that while the third option is likely to prove the most viable and acceptable, it is necessary to ensure that alternatives to reliance on informal care are not neglected.

# 1    Introduction

With the adoption of community care as the guiding principle of long term care for the frail elderly and for people with disabilities, private households have now become the preferred site for the exercise of public responsibility for many of the most vulnerable and dependent citizens.  The principles of community care recognise the informal care provided by and within these households as the linchpin of many people's prospects of living in the community.  Rather than being an alternative to formal intervention, informal caregiving has now been recognised as a fundamental part of the system of social policy.

The concern with informal care is both a product of and a response to deeper and more broad-ranging changes taking place in Australian society and its social policy frameworks.  These include changes in the structure and temporal rhythms of families and households, the emergence of an increasingly service-based economy with post-industrial employment arrangements, and new patterns in the divisions of labour between men and women and paid and unpaid work.  Demographic changes signal continuing increases in the need for care, while constraints in the political economy of the welfare state raise doubts about the ability and willingness of government to commit public revenues to institutional and high-cost professional care.  Cutting across these are visions of citizenship which put a high valuation on the needs and wishes of the individual.  Implicated in all are changes in the roles and relationships of state, family and community in the support of informal care.

In this paper we attempt to put some of the issues raised by support for informal care in broader perspective.  In the following section of the paper we identify trends in the adoption of community care policies, recent but growing recognition of carers and caregiving work, and policy mechanisms developing a mixed economy of welfare in the context of changing roles and responsibilities of state, market and family.  Sections 3 and 4 then focus on two particular developments: employment in the post-industrial labour market and the active society policy strategy; and claims for the recognition of social diversity and policy approaches sensitive to social difference.  Then in Section 5 we examine some widely offered general prescriptions for policy in support of informal care, concluding that the prescription promoting a vision of a 'partnership in care' linking public and private

contributions to the care of people at home and in the community is of greatest relevance to contemporary Australian social policy. In Section 6 we therefore consider how such an approach could be implemented, paying particular attention to the concepts of the co-production of care, payments for caregiving and the dilemmas associated with targeting scarce resources.

## 2　Trends in Caregiving and Policy

Australia, in common with other advanced industrial societies, has experienced fundamental changes in the last decade and more, with important implications for the social policy agenda. Many of these changes stem from economic developments and reflect the transition from the nationally based manufacturing economy of the post-war period towards a post-industrial service economy in an increasingly global economic system (Offe, 1985; DEET, 1991). These changes have important implications for the incomes and living standards of those who give care and those who receive it. Later, we explore one aspect of these changes, the shift to a post-industrial employment structure and the ramifications this has had for those involved in providing informal care.

Other changes stem independently from normative, cultural, and demographic developments in Australian society. The nation's population is ageing, with pronounced effects in the oldest age groups and less widely recognised effects in the greater longevity of groups with severe disabilities (Schulz, Borowski and Crown, 1991: 9). Associated attitudinal changes put new emphasis on the social participation and quality of life available to the aged and persons with disabilities. Profound changes in gender identity, marriage and family life are also occurring (Bittman, 1995). While the causes are many, they clearly include rising levels of workforce participation by married women and the claim of women to equality as individuals in all aspects of social and political life. Social movements for affirmative recognition of gay and lesbian sexuality are also important. Changes in household and family patterns are multi-faceted. They include divorce and re-marriage as common experience in the lives of adults and children; there is now a diversity of family forms, among which are households of a single person, of more than one single adult, of a sole parent and children (ABS, 1994). Continuing immigration has also brought growing cultural diversity, one aspect of which is new social contours of urban settlement. Social

developments of all these kinds are also taking place in many other countries.

These changes are affecting the very foundations of informal care, reshaping the social fields within which individuals perceive and express needs for assistance and the capacity to provide support (ABS, 1995).  Some, such as the ageing of the population, have immediate implications with respect to types and levels of need.  Others, such as the communities formed around the HIV/AIDS epidemic, suggest new ways of perceiving and enacting a commitment to care.  Others still, such as changes in the family and patterns of paid and unpaid work, affect the ability of men and women to fulfil obligations of kinship and communal association in the provision of care without support (DHSandH, 1995).  Together, many changes suggest greater vulnerability than in the past in the capacity of family members to provide care within and between generations.

Policies in support of informal care cross the social boundaries between state and civil society, and between public and private areas of social life.  These boundaries have themselves been changing in complex ways.  The growth and development of the welfare state in Australia as in other comparable countries saw extended intervention by the state in both civil society (markets and associational life) and in the private domain of the family household.  Its contemporary reshaping is at once a product of calls for greater economic efficiency in the performance of social programs and demands for greater responsiveness to the needs and wishes of individual citizens (Taylor-Gooby, 1991: 137-67).

Political reactions against rising social expenditure, heightened concerns about the effectiveness of welfare programs, and an ideological climate of economic rationalism have put established social welfare programs in question in most, if not all, countries with developed welfare state systems (OECD, 1994).  Political competition to reduce levels of taxation and welfare spending are making the funding of social programs increasingly difficult.  One outcome has been to seek mechanisms directing, and often limiting, the provision of benefits and services to those whose need is thought to be greatest, such as targeting, eligibility review and fraud control (Saunders, 1994: 14-49).  In the result, the growth of direct service provision by the state has been minimised.  At the same time, there has been a move away from large-scale institutional provision toward small-scale and

community-based services. The effect of these measures has been to diminish expectations of the state in favour of reliance on self-care and care provided through the market, family and community.

While pressures to reduce public expenditure and taxation have given impetus to the reshaping of social provision, not all of the motivations for change have been economic. The move also reflects changing social expectations about the nature and appropriate limits of social provision and the importance of the individual. There has been some convergence between values associated with the 'right', such as freedom, choice and self-help, and concepts of the 'left' such as independence, normalisation, citizenship and community. Valuation of the individual is also reflected in new appreciations of privatised care arrangements and consumer rights as empowering service users and fostering personal autonomy (Taylor-Gooby, 1991: 137-67).

In the last decade there has been increasing recognition that social policy interventions are more complex than indicated in the two-dimensional terms of state and market and the conception of social policy as altering market outcomes to accommodate social needs (Evers and Svetlik, 1991). The balances and linkages between market, state, family and community in the provision of social support have been changing, calling for review and reconsideration of social needs and the way policies affect the relations between sectors in meeting them. Family and kinship are also centrally involved in social policy, both as objects of policy intervention and as means of achieving social policy ends. Social policies also address the family and family structure in the pursuit of societal goals such as redistributive equity and social care. Most recently, attention has been paid to the 'third sector' of the welfare state, i.e. voluntary or non-government associations, including churches, non-government welfare organisations and mutual aid societies (Wolch, 1990; Wuthrow, 1991).

The emergence of a reinvigorated 'mixed economy of welfare' is one expression of these trends. A role for private welfare initiative in Australia is not new (Dickey, 1980). Increasingly, policy has been addressing the relative roles of public and private provision, and bringing the provisions which individuals, families and communities make for themselves into concertation with public support. New programs have directly affected the mentally ill, children in care, people with disabilities and the frail aged and

provided income support to individuals kept out of the labour force by the need to care for others.  Policy developments have also included mechanisms aimed at new ways of integrating public and private provision, such as the contracting out of services, and the use of market and market-like mechanisms to allocate resources within bureaucratic structures (Graham, Ross and Payne, 1992; Alford and O'Neill, 1994).  Some labour intensive non-government services depend on unpaid volunteers to a significant degree.  Still more fine-grained forms of integration between public and private activity are evolving, such as in the incorporation of market suppliers of personal services in supported care of the elderly and people with disabilities.

One of the most significant manifestations of these changes is the adoption of community care policies.  Community care or, as it is sometimes called, community support, is essentially a policy encouraging those who need assistance to remain in their own homes in the community whenever possible.  This development, which has been adopted as the preferred approach to the care of the mentally ill and people with disabilities of all ages, including the frail aged, has seen a move away from an emphasis on care provided in long-stay residential institutions towards a more broadly based system based on the promotion of care in the home.

In the field of aged care, for example, a range of measures introduced in the mid-1980s by the Commonwealth Government saw a reduction in the use of nursing homes, a limited expansion in the provision and use of the less intensive forms of residential care provided in hostels, growth in the provision of community support through the Home and Community Care (HACC) Program, and a significant increase on expenditure associated with Geriatric Assessment (DHHCS, 1991).  Subsequent developments have seen an expansion of other alternative forms of provision, perhaps most notably the expansion of Community Aged Care Packages (CACPs) and, in some rural regions, advanced trials with Multi-Purpose Services, increasing the flexibility and variety of service provision (DHHLGandCS, 1993).  In the early 1980s, eleven dollars were spent on nursing homes and hostels for every one dollar spent on community care (McLeay, 1982).  By 1991, this ratio had changed to 4.7:1.  According to the projections this will have become a ratio of approximately 3:1 by the year 2001 (DHHCS, 1991).

Similar developments affecting the support of younger people with disabilities and the developmentally disabled have also been introduced at both State and Commonwealth level (AIHW, 1993: 266-79; Fine, Graham and Matheson, 1995). These trends have been accompanied by an increasing emphasis on assessment and targeting in an attempt to reduce the 'inappropriate' use of services and ensure that individuals with the greatest need receive suitable levels of assistance (Fine, 1995). As a result of these changes, a gradual shift in expenditure patterns in favour of community care has taken place over the last decade, which unless there is a sudden and unexpected reversal of policy, is likely to be continued well into the foreseeable future. This success has been such that the approach is already being extended to other fields, such as health care, where it is spurred on by cost pressures to reduce the length of hospital stays, by technical developments such as day surgery, and by social pressures, as evidenced by the movement for home births.

An important feature of community care in practice is that formal services seldom maintain a person at home without the additional input of assistance from informal sources (Fine and Thomson, 1995a). This is well illustrated in the most recent national figures on the receipt of assistance by those in need of help as a result of disability (ABS, 1995), which show that many more people relied on informal care, and informal care supplemented by services, than on services alone (Table 1). Although the proportion of people relying on services increased amongst those who live outside family settings and is still higher amongst those who live alone, the receipt of assistance from informal caregivers was more prevalent than formal services in all domestic classifications. This is reflected in the pattern of provision of the more traditional forms of community support service, such as community nursing, home care and meals-on-wheels, just as it is amongst innovatory forms of intervention such as respite care, the use of different forms of payment for caregiving and the fostering of carer education and self-help strategies (see Section 5), the provision of each of which is based on the assumption, often unstated, that informal care will continue to be available.

Despite the importance of assistance provided by informal caregivers in the home, the adoption of community care policies does not signal the substitution of the unpaid work of caregiving for the paid work of professionally organised services. Rather it suggests new, hybrid patterns of

**Table 1: Persons with a Handicap Living in Households:  Type of Assistance Received and Living Arrangements, 1993**

| Type of Assistance Received | Living with Others, in a Family | Living with Others, not in Family(a) | Living Alone | Total |
|---|---|---|---|---|
| | percentage | | | |
| Informal only | 68.6 | 50.6 | 30.9 | 60.2 |
| Formal only | 3.2 | 18.1 | 24.8 | 8.1 |
| Both | 28.2 | 31.3 | 44.3 | 31.7 |
| Total number ('000) | 1,016.7 | 39.8 | 277.6 | 1,334.1 |
| Total percentage | 100.0 | 100.0 | 100.0 | 100.0 |

Notes:      a)      Unrelated individuals living together or with families.

Source:      ABS, 1995, Cat. No. 4423.0: 9.

organisation in which informal care and formal provisions are combined.  In the process, as Baldock and Evers (1992: 291) have pointed out, interaction between formal and informal care has shifted from an implicit to explicit pattern.   Informal care, conventionally treated as a private matter and unrecognised in the planning of public services, has thus come to be regarded as part of the overall package of support and is carefully monitored and regulated.  Instead of operating as substitutes, informal and formal care have increasingly come to be seen as complementary.

The possibilities of explicit interaction between public support and informal care are many.  Recognising the organisational differences between formal, bureaucratically organised and professionally staffed services, Litwak (1985) claims that formal services tend to undertake specific tasks for which technical expertise is required, such as giving injections, complementing the ongoing supervision, companionship and more routinised tasks undertaken by informal caregivers.  This represents just one possibility.  Formal services may also be thought of as organisations in which the work of caring has been made paid work, or, in some cases, voluntary (that is formally organised but

unpaid) work. Their work may be deliberately tailored to complement that of caregivers by relieving them, temporarily, of their caregiving responsibilities to allow them to support themselves financially, to pursue a career or engage in other interests. To understand the increasing need for this form of complementarity it is necessary to consider how patterns of employment and the potential availability of informal caregivers is being reshaped by the changing demands of the workplace.

# 3 Caregiving and the Active Society

As in other advanced industrial nations, the structure of Australian employment has changed significantly in the last decade or so. While economic activity and employment grew more or less steadily throughout the postwar period, a relative decline of manufacturing and the increasing importance of services was firmly established by the beginning of the 1980s. A dramatic transformation from an industrial to a post-industrial pattern of employment took place in the 1980s, with the shift from manufacturing to services reflected in the structure of employment. Between 1979 and 1989 the proportion of employees in production jobs (agriculture, mining, manufacturing, energy and construction) fell from 38 to 32 per cent, while the proportion in service employment (wholesale and retail, transport and storage, communication, finance services, public services and recreation) grew from 62 to 68 per cent (ABS, *Labour Force Australia*, Cat. No. 6203.0, August, various years).[1]

Most of the increase in employment came in the service sector. The number of positions in finance, insurance, real estate and business services grew by just under six per cent, and the number in community, social and personal services by around three per cent. Australia had the third highest rate of growth in each area of all OECD countries. Job losses in Australian manufacturing were proportionately lower than in most other OECD countries. Employment growth was much greater in the private than in the

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1    Australia had very high employment growth during this period. Indeed, job growth was greater in the OECD countries of Oceania (Australia and New Zealand) than any other OECD region except North America. The greatest growth has been in the private sector. By the mid-1980s more than half of the jobs created since the early 1970s were in private sector employment, with more than three quarters in the private sector by the end of the decade (OECD, 1994: 17, 21).

public sector. Australia also shared moderately in the reversal of the long-term trend away from self-employment (OECD, 1994: 20).

Australian women have taken much of the new employment. The labour force participation of Australian men has been declining slowly over the last three decades. It decreased from 79 to 75 per cent of men aged 15 or more between 1979 and 1989, and by 1994 stood at 74 per cent. Women's participation in the paid labour force has been rising steadily over the same period. This increase accelerated during the 1980s, rising from 43 per cent of women aged 15 or more in 1979 to 51 per cent in 1989, and to 53 per cent in 1994. Until recently, labour force participation was higher among single than married women, but participation among married women overtook that among single women in the mid-1980s (ABS, *The Labour Force Australia*, Cat. No. 6203.0, February, various years).[2]

Bryson (1994: 210-11) points out that the post-industrial transformation of work has served to increase the gender segmentation of employment in Australia. This is, of course, the obverse side of growth in those sectors in which women's employment is best established. Of particular importance is the concentration of women's employment in the community service industry. Bryson points out that this entails women moving into the caring roles in the community rather than being equally involved across the employment spectrum. Most community sector employment is in the public sector. For many professional workers employed in positions such as nursing and teaching this is in established public service positions, but much of the expansion in community service employment has taken place in or through non-government organisations dependent on government contracts or grants. The employment conditions offered by these organisations are often inferior to those of direct public service employment.

As was true across the OECD during the 1980s, a growing share of Australian employment is in part-time positions. Of all OECD countries in that decade, Australia had the third largest increase in part-time work, much of which was in services. As elsewhere, the rise in part-time employment has been concentrated among women (OECD, 1994b: 20). The share of

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2    Women now make up 45 per cent of the labour force in wholesale and retail trade, 49 per cent in finance and property services, 57 per cent in recreation and personal services, and 66 per cent in community services (ABS, 1994, *The Labour Force Australia*, Cat. No. 6203.0).

employed males working part-time increased from 5.2 per cent in 1979 to 10.5 per cent in 1994. During the same period the share of employed women working part-time rose from 35.2 to 42 per cent (ABS, *Labour Force Australia*, 1979 and 1994, Cat. No. 6203.0,). While women make up 42 per cent of all employees, they represent 75 per cent of workers in part-time employment (ABS, 1994, *The Labour Force Australia*, Cat. No. 6203.0).

While some part-time positions carry fractional benefits equivalent to those of full-time employment, part-time workers are increasingly employed on a casual basis (DEET, 1988: 36). In August 1992, for example, 16 per cent of males and 31 per cent of females were employed casually (ABS, 1993a, *Women In Australia*, Cat. No. 4113.0). Where it is subject to legal awards, casual employment carries a loading to compensate for employment benefits such as recreation and sick leave, making casual work attractive as a source of immediate income. At the same time, most casual work is low skilled and provides no job security, even to the limited extent of a foreseeable number of hours of employment in coming weeks.

For the people providing informal care in the community, the post-industrial transformation of the economy has both positive and negative implications. On the one hand, it means much greater flexibility in employment with respect to both the availability of part-time work and the terms under which it is undertaken. This flexibility has important advantages for workers trying to combine employment with caring work. In principle, it should be more possible than a decade ago for such people to find a job the location, hours and duties of which are compatible with their caring commitments. In the same vein, employers should be more accustomed than in the past to employees combining employment with responsibilities to family and community and may be willing to accommodate these in the rostering of work. On the other hand, the labour market within which carers must find acceptable work is highly competitive. Sustained high levels of unemployment mean that there are many people seeking part-time or full-time work, and in some areas of the labour market carers must compete not only with others who are fully or partially unemployed, but with secondary and tertiary students. Given the constraints of caring obligations, there are often many others able to respond more single-mindedly than carers to employers' needs and demands.

Not surprisingly, the recognition of caregiving as an important issue for social policy has coincided with changing patterns of employment, in particular the increasing participation of women in the labour market and the growth of the service economy. It is easy to forget that the term 'carer' is one of the most recent words adopted in the English language and that attention given to the subject has long tended be couched in terms of the responsibilities and duties of family members towards each other. The result was that informal caregiving was taken for granted, remaining more or less invisible in policy terms. This may reflect the more conventional dichotomy between state supported formal interventions and the policy assumptions made about women's place in the home and their responsibilities for providing informal care. But it is also indicative of a dilemma that continues to be central to community support policies. Since community care actually depends on informal care, might not the extension of community care further increase the reliance on, and exploitation of, such caregivers?

Over the last two decades, research and advocacy have systematically uncovered the scale of informal caregiving and drawn attention to its economic and social significance. In Australia, one of the important landmarks in this process was the publication in 1976 of the report *Dedication* by the Council on the Ageing (NSW) (Stephenson, 1976).[3] Research on community support over the years has demonstrated that services do not displace any but the most marginal of carers, such as reluctant neighbours (Chappell and Blandford, 1991; Sitsky, 1994). Since advocacy on behalf of caregivers is unlikely to diminish over the next 20 years and beyond, there will be increasing pressure on governments to tackle the issue.

In Australia as elsewhere, social policy developments such as the 'active society' (Kalisch, 1991) reflect concerns that social policy frameworks inherited from the post-war period are no longer appropriate, maintaining passive dependency rather than supporting adaptation to changed conditions. The active society concept represents a view of social policy as properly integrated with and contributing to economic policy, with the goal of policy

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3    The author of the report, Clare Stephenson, later went on to establish the Carers Association in New South Wales. Since then the Association has joined social scientists, consumer representatives, feminists and the health professions in attempting to gain increased recognition for the inequity experienced by the predominantly female workforce of informal caregivers and spouses of both sexes.

going beyond the simple allocation of welfare resources to foster closer integration of public and private responsibility in social protection (OECD, 1988, 1994).

A concept of this kind has underpinned the reform of the Australian social security system which has been underway since the late 1980s, is reflected in the *Working Nation* (Australia, Prime Minister, 1994) initiatives, and has also been reflected in social service policies at both Commonwealth and state levels. The OECD view is that a high-productivity, high-wage job strategy is viable only with a well educated labour force. Such a labour force will, moreover, require training and retraining over the course of working life. Active labour market policies are an essential policy tool in an economy of this kind. Their function is to make labour markets more efficient by developing job-related skills and improving workers access to employment, including that of the long-term unemployed and first-time job seekers. Active labour market policies are necessary to assist workers whose skills have become redundant to rejoin the labour market, as workers unable to meet the skill requirements of the post-industrial economy will experience prolonged unemployment or be forced into low-skill, low-wage jobs.

The policies of the active society signal a shift from the 'differentiated welfare state', in which social policy was a counterbalance to the effects of economic growth, to the 'integrated welfare state', in which social policy is integrated with and supportive of growth (Mishra, 1984: 102-5; see also Shaver, 1995). Increasing the value of human capital, training is seen as a form of social investment. The logic of the active society invites the view that both the recipients and the providers of informal care have new social rights of citizenship going beyond the passive dependency of support. Key among these are rights to education and training over the life course. The recipients should have available to them, within the limits of their disabilities, such support, training and rehabilitation as would enable them to be active, independent citizens, and where possible also employees. The providers should be supported to contribute to society not just as carers but also as individuals over a life course in which caring and paid employment may be combined in varying proportions at different times.

# 4 Social Diversity and Post-bureaucratic Organisation

Associated with changes in the pattern of employment and developments in the provision of formal support services, there has arisen in the 1980s a new consciousness of the social diversity of Australian society. Along with this has been a growing awareness of issues concerning the ways in which social policy should respond to social differences of gender, race, ethnicity, disability, religion, marital status, sexuality and the like. The terms of Australia's increasing social diversity need not be laboured here. Reference has already been made to the changing roles of men and women in family, paid work and community life, and the many lifestyles that now exist side by side in Australian cities. Australia's ethnic diversity is widely recognised. Social movements, have claimed, and largely received, recognition of the distinctive social identities of Aboriginal and Torres Strait Islander peoples, gay and lesbian communities, and, though often less visibly, people with disabilities.

The trends in social policy response have been mixed. On one hand, there has been a long-term shift from policies assuming gender difference in the roles of men and women to policies written in the language of gender neutrality. This shift has been associated primarily with changes in the sexual division of labour in paid and unpaid work. The trend has been particularly clearly expressed in social security provisions. Beginning in the 1970s, the terms of eligibility for pensions, benefits and allowances have been revised to treat men and women in the same way as claimants and dependants. A further round of changes beginning in the late 1980s has begun to eliminate the provisions for a distinctive female life course shaped by wifehood and motherhood (Shaver, 1993). The *Working Nation* reforms of 1995 have begun to individualise the entitlements of marital partners. This development has been paralleled to some extent by the mainstreaming of ethnic services and by changes in the delivery of services to people with disabilities (Mitchell and Graham, 1993).

On the other hand, there have also been countertendencies toward specific services in some program areas and to some groups. This has been most marked in the case of services to Aborigines and Torres Strait Islanders, where the history of assimilation policies has been supplanted by approaches aimed at self-determination. Group-specific services have also been

established where the initiative and impetus has come from social movements. Women's refuges and sexual assault services are one example, and health and support services to people living with HIV/AIDS another.

Social policy is now challenged by demands for positive affirmation of social difference. Oliver Sacks presents a compelling version of the paradigm of difference in his *Seeing Voices* (1989), an account of his own journey of discovery of the distinctive culture of the deaf. Deafness at birth or an early age can mean deprivation of the language essential for the social development of the human individual. Excluded from ordinary society, deaf people have evolved visual signs and gestures for communication with one another which, while functional for the deaf, have frequently been regarded by the hearing world as primitive mimicry of spoken language. Sacks narrates the violence done by educational practices prohibiting the use of sign language in the mistaken belief that it inhibited the mastery of spoken language. Deprived of free communication with others, pre-lingually deaf children were crippled in their intellectual and social development in ways that did not occur among children allowed the free use of sign language.

Sacks argues that Sign, constituting a system of visual rather than aural symbols, is a language in its own right, a complete and valid mode of communication that is 'equally suitable for making love or speeches, for flirtation or mathematics' (Sacks, 1989: 127). The deaf thus claim recognition not only of their particular needs but also of their distinctive culture as a valid alternative to the hearing world. The key elements of the paradigm of social difference are the assertion of a distinctive and shared identity and culture among the group, the validity of this culture in its own terms, and the right of such people to represent and speak for themselves about the nature of their needs and the policy responses that are appropriate. It is reflected in demands for social policies which are responsive to social difference and distinctive values of care in communities of shared sexual, ethnic and religious identity. These demands raise new questions about the role of public support for caregiving and for the private relationships through which it is provided.

Sacks' paradigm of difference does not necessarily entail separatist service provision, though it may support such in particular cases. It may equally mean inclusion in mainstream activities on terms which are cognisant of

difference.[4] Yeatman (1994: 86-9) interprets the recognition of difference as requiring an alternative vision of citizenship, the social policy image for which she draws from the advocates of multicultural service delivery: 'a service oriented to the substantive particularity of individual and group needs, where this orientation is a function of ongoing dialogue between users and service deliverers' (Yeatman, 1994: 87). It is one which invites conflict and confrontation and works positively with them. Yeatman argues that public services informed by a positive politics of difference would replace the adversarial, rights-oriented culture of the law with a civic culture in which there is a high degree of flexibility and discretionary action. This calls for organic styles of decision-making and decentralised administration within negotiated guidelines.

Increased social diversity has the further implication that variability in needs, demands and cultural expectations concerning informal care, demand particular sensitivity and policy imagination. The politics of difference raise questions about power in the development and administration of services responsive to cultural pluralism and the needs and preferences of individuals. We are familiar with issues of politics and culture at the level of the institution. Sacks' account saw the deaf struggle for control of an institution critical to sustaining their culture.

Other social movements have been similarly concerned with the control of their institutions. Indeed, these represent some of the most fraught debates of the mixed economy of welfare, as exemplified in arguments about whether control over Aboriginal health should be exercised by the Aboriginal and Torres Strait Islander Commission (ATSIC) or the Department of Human Services and Health, and by women's movement concerns about welfare state incorporation of women's services. These are less obvious when the politics of difference arise at the level of the individual. There are, of course, potent opportunities for discord, even opposition and conflict, in the needs and wishes of the giver and recipient of informal care. The paradigm of difference provides a valuable reminder that such discord may be contoured by social and cultural difference, giving particular and varying inflections to

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4    While this paradigm has similarities to the way in which needs and entitlements of Aboriginal and Torres Strait Islander peoples are represented, there are also important differences. In particular, it does not base its claim for the recognition of difference on a notion of violence equivalent to that of colonisation or its implications for policy on notions of compensation or self-determination due to indigenous peoples.

the emotions and duties of mothers and daughters, friends and lovers, neighbours and co-religionists. Yeatman's version provides no tools, however, to deal with differences in the power and capacity of such individuals to participate in the dialogue of difference.

There is some coincidence of the individualism inherent in the politics of difference and the development of an increasingly mixed economy of welfare. The pluralism of the mixed economy gives flexibility to the roles of state, market, family and non-government organisations in the support of informal care, and in the balances with which forms of support can be combined in individual cases. As community service provisions have been expanded, new approaches to the organisation and delivery of services have been embraced, effectively increasing the importance of informal caregivers as advocates and representatives of dependent clients and as clients in their own right. Strategies such as the decentralisation of state bureaucracies, the development of community-based and auspiced services and the introduction of devolved budget holding and individualised funding have been deliberately introduced to increase the participation of community members in the planning and operation of services and to make them more responsive to the needs of individual consumers (Howe, Ozanne and Selby-Smith, 1990).

Paul Hoggett (1994) refers to advances of this kind as the emergence of 'post-bureaucratic' organisation a development which he argues is closely associated with attempts to increase the effectiveness of organisations in both the public and private sectors. These developments also reflect an increasingly consumerist approach to service provision (Hambleton and Hoggett, 1993). Julia Twigg's research on the relationships between caregivers and community services also shows how developments of this sort are increasingly forcing services to recognise the contribution of informal carers and to adapt their provisions to accommodate to their needs (Twigg, Atkin and Perring, 1990; Twigg, 1993).

Drawing on this body of work, it can be argued that the accustomed response of professional/bureaucratic organisations to clients has been to treat them as passive recipients of assistance: as patients or welfare recipients. Where caregivers were identified they tended to be regarded as either a viable source of support, thereby disqualifying the dependent from further formal help, or as interfering with the task undertaken by the professionals. As

post-bureaucratic modes of organisation become more prominent, it is becoming increasingly untenable to attempt to exclude caregivers from the decision making process surrounding the allocation and delivery of support. Developments intended to increase the effectiveness and efficiency of service provision, in turn, are increasingly required to come to terms with the issue of informal caregiving (Fine and Thomson, 1995a). In particular, the trends toward individualised funding and contracted service arrangements offer mechanisms by which cultural differences of need and preference might be accommodated in the support of informal care. To actually do so, however, depends on whether the mechanisms of the mixed economy work through the rationality of respect for difference and individual need or through the more impersonal rationality of market forces and minimum cost to the public purse.

# 5 Three Policy Options

The recognition of informal care raises important challenges for understanding citizenship and the need for social protection. The concept of an active society has at times been rather narrowly understood as implying that the rights and duties of citizenship can best be realised through assisting individuals to gain employment. In recognition of the changes that have taken place in employment patterns over the last decade or so and the unlikely prospect of Australia's return to 'full employment' in the near future, Cappo and Cass (1994) have recently argued that the notion of work and employment needs to be understood as including any form of socially useful form of work participation, including that of caregiving (Shaver, 1995). Their proposition invites further questions: What rights to protection and broader social support should be associated with the provision of informal care, and how might the citizenship rights of those who need care be ensured?

As Qureshi and Walker (1989: 262-71) have pointed out, the main policy options for government can be divided into three broad alternatives:

- the enforcement of familial responsibilities for care through the withdrawal of public assistance and the enforced reliance on the provision of care by family members;

- relieving informal caregivers of responsibility by providing alternative forms of support for those who depend on assistance; and

- the support of informal caregivers through the development of shared care approaches in which state, community and family work together in partnership.

Before considering some of the more concrete elements that might constitute a policy on caregiving, we briefly discuss each of these broad options.

The first option for government is to enforce reliance on family and other informal caregivers by providing only minimal services and assistance and/or by legislating to enforce the responsibilities of kin to provide ongoing care. This approach, inherent in the historical reluctance of Australian governments to intervene in family responsibilities, has been recently advocated by the Conservative Party in the United Kingdom where it is argued that government initiatives essentially crowd out efforts by the family (Qureshi and Walker, 1989: 262). Similarly, conservatives in the United States have argued that any increase in support would lead to a 'shirking of family responsibility', undermining family commitment to care and destroying the efficiency of the market-based system of private provision (Chappell, 1992: 55).

Systematic and detailed research has, however, failed to demonstrate these effects in practice. For example, evidence from the Channelling Projects, a series of very large scale demonstration projects on community care conducted in the United States during the 1980s, suggests that the viability of informal care provided by family members was enhanced when adequate publicly financed formal services were available to complement their efforts (Christianson, 1988; Kemper, 1992). Other evidence from the United States suggests that when support services are not available, the incidence of other problems, such as family abuse and neglect of the dependent, increases significantly (Steinmetz, 1988; Wolf and Bergman, 1989).

By contrast, in Sweden, in which there has been considerable experience with what many would argue are the most extensive public provisions for care in the world, it has been found that informal caregivers continue to provide approximately twice as much care as public agencies. In a series of recent studies of the Swedish experience, it has been suggested that rather than undermining informal familial support, publicly supported provisions

have sustained affective bonds between family members, facilitating the ongoing commitment of family members who are secure in the knowledge that alternatives are available should the tasks of caring become too overwhelming (Johansson, 1991; Johansson and Thorslund, 1991; Thorslund and Parker, 1994).

The second policy option is for governments to obviate the need for reliance on informal care by providing those who depend on assistance with access to alternative forms of support. This approach, advocated by some feminists (Dalley, 1988), sees unpaid caregiving as essentially exploitative and searches for a way to liberate (the predominantly female) carers from the burden of an open-ended commitment. Hence, some authors have argued that rather than increasing reliance on the unpaid labour of women, informal caregivers should be relieved of their responsibilities by an expansion of substitute services, including residential care, through which collective social responsibility for support of the vulnerable can be exercised.

A variant on this approach, which combines a feminist and a disability rights perspective, is critical of both the concept of community care and the orthodox feminist critique of it (Morris 1993, 1994). According to Jenny Morris, the current system of care is reliant on unpaid domestic and familial labour in a way which not only exploits the women (and those men) who provide it, but also degrades and disempowers the recipients. Morris rebukes some of her feminist colleagues for regarding caring as simply another form of household drudgery and portraying the recipients of care as nothing more than a burden. But she is also scathing in her analysis of community care practices which generally leave 'disabled people' (her term) with no choice but to rely on family members, especially spouses, partners and parents, who are then faced with a task which, too often, overwhelms their relationship. Morris argues instead for 'independent living' (for example through forms of attendant care in which disabled people are funded to employ their own assistants) rather than substitute institutional provisions.

The approach of providing an alternative to caregiving has been criticised on conceptual grounds for identifying the relationship between caregivers and those who are forced to depend on them as the primary site of conflict, while the social issues associated with inadequate state support are obscured (Qureshi and Walker, 1989: 263). The approach may also be criticised on empirical grounds. Government resources are too constrained to allow all

informal care to be replaced by formal services, so any attempt to provide alternatives must utilise rationing mechanisms of some kind. There are also problems associated with the equity and effectiveness of alternative methods of service provision. Residential institutions, for example, do not provide an optimal environment for most clients and seem unlikely to be able to provide for all future care needs.

Attendant care appears, in contrast, to have much to recommend it, but as funding problems appear to prohibit its use on an indiscriminate basis, any extension of its use is still likely to leave many people dependent on informal caregiving. Finally, it need hardly be said that caregiving is a deliberate and considered relationship entered into willingly by most caregivers and by those they assist, and is unlikely to be relinquished easily by either party. The tenacity of the caring relationship is attested to in the continuation of the relationship between the residents of institutions and their most frequent visitors.

The debate about replacing informal caregivers raises a number of issues of importance. Do the conditions under which care is provided at home disempower clients and caregivers? Does the well-being of clients have to depend on another's sacrifice, the loss of their quality of life or opportunities to participate in the world outside the home? Or can assistance be provided in a way which supports both the recipient of care and informal caregivers so as to facilitate the development of their relationship?

The third approach suggested by Qureshi and Walker is the one with which we are most concerned in this paper - the development of a shared approach to care. This approach is often also described as involving the development of a 'partnership' between the state, community and family, requiring the 'interweaving of formal and informal care'.

Clearly, many people with disabilities of all ages remain at home with little or no assistance whatsoever (ABS, 1993b). Others receive small amounts of help from single specialised services or more extensive assistance from a range of different agencies, while relying for the remainder of the time on their own efforts and/or help provided by informal caregivers. Because of the mix of different inputs encountered in the home, community support appears to be inherently far more flexible than most forms of residential care. Formal services for those at home are not provided to replace informal family-based support but to stand alongside it, with the result that it is

possible to extend assistance to a far greater range of people. By fostering low cost provision from community-based voluntary organisations and other providers, the state's role ceases to be confined simply to the funding of 'all or nothing' institutional provisions for a select group of recipients. The ideal, as expressed in the slogan 'Sharing Community Care' adopted by the then Commonwealth Department of Community Services in 1986-87, appears to have become one of partnership with the caregivers and other providers of informal support to those in need. In Britain, the ideal of a partnership has for a number of years been referred to as the 'interweaving of formal and informal care' (Bulmer, 1987; Twigg, 1993). More recently the term 'co-production of care' has been used (Wilson, 1994) to emphasise the importance of service providers, caregivers and clients all taking an active part in the tasks required for support in the home.

The ideal of a partnership in care represents, in a sense, a pragmatic comprise which is unlikely to satisfy social fundamentalists, either those who wish to see government withdraw from all aspects of social life or those who would like to see responsibility for human vulnerability managed under collective rather than familial forms of provision. Because attempts to encourage informal care may reinforce rather than undermine patterns of familial responsibility, critics often portray the approach as a return to traditional values and a back down from the cause of an increasingly interventionist state.

The criticism is sharpened by the fact that women bear a disproportionate amount of the responsibility for the unpaid caregiving work undertaken within the family (as, indeed, outside it), so that attempts to support and promote informal caregiving may be portrayed as attempts to reinvent or reinforce women's dependence on domestic activities. Criticism of the inadequacy of state interventions, in turn, have been taken up by conservative opponents of state welfare.

The lack of appeal to fundamental principles in the vision of shared care is, however, of only minor importance alongside the practical difficulties associated with the implementation of the ideals. Even if some form of consensus can be reached regarding the decision to support informal caregiving, the question remains, how is it to be done? Indeed, is it at all feasible? As Parker (1981) has argued, this can not be simply assumed.

> Sharing care may be a much more difficult undertaking than is generally believed. 'Sharing' has an attractive sound to it; it is commendable. That does not mean to say that it is easily achieved. It may be hard to achieve emotionally and, practically, it may be exceedingly difficult to organise. (R. Parker, 1981: 24, cited in Qureshi and Walker, 1989: 264)

A number of practical difficulties have been identified by Qureshi and Walker (1989: 264-8). These operate at different levels of the support system. Within the family/domestic setting, the social isolation of many primary caregivers and the absence of spontaneous help by other family members often limits the sharing of care amongst different family members and other possible informal caregivers. This is compounded in many cases by the identification of caregiving as an activity most suited to females, with the result that where there are both women and men available, men do not generally become involved, at least as the primary caregiver.

Difficulties also arise at another level, at the point at which caregivers may come into contact with public assistance. Help-seeking behaviour which could lead to obtaining assistance from formal services is constrained, as many informal caregivers, and indeed, many clients, especially amongst the elderly, are reluctant to request assistance from formal services and health professionals. But it is not simply in terms of the demand for assistance that such difficulties arise. There are also considerable problems with supply. Staff of formal services, for example, are sometimes reluctant to adapt to working alongside non-professional helpers or do so by demarcating the tasks in rather technical and possibly impersonal ways. Many services simply refuse to intervene where there is already evidence of adequate support, giving priority instead to clients without caregivers. Others may attempt to adjust to the situation of sharing responsibility for the care of a client by simply taking charge, more or less negating the caregiver.

The extent of these difficulties, a number of writers have hypothesised, reflect the differing orientations of informal caregivers and services. Caregivers are concerned with the emotional and personal aspects of a particular personal relationship which has developed over time; and the rational, bureaucratic mode of operation of formal services, charged with providing care regardless of their feelings for the individual concerned (Litwak, 1985). The different time commitments and knowledge bases that

services and informal caregivers bring to the task also differ considerably. As a result, in contact between the two, the interests of services are often seen to dominate (Bulmer, 1987: 188-201; Qureshi and Walker, 1989: 264-268).

# 6   Implementing Shared Care

Caregiving, as Hilary Graham (1983) has argued, involves both **caring about** and **caring for** someone.  In other words, as well as the physical work of actually providing assistance, there is an emotional relationship between the carer and the recipient.  For caregiving to be satisfactory and satisfying to each person involved, both are necessary.  Service interventions, that is the provision of direct physical assistance, in person, to either the dependant or the caregiver by formally constituted agencies, have been developed which have been shown to have at least some capacity to achieve one or both of these tasks.

The capacity of services to assist caregivers by undertaking some of the tasks that they might otherwise have to undertake on their own, has been reviewed in a number of recent British publications (Twigg, Atkin and Perring 1990; Parker, 1990; Twigg, 1992; Leat, 1992).  Both mainstream services, such as home help and home nursing, and more innovatory schemes such as flexible home attendance, based on direct payments to individual clients (Morris, 1993; Twigg et al., 1990) have been shown to be capable of sharing some of the physical tasks involved in caregiving.  This is achieved by either directly relieving carers of the work, or by complementing them, undertaking aspects of the work they would be unable to undertake on their own.

Various forms of respite care, notably in-home respite (sitting services), centre-based day respite (day centres) and residential respite (provided in a nursing home or other special accommodation over a period of several days or weeks) have also been found, under certain circumstances, to be of benefit in relieving the caregiver of responsibility on a temporary basis and refreshing the emotional ties between caregiver and the recipients of care (Levin, Moriarty and Gorbach, 1994).  There are, however, numerous problems with respite care, most pronounced in the form of residential respite.  Leaving aside the widely reported problems of dubious outcomes for some clients and caregivers, one of the biggest problems appears to be the widespread reluctance of many potential consumers to use these services,

especially centre-based and residential respite (Twigg, 1992). Consumer reluctance appears to stem, at least in part, from a resistance to relinquishing control and to the forced removal of the recipient from their home.

This last issue is important because it suggests the possibilities of developing a 'co-production' approach to the provision of support, one of the key principles that needs to be addressed in developing an agenda for shared care. Co-production, a rather awkward term that has only recently come into use, can be thought of as a form of assistance that lies somewhere between the passivity expected of clients in the more conventional medical/professional approach to care, and the total independence implied in the notion of self-care (Wilson, 1994; Penning and Chappell, 1990). This vision of co-production can be thought of as teamwork on a small scale, with the person receiving care, the caregiver and formal service workers actively co-operating to achieve a common goal. Flexibility and informality are the watchwords for service staff in such an approach. For formal services and informal caregivers to produce care on a co-operative basis, a significant rethinking of the operation of most community service agencies would be required. Where community service staff are currently charged with undertaking work according to the routines and specifications of their organisations and are accountable primarily to their own staff hierarchy (Fine and Thomson, 1995b: 179-94) a new form of teamwork emphasising accountability to the caregiver needs to be envisaged.[5]

Payments for caregiving, in various guises, represent the second common form by which the state can intervene in the support of informal care. As these are the subject of a recent paper (Rosenman and Le Broque, 1995) we will confine ourselves to identifying one of the central dilemmas for governments. If public support for caregiving is considered desirable, is it better to extend the system of payments and rewards that operate in the labour market to the work of informal caring, or should payments be confined, by and large, to the field of income support? Paying a 'wage' for informal caregiving is a relatively new development, enthusiastically adopted in a number of Scandinavian countries in recent years. The second form of payment, which some commentators refer to as a 'caregiving

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[5] A range of other approaches that could facilitate the integration of carers into the service system has also been recently proposed by Julia Twigg (1993).

allowance', is very widespread and is found in one form or other in most welfare states (Glendinning, 1993; Evers, 1994; Bradbury, forthcoming).

As Hilary Land (1995) recently demonstrated, the principle of compensating the expenses incurred by those who provide informal care of various sorts (e.g. foster care of children) has been long established. In English speaking countries, however, there has been a persistent reluctance to pay for informal care due in part to the fear that it could devalue the relationship between the caregiver and recipient. Other arguments commonly raised against caregiving wages include the difficulty of determining the legitimacy of different claims for informal care and the fear of creating a system of incentives which would either alter existing patterns of behaviour in undesirable ways, or encourage a rash of new claims without extending the availability of informal care to any great extent. Further, the introduction of payments for informal care is likely to be at the expense of the provision of formal services, a rather invidious and perhaps unnecessary trade-off.

Given the limited resources available to government, deciding the form that any direct intervention in support of informal caregiving may take is crucial. If resources are to be available, the dilemma arises as to whether they should be invested to assist caregivers or provided instead to those who need assistance, including those who lack informal support. Should the available resources be used to extend payments to caregivers, possibly reducing the future availability of services, or should direct payments be limited, with the resources directed instead towards assistance in-kind?

# 7    Conclusion

We have argued that far reaching social changes have been taking place over recent decades which have served to elevate informal caregiving from its status as a largely unrecognised duty of family life to become an important component of, and issue for, social policy. We have pointed to two dimensions of change raising issues for the support of informal caregiving at the present time, the post-industrial transformation of paid employment and the demand that service provision be conducted in terms recognising social differences such as those grounded in gender, race, ethnicity, religion and sexual preference. Developments of this kind require social policy responses supporting new patterns of interconnection between the private sphere of family, kinship and community and the public domains of market and state.

In response to the issues that these developments raise, we have suggested that a policy framework promoting the co-production of care as a shared responsibility of family and community, although not without difficulties, is preferable to its main alternatives.  Given the relatively recent recognition accorded to issues of informal caregiving, it is neither appropriate nor possible to recommend a set of ready-made solutions to the problems experienced by caregivers or the challenges that their recognition raises for policy, for the community and for families.  Rather, we have briefly canvassed two possible approaches to such a partnership in shared care, those of support in-kind with the tasks of caregiving, and of support in money form through payments for caregiving.  Such approaches, alone or in combination, have the best prospects of harmonising social policy and personal life in the need for and support of informal caregiving.

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