



4 Deinstitutionalisation: the move towards community-based care

4.1 Introduction

The term deinstitutionalisation has traditionally been most closely associated with mental health and intellectual disability. In this context, its original meaning lay in relation to the movement of actual individuals from an institutional setting to a community setting. But over time the term has attained a broader meaning in policy debates, being used in relation to the shift away from institutional services and towards care in the home and the community, regardless of the movement of particular individuals.

In this sense, deinstitutionalisation is a shift in the system of service delivery the process can be observed in a diverse array of service areas, including aged care, out-of-home care for children, services for people with disabilities, accommodation for the homeless, and acute hospital services. This latter category may be regarded as somewhat tangential to the topic of deinstitutionalisation. However, the expansion of day surgery and hospital in the home initiatives, taken together with home-based post-acute care services, has moved a set of services which were previously provided in an institutional setting out into the community. And aged care institutions, while not subject to the large-scale closures which characterised mental health and intellectual disability institutions during the 1970s and 1980s, have progressively come to cater to a smaller proportion of the older population as the growth in residential aged care beds has been kept to a slower pace than that of the growth in the aged population.

The process of deinstitutionalisation was undoubtedly one of the leading policy and structural transformations in health and community services over the second half of the twentieth century. But while we have documentation of the processes and outcomes of specific institutional closures (Molony & Taplin 1988, 1990; Parmenter et al. 1994; Young et al. 2001), and reports of reviews and inquiries advocating deinstitutionalisation (e.g. Burdekin 1993; Richmond 1983; Senate Select Committee on Private Hospitals and Nursing Homes 1985), there has been no national appraisal of the size and scope of deinstitutionalisation across the diverse array of fields in which the transformation has occurred. This absence is hardly surprising, as the data which are available to paint such a broad picture are in many ways inadequate to the task. There has been no central repository for such information.

These various services are not only funded and provided by a mixture of Commonwealth, State and Territory and local governments, and not-for-profit and for-profit providers, but they also operate within different frameworks and from different service and disciplinary philosophies, aiming to provide services and assistance to very different client groups. Considering the frequently conflicting priorities of different

levels of government, the competing paradigms of various professional groups, and the ideological tensions manifested by proponents of the medical versus social models of service delivery, particularly when these are compounded by programmatic tensions, it is hardly surprising that a single coherent picture has failed to emerge.

This chapter attempts to develop a comprehensive picture of the nature and scope of the deinstitutionalisation process in Australia over recent decades. While the move from institutional to community-based care is widely recognised, and frequently cited, its dimensions and implications are less well understood. The chapter is concerned not only with the move away from institutions, but equally with the move towards community care and community living. It is concerned not only with what has gone, but also with what has appeared to replace it. The broad scope of the chapter includes health and welfare services, but not educational or corrective facilities. More detailed data and examples are drawn from the areas of aged care, disability services, mental health, acute hospitals, and out-of-home care for children.

The chapter begins by considering the concept of institution, taking into account both historical developments and programmatic differences (Section 4.2). There is no intention to develop one single concept of institution that is appropriate for all services at all points in time, but rather to identify some of the elements that have been centrally associated with the term *institution*. This discussion is undertaken partly for purposes of clarity and definition, but more importantly to contribute to an understanding of how and why deinstitutionalisation emerged as a policy direction with such a broadly based coalition of support in the 1970s and 1980s. Understanding why deinstitutionalisation was so strongly supported in the past provides a useful basis from which to explore the situation as it has developed today, not simply in numerical terms, but also in terms of policy developments. Is, for example, the ultimate goal of deinstitutionalisation the closure of all forms of institutional care in all service delivery fields? The maintenance of some bare minimum? Or the maintenance and reform of institutional care where it is necessary, supported by a plurality of alternative forms of community-based care and accommodation? Or simply a strategy to replace more costly forms of institutional provision with cheaper forms of community-based care?

The next section of the chapter (Section 4.3) uses national census data to explore the broad dimensions of the shift from institutional to community living. While there are limitations on the quality of data capture pertaining to the non-household sector, these are nonetheless the most comprehensive data available on the living arrangements of Australians, and the proportion who live in health and welfare institutions. The section provides an overview of the process of deinstitutionalisation in Australia between 1981 and 1996, and the population sub-groups most affected by the observed changes.

The final substantive section (Section 4.4) deals with key policy developments and the dimensions of change in each of five program areas: aged care, disability services, mental health, substitute care for children, and acute hospitals. At this more specific level, more detailed information is available on the alternative models of care developed in different fields to replace institutional modes of service delivery, with data on types of programs, the number of clients and changing patterns of expenditure.

4.2 From institution to community

The 'traditional' institution

What is an institution, and why did it come to be viewed as the wrong vehicle for the provision of health and community services? There are a range of factors which have been used implicitly or explicitly to define institutions, including size, separateness from the community, regimentation, external control, residents who lack identity, choice and autonomy, and a physically and emotionally barren environment. Institution is rarely taken to be a positive term. The classic and often quoted definition is that provided by Goffman in 1961:

A basic social arrangement in modern society is that the individual tends to sleep, play and work in different places, with different co-participants, under different authorities, and without an overall rational plan. The central feature of total institutions can be described as a breakdown of the barriers ordinarily separating these three spheres of life. First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of the member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials. Finally, the various enforced activities are brought together into a single rational plan purportedly designed to fulfill the official aims of the institution. (Goffman 1968/1961:17)

This description of an institution is specific to a particular place and time, yet these kinds of attributes have come to be synonymous with the term institution. Going back even further in history, to the nineteenth century, there was also a punitive aspect to some forms of institutional care. Workhouses, for example, did not just happen to be undesirable places to reside, they were actively intended to be so. A high level of regimentation served, first, to control and regulate these potentially disruptive members of society and, second, to make workhouses and almshouses unattractive options for those capable of working to support themselves (Fraser 1983:260). Third, there was an emphasis on the physical separation of these individuals from mainstream society, a belief that society was better off if protected from those who were physically or mentally ill, frail, old, or disabled. This perception of the advantages of providing institutionally based assistance to people who were sick, destitute or disabled was one of the key arguments employed against those who were proponents of outdoor relief (or providing assistance to those in need in their own homes) (Dear & Wolch 1987:35—7). In contemporary terms, outdoor relief can be translated to mean income support and home-based care.

An appreciation of the history of institutional care, and its emphasis on controlling and separating from mainstream community life those who were poor, disabled, ill or simply old, provides a useful context for understanding the strength of the attacks launched on institutional care in the 1960s by such influential critics as Goffman (1968/1961) and Townsend (1962), by advocates of human rights, and by the families and lobby groups engaged in assisting particular client groups.

If regimentation, isolation from the community, lack of independence, dignity and privacy, poor quality of care, and control by others were seen as the essence of an institution, then there is little wonder that social reformers and health and welfare advocates in the 1960s and 1970s argued for deinstitutionalisation. Yet while this period saw the deinstitutionalisation movement translated from philosophy into a tangible social program in the United States (Dear & Wolch 1987:3), the implementation of deinstitutionalisation came somewhat later to Australia for most service areas.

Forces for change

Apart from the criticisms that were aimed at traditional institutions by social researchers and social reformers, there were also important influences at work in the emergence of normalization theory and the application of human rights discourses to the fields of mental health, and intellectual and physical disability. The normalization principle emerged from Scandinavia in the 1960s (Bank-Mikkelsen 1969; Nirje 1964), and was popularised by Wolfensberger in the early 1970s (1972). While Wolfensberger's definition and philosophy developed over the next decade, he consistently emphasised the means of achieving the desired end, rather than simply the endpoint itself. In 1980 he defined normalization as 'The use of culturally valued means in order to live culturally valued lives', but suggested a change in terminology to social role valorization (Wolfensberger 1980, 1983). A key associated concept was that of the least restrictive alternative principle, which requires that the level of support provided should be at the minimum level to support the person with a disability. The intention of this principle is not to minimise assistance, but rather to minimise the creation of dependence (or indeed to avoid interference with the further development of an individual's independence). This concern with the possible creation of dependence has emerged not only with regard to areas such as intellectual and physical disability, but has also become evident among those working in the field of aged care (Baltes & Baltes 1990; Baltes & Silverberg 1994; Gibson 1985).

These trends were mirrored in such human rights developments as the United Nations Declaration on the Rights of Mentally Disabled Persons in 1971, and the United Nations Declaration on the Rights of Disabled Persons in 1975. These declarations emphasised the inherent right to human dignity, the need to become as self-reliant as possible and to hasten the process of their social integration and re-integration. Further attention was drawn to human rights issues among potentially vulnerable populations by the International Year of the Child in 1979, the International Year of Disabled Persons in 1981 and the United Nations Convention on the Rights of the Child 1989. The United Nations Resolution on the Protection of Rights of People with Mental Illness (UN 1991) also emphasised both the importance of human rights and the desirability of a more community-based pattern of service delivery.

As these trends among intellectuals and advocacy groups gained momentum, more attention began to be paid to the views of clients themselves. Developments in the USA in the 1950s and 1960s wrought change in that country, mirroring and influencing developments in other countries. The growing awareness of conditions in mental hospitals for people with intellectual and psychiatric disability was sharpened by the autobiographies and activism of former inmates. The search for and availability of treatment brought other options to the fore, as did the activism of parents of children

with disabilities who sought improvements in institutions or support for care in the community (Braddock & Parish 2001). By the 1980s, it had become more common to read of the preferences of older people and those with disabilities to remain in their own homes. In the United Kingdom, the independent living movement gained rapid ground, particularly among people with physical disabilities (Morris 1993:17–21; Shearer 1982). In Australia, these ideas were emphasised with regard to older people in the aptly titled report of the House of Representatives Standing Committee on Expenditure *In a Home or at Home* (HRSCE 1982). This report emphasised the need to develop community-based services to allow people to remain at home in keeping with their own preferences.

Last, but certainly not least, there was the strong conviction among many policy makers, both politicians and public servants, that community-based care was a less costly alternative to institutional care (AIHW 1993:11). Where care is provided at home, there are often substantial cost savings associated with the availability of informal carers, and certainly home-based care does not (in the vast majority of cases) involve the provision of 24-hour care characteristic of most institutions. Moreover, there are also the substantial savings to be generated by the much more limited capital costs associated with the provision of home-based care services. In the field of aged care, for example, the issue of capital funding for aged care homes has proved to be a highly contentious policy issue as attempts to improve the quality of stock placed financial demands upon the aged care system (Gregory 1993, 1994). The closure of large-scale institutions in many cases also provided windfall gains for State and local governments through the sale of valuable real estate in prime positions. These capital savings are, of course, less relevant where large-scale institutions are replaced by group homes or small-scale community-based facilities which themselves require capital investment. The transitional costs of specific deinstitutionalisation initiatives can be considerable. The Richmond report in New South Wales considered a range of relevant transitional issues, including a chapter devoted to staffing and industrial issues staffing levels, entitlements, union demarcations, budgetary practices and other conflicting rigidities in the institutional system that had to be addressed in achieving a shift to community care (Richmond 1983, Part 1, ch. 8).

Implementation in Australia

While these ideas were gaining increasing currency, and there was growing activity among advocacy and special interest groups, there was little evidence of broad-scale implementation of deinstitutionalisation policies in Australian health and welfare services until the 1980s. But this decade, and the one that followed, saw the emergence of a range of important policy developments across all of the service areas discussed in this chapter. In the field of mental health and intellectual disability, the New South Wales based *Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled* (Richmond 1983) and the federally based *National Inquiry into the Human Rights of People with Mental Illness* (Burdekin 1993) were key developments. In aged care, the so-called McLeay (HRSCE 1982) and Giles (Senate Select Committee on Private Hospitals and Nursing Homes 1985) reports were highly influential, supported by some of the work undertaken by advocacy groups, with such titles as *Prisoners of Neglect* (Social Welfare Action Group 1985), *If Only I'd Known* (ACC 1986) and *A Consumers' Eye*

View of Nursing Homes: Straight from the Heart (ADARDS 1987). In 1983, a major review of the Handicapped Persons Assistance Act and the associated programs and services for people with a disability was initiated by the Commonwealth Government. The recommendations of the review were published in a report entitled *New Directions* (DCS 1985), and implemented with the enactment of the *Disability Services Act 1986*.

Despite this upsurge of activity in the 1980s, one service area discussed in this chapter had begun its migration away from institutional care some decades earlier. Child protection services, having oscillated between home-based and institutional provision in the first part of the twentieth century, began to move steadily away from institution-based services in the late 1950s and 1960s. A highly influential piece of work by Bowlby (1951) on maternal deprivation linked emotional adjustment and mental health to maternal love and care in childhood, and other research in this period pointed in a similar direction. Government and non-government child welfare agencies reviewed their practices towards the institutionalisation of children in the light of this emerging research. The increasing emphasis was on care of children in the home, preferably their own home, but, if not, either in the care of family members or where necessary foster care. Western Australia and Queensland led the way, but a national trend was generally in place by the 1980s, with the closure of many large institutions (Senate Standing Committee on Social Welfare 1985:14).

In all of these reports and reviews, the principles of facilitating the move from segregated, institutionalised services to community-based services, and increasing the range of service options available, have been both central and explicit. The idea of improving the nature of institutional services themselves has received less consistent attention, although some (in particular the Richmond and Giles reports) have explicitly recognised the need for improved quality of services for those remaining in institutional care.

The nature of the shift varied partly with the field; in aged care services, for example, it was assumed that many older people could remain living in their own home, and assistance could be provided to them there through government services and the care of family members and friends. For a more dependent sub-set, it was assumed that the need for institutional care would continue, but that the conditions under which that care was provided could be improved.

In disability services, group homes emerged as a dominant service model in the deinstitutionalisation process in the 1980s, acting both as a destination for people moving out of institutions and an alternative for those who had previously lived elsewhere, and particularly with their families. In more recent years there has been an increasing awareness that a mix of services is preferred. There is recognition of the need to offer genuine choice, including not only group homes, home-based support services and individualised funding packages but also residual and redesigned facilities, such as cluster housing developments where that is the choice of the people and families involved (AIHW 1997a:47—8; Bracks 2001; Ryan 1997). The non-institutionalisation of people with disabilities was recognised as a significant trend, underpinned by the care and support of relatives with whom they live (see, for instance, AIHW: Wen and Madden 1998). The nature and quality of arrangements in the community remain important issues:

We have recognised for some time that the greatest post deinstitutionalisation period challenge was to help people with intellectual disability become part of the community rather than being merely physically located in it. (Parmenter 2001:289)

In the mental health area, community-based care was intended to be substantially non-residential assistance, a shift facilitated by changing models of medical and pharmaceutical management of mental health problems. Here the movement towards deinstitutionalisation was undertaken in conjunction with an emphasis on the mainstreaming of mental health services. It was accepted that some institutional services would continue to be required, partly for the management of acute episodes, and for some on a continuing basis. A policy emphasis was placed on opening psychiatric wards within or in association with acute care hospitals, rather than the continuation of large-scale stand-alone psychiatric hospitals.

In the fields of aged care, disability services and mental health, the establishment of income support payments has been a significant underpinning to the shift towards community-based care. The emergence and growth of cash payments to sick people, older people and people with disabilities was, of course, the policy change that signalled the end of workhouses and almshouses at the turn of the century. While the term outdoor relief is now an historical oddity, it was the emergence of these cash payments (for example, the introduction by the Federal Government of the invalid and aged pensions in 1908) which signalled the first shift away from institutional provision for the old, the chronically ill, and the so-called blind, paralytic, lame, or idiotic (Dickey 1989). The contemporary array of income support payments includes the Age Pension, the Disability Support Pension, the Mobility Allowance, the Sickness Allowance, the Carer Allowance, and the Carer Pension (see Chapters 6 and 7).

For out-of-home care for children, the emphasis was initially on foster homes, and later on in-home placement with relatives and friends, and support of children within their own family home. In this area, too, the growing role of cash payments to support low-income families and sole parents which dates from the 1970s was an important component of the trend toward deinstitutionalisation, although generally not perceived in exactly those terms.

The term deinstitutionalisation has had little salience with regard to acute care hospitals, but here too the 1980s saw a trend towards limiting the use of institutional services. This shift came about partly through earlier release back to the community and partly through the dramatic expansion of day surgery, but both developments meant that more care was occurring in the home, and less in the institutional context. Thus, while the term deinstitutionalisation has not been applied in this sphere, it is certainly the case that there has been a shift of care, including post-acute care, from the hospital to the community setting.

In the area of housing, there is evidence of the demands that deinstitutionalisation is placing on services. The 1999—2003 Commonwealth—State Housing Agreement (CSHA) has an increased emphasis on social housing meeting the needs of low-income households whose needs cannot be met by the private rental market. Many of the households targeted in the new CSHA are not traditional low-income families but those that require some additional support for their housing needs to be met. This includes the need for modification to dwellings, access to specific health and community support

services or for appropriate group housing. Criteria used in the wait list for public and community housing have been revised to include priority access to those groups who previously would have accessed institutionalised care. Housing agencies now, more than ever before, are providing the shelter component of assistance previously provided as part of the institutionalised setting.

Deinstitutionalisation, then, was about much more than the closure of large traditional types of institutions. It was about the need to provide a range of services which best suited the needs of the individuals requiring assistance. It involved the belief that many of those services would be better provided in the community, either in small community-based services or in the recipient's own home. It included an emphasis on cost containment. It was about a philosophy of care which emphasised better outcomes for individuals, and the maximisation of independence. It was about the need to develop community-based alternatives as much as the need to close large-scale institutions, and it was also about the need to reform institutional care itself.

In more recent times, deinstitutionalisation has emerged as a vehicle for promoting client choice and independence. However, there has been some recognition that deinstitutionalisation in itself is not a sufficient condition to ensure quality of care and quality of life. For some people institutional care will continue to be the best alternative; the challenge then becomes to develop a new generation of institutional care which maximises the advantages of such services for the individual resident, while minimising the disadvantages. Parmenter (1994), for example, has pointed to the prime importance of trying to determine the quality of life of people with a disability, wherever they live, and Young et al. (1998) have identified with some concern the relative lack of critical evaluation of deinstitutionalisation initiatives in Australia. Such reminders indicate a second sense in which governments and service providers can continue to pursue a policy of deinstitutionalisation by further reducing the institutional aspects for those who continue to require 24-hour care in a residential setting.

Institutions: context and history

These brief descriptions of deinstitutionalisation in different areas of service, when considered together with some of the historical material presented earlier, illustrate an important but often neglected aspect of our understanding of institutions that understanding is historically and contextually specific. The concept of institution evident in the quote presented early in this chapter does not represent a modern-day aged care home; the nature of what constitutes acceptable institutional care has undergone a substantial transformation over the course of the last 40 years, and indeed over the course of the last century.

But these historical changes are not limited to our understanding of the traditional institution. The shift towards group homes for people with intellectual disabilities, which was seen as the epitome of deinstitutionalisation in the 1970s and 1980s, is now being regarded by some in the disability services field as a staging post, a type of halfway house between institutional care and independent living. The perception of independent living for people with intellectual disabilities has itself undergone its own

transformation, with changing expectations compared with those which predominated 20 years ago. The shifting nature of what constitutes an institution is a contemporary, as well as an historical, phenomenon.

These perceptions do not only change over time, they also differ from field to field. There is no evidence in the aged care field, for example, of a belief that institutional care as provided in a large-scale aged care home is an inappropriate form of care for frail or disabled older people, once a certain level of dependency is reached. Yet such statements are regularly made with regard to younger people with disabilities, and with regard to people with mental illnesses, and with regard to children. The idea of a group home has hardly emerged in the aged care services area, although it is commonplace in both disability services and substitute care for children.

These changing perceptions of institutions have interesting implications for policy makers and advocates, who may find that there are useful models or examples which can be borrowed from quite separate fields of community and health services. Changing perceptions also have implications for data development the statistician who attempts to document the process of moving from the institutional context to the community context has a difficult task, as the category of institution is itself changing. Just as census and survey definitions change over time, so too do people's perceptions of what falls into a specific category. It is impractical and indeed undesirable to halt such changes, but the consequence is that we must learn to live with some imperfections in our counting rules when we are describing a social phenomenon which is itself changing over time.

The role of informal care

Informal carers have traditionally provided the bulk of care and assistance to those who cannot fully care for themselves.¹ The shift from institutional care to community care has in many cases included the recognition that there is an increased reliance on informal carers. This has resulted in the development of programs specifically aimed at supporting carers, in particular respite provisions either at home, in a day centre or in a residential context, and the provision of income support through the Carer Payment, and further cash assistance via the Carer Allowance.

The question of cash payments for carers is an area of some policy debate. In Australia, informal carers are generally not paid from government funds for the care which they provide. Foster care programs, for example, reimburse carers of children in substitute care for expenses but provide no financial reimbursement for the work and care involved. Carers' pensions are a form of income support for those unable to participate in the labour market as a result of their caring responsibilities; they are not intended as payment for services provided. Some overseas countries have, however, chosen to move partly in this direction. In Germany, under the current system of provision,

1 See Chapters 2, 6 and 7.

eligible recipients may opt for a discounted cash payment as an alternative to direct service provision. They may then use that money to pay family or friends to perform the caring role (OECD 1996:44).

The adequacy of community-based support is of direct relevance for such carers, and there are also questions to be considered as to what degree of assistance can be expected from informal carers, particularly where ongoing care is required. Is the right to participation in the paid workforce, for example, something that informal carers can legitimately claim? Current respite services are aimed at giving carers a break from their caring responsibilities, and not at providing them with regular assistance consistent with paid workforce participation. In a system which aims to accommodate increasingly disabled people in the community, the needs and rights of carers is an area which undoubtedly deserves further scrutiny.

4.3 Analysing the census data

Despite the differences evident among the program areas, there was a clear trend emerging by the 1980s towards policies which emphasised the deinstitutionalisation of health and welfare services. The impact of these policy trends is examined at the broadest possible level by exploring the patterns evident in the national census data for the period from 1981 to 1996.

Table 4.1: Living arrangement, by sex, 1981, 1986, 1991 and 1996

Living arrangement	Males	Females	Persons
1981			
Private dwellings	6,807,842	6,926,223	13,734,065
Health and welfare institutions	73,574	121,669	195,243
Other institutions	37,578	26,799	64,377
Non-institutional population	129,637	59,433	189,070
Other (including not stated)	218,445	175,130	393,575
1986			
Private dwellings	7,397,455	7,522,775	14,920,230
Health and welfare institutions	83,278	145,436	228,714
Other institutions	39,954	25,151	65,105
Non-institutional population	122,141	57,293	179,434
Other (including not stated)	126,399	85,579	211,978
1991			
Private dwellings	7,960,489	8,137,289	16,097,778
Health and welfare institutions	61,598	107,342	168,940
Other institutions	36,849	25,293	62,142
Non-institutional population	88,450	48,020	136,470
Other (including not stated)	215,429	169,781	385,210
1996			
Private dwellings	8,514,393	8,753,432	17,267,825
Health and welfare institutions	74,275	135,911	210,186
Other institutions	46,222	31,788	78,010
Non-institutional population	107,065	56,957	164,022
Other (including not stated)	107,272	65,115	172,387

Source: AIHW analysis of ABS census data.

The broad trends

In 1996, and indeed for the entire period under scrutiny in this chapter, the vast majority of people lived in private dwellings (96.5%). The focus of this chapter, however, is on that small minority of the population who did not live in private dwellings those 210,186 people who, at the time of the 1996 Census, were resident in a health or welfare institution. Health and welfare institutions as defined here are based on relevant census data categories and include residential services for children, corrective institutions for children, residential services for people with a disability, aged care residential services, psychiatric institutions, and hospitals.

The number of people living in health and welfare institutions increased by 8% between 1981 and 1996, but this overall trend conceals a shift in trends over the 15-year period. In broad terms, there was substantial growth between 1981 and 1986, followed by a reduction in the following decade. In 1981, there were 195,243 people living in health and welfare institutions, a figure which increased to 228,714 by 1986. By 1996, this figure had dropped to 210,186, an 8% decrease over the decade (Table 4.1).

These trends are consistent with the information reported in the next section, where the data are drawn from administrative by-product collections. They are clouded, however, by the other category in Table 4.1, which includes a proportion of not-stated responses. The quality of classification of non-private dwelling data for the Census has been the subject of criticism in the past, and considerable effort was made to improve this aspect of the data in the 1996 Census, with a pleasing consequent decrease in the other category.² In particular, it seems likely that the substantial increase in the number of other responses in 1991 (an 82% increase from 1986) is partly responsible for the decrease in the number of people recorded as accommodated in health and welfare institutions in that year (and indeed for the decrease in the other institutions and non-institutional population categories). For this reason, the 1986 to 1996 trend is taken to be a more robust indicator of the pattern of change over the period.

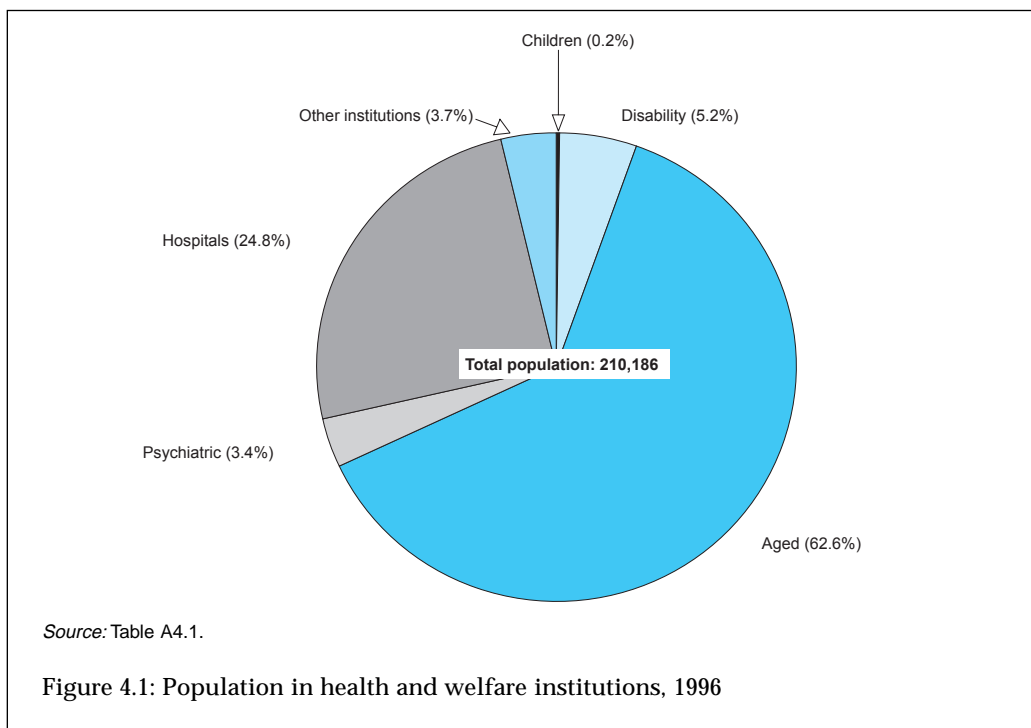
The pattern of growth in the institutional population followed by decline should be interpreted, of course, in the context of a substantial amount of growth in the population as a whole over the 15-year period (24%). Residency rates provide a useful measure of the pattern of institutionalisation, as they illustrate the rate of use independent of the effects of the growth of the population. Residency rates increased marginally from 13.1 per 1,000 people in 1981 to 14.3 per 1,000 in 1986, dropping to 11.5 per 1,000 by 1996.

Types of institutions

While considering the overall trends discussed in this section of the chapter, it is important to recognise that these six types of institutions (residential services for children, corrective institutions for children, residential services for people with a

2 See Fine et al. (1995) for a further account of the difficulties in analysing non-private dwelling census data. This report also provides a useful resource on institutional populations between 1976 and 1991.

disability, aged care residential services, psychiatric institutions, and acute care hospitals) do not account for equal proportions of the population resident in health and welfare institutions. Residential aged care services account for by far the largest proportion (62.6% or 131,598 people in 1996). A further 52,193 people were accommodated in hospitals at the time of the 1996 Census. Disability services institutions accounted for 10,919 persons and psychiatric institutions for 7,135 residents. Children in residential services or corrective institutions constituted only a small proportion of the health and welfare institutional population (Figure 4.1).



Age and sex trends

In 1996, the majority of people in health and welfare institutions were women (64.7%). Women aged 80 or over made up 58.4% of women, and 37.8% of all people, in such institutions. While older age groups also predominate in the male population, the trend is much less marked, with only 32.3% of men in health and welfare institutions being aged 80 or more. Men aged 80 and over make up only 11.4% of the total population of health and welfare institutions, but, taken together with women aged 80 and over, this means that 49.2% of people in these institutions in 1996 were aged 80 and over. The higher proportion of women is a consequence of higher rates of use at older ages. Women on average have a higher life expectancy than men and therefore are more likely to be both alive and without the informal care of a spouse at extreme old age. At younger ages, the proportions of males and females in health and welfare institutions are similar (Table 4.2).

Table 4.2: Australians living in health and welfare institutions, by age and sex, 1981, 1986, 1991 and 1996

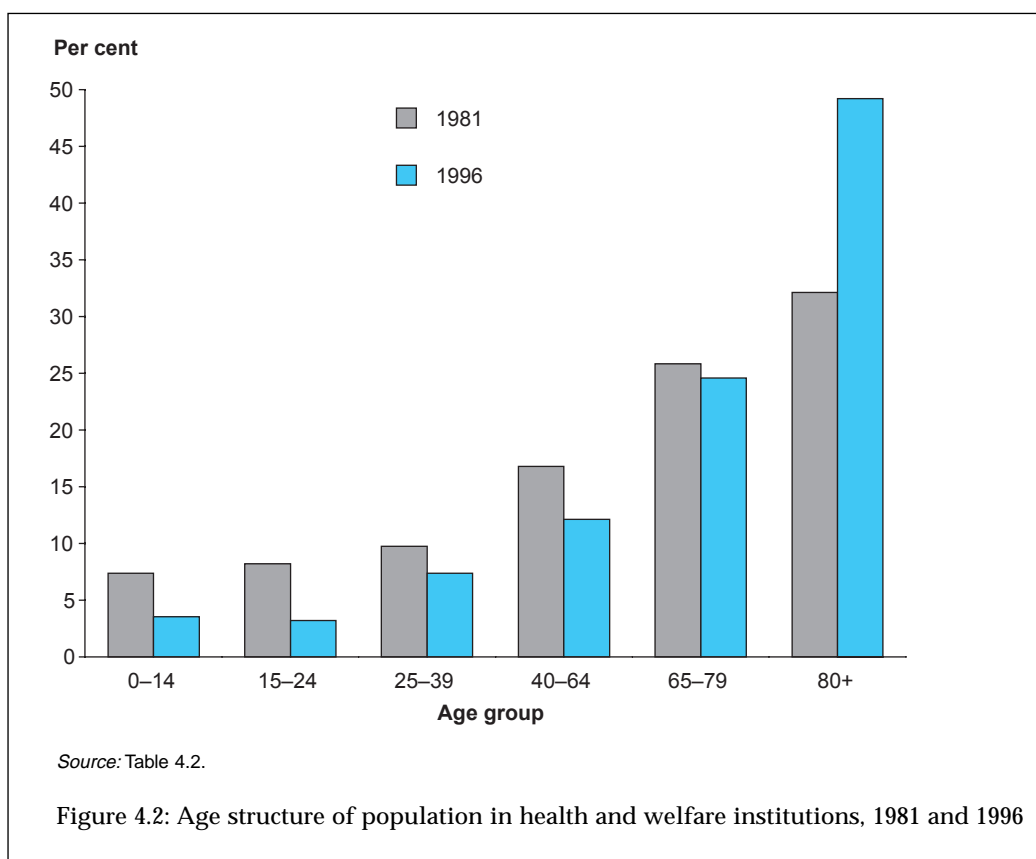
Age/sex	1981	1986	1991	1996
Males				
0–14	8,126	6,563	5,182	4,100
15–24	6,804	6,537	3,120	3,219
25–39	7,665	9,340	5,706	7,083
40–64	17,409	17,893	12,082	13,836
65–79	19,971	24,405	19,136	22,023
80+	13,819	18,540	16,372	24,014
<i>Total males</i>	<i>73,794</i>	<i>83,278</i>	<i>61,598</i>	<i>74,275</i>
Females				
0–14	6,256	5,182	4,955	3,337
15–24	9,195	8,292	3,763	3,512
25–39	11,372	12,370	7,591	8,361
40–64	15,405	15,691	10,135	11,606
65–79	30,580	39,335	27,432	29,668
80+	49,031	64,566	53,466	79,427
<i>Total females</i>	<i>121,839</i>	<i>145,436</i>	<i>107,342</i>	<i>135,911</i>
Persons				
0–14	14,382	11,745	10,137	7,437
15–24	15,999	14,829	6,883	6,731
25–39	19,037	21,710	13,297	15,444
40–64	32,814	33,584	22,218	25,442
65–79	50,551	63,740	46,567	51,691
80+	62,850	83,106	69,838	103,441
Total persons	195,633	228,714	168,940	210,186

Source: AIHW analysis of ABS census data.

Back in 1981, at the beginning of the period under scrutiny, women also predominated, although to a slightly lesser extent (62.3%). The 15 years have, however, seen a fairly dramatic change in the age structure of the group, with only 32.1% of those in health and welfare institutions being aged 80 or over in 1981 (Figure 4.2). This represents a substantial increase in the proportion at older ages, and a corresponding decrease in the proportions at younger ages.

The dimensions of this change in patterns of institutionalisation are evident (Table 4.3) when one examines the percentage change in the institutional population for different age groups over the period. There was a marked decline at younger ages, a more modest decline in the middle age groups, and an increase for those aged 80 and over.³

3 As already noted, the 1991 data appear less reliable with regard to the numbers of people in health and welfare institutions given the large increase in the 'other' category in that year. Consequently this discussion emphasises the trends between 1981 and 1986 and between 1986 and 1996.



Between 1981 and 1996, there was a 48.3% decline in the number of people aged 0–14 accommodated in health and welfare institutions, and a 57.9% decline among those aged 15–24. These decreases were similar for both males and females, except in the 15–24 age group, where the number of females decreased faster than the number of males. This decrease occurred despite the fact that the total number of people in these age groups was growing as a result of population growth. The movement away from institutional care has thus, on the evidence of these data, been strongest among children and young adults.

For those in the next two age groups (25–39 and 40–64), there has been a more modest decline in the number accommodated in health and welfare institutions (18.9% and 22.5% respectively), with the change occurring in the period between 1986 and 1996. When the data are examined separately by sex, however, it is clear that this decline was much less evident among men aged 25–39 (a 7.6% reduction).

For the older age groups, there has been a very small increase in the numbers of people aged 65–79 living in institutions (2.3%). However, this 15-year trend is a combination of an increase between 1981 and 1986, and a decrease between 1986 and 1996. Again, the decrease in the decade to 1996 is much more marked in the female than the male

population. In the 80 and over population, there has been a substantial growth in numbers between 1981 and 1996, a trend which is evident for both sexes. Overall, the size of the institutionalised population aged 80 and over grew by 64.6% during the 15-year period.

Table 4.3: Growth rates for persons in health and welfare institutions, by age and sex, 1981–1986, 1986–1996, and 1981–1996

Age/sex	1981–1986	1986–1996	1981–1996
Males			
0–14	–19.2	–37.5	–49.5
15–24	–3.9	–50.8	–52.7
25–39	21.9	–24.2	–7.6
40–64	2.8	–22.7	–20.5
65–79	22.2	–9.8	10.3
80+	34.2	29.5	73.8
<i>Total males</i>	12.9	–10.8	0.7
Females			
0–14	–17.2	–35.6	–46.7
15–24	–9.8	–57.6	–61.8
25–39	8.8	–32.4	–26.5
40–64	1.9	–26.0	–24.7
65–79	28.6	–24.6	–3.0
80+	31.7	23.0	62.0
<i>Total females</i>	19.4	–6.5	11.5
Persons			
0–14	–18.3	–36.7	–48.3
15–24	–7.3	–54.6	–57.9
25–39	14.0	–28.9	–18.9
40–64	2.3	–24.2	–22.5
65–79	26.1	–18.9	2.3
80+	32.2	24.5	64.6
Total persons	16.9	–8.1	7.4

Source: AIHW analysis of ABS census data.

This growth in the very old population living in health and welfare institutions reflects the rapid growth occurring in that age group over the period in question. Residency rates give an indication of the pattern of use distinct from changes driven by population size. They show the proportion of the population in that age and sex group who were living in institutions at different points in time, thus controlling for the effects of population growth in making a time-series comparison (Table 4.4).

The data on residency rates for the younger age groups confirm the strong trend towards reduced use of institutional accommodation, with the rate of use essentially halving. For those aged under 14, residency rates dropped from 3.9 per 1,000 to 1.9 per 1,000 between 1981 and 1996, with the corresponding figures for the 15–24 age group being 6.2 and 2.5. The patterns were consistent for both sexes.

There has also been a reduction in residency rates for those aged 25–39, although this trend is less pronounced than that for younger ages. The rate of use dropped from 5.5 per 1,000 in 1981 to 3.6 per 1,000 in 1996, with the reduction being more pronounced among women. There was a more substantial shift in the 40–64 age group, from 8.9 per 1,000 in 1981 to 4.9 per 1,000 in 1996.

Table 4.4: Residency rates of people living in health and welfare institutions, per 1,000 persons in the total population, by age and sex, 1981, 1986, 1991 and 1996

Age/sex	1981	1986	1991	1996
Males				
0–14	4.3	3.5	2.7	2.0
15–24	5.2	4.8	2.2	2.4
25–39	4.4	4.8	2.7	3.3
40–64	9.3	8.7	5.1	5.3
65–79	37.5	40.1	27.0	27.8
80+	173.1	183.5	127.3	144.5
<i>Total males</i>	<i>9.9</i>	<i>10.4</i>	<i>7.1</i>	<i>8.2</i>
Females				
0–14	3.4	2.9	2.7	1.8
15–24	7.2	6.3	2.8	2.7
25–39	6.7	6.4	3.7	3.9
40–64	8.4	7.8	4.4	4.5
65–79	45.9	51.8	31.9	32.1
80+	277.2	302.7	209.3	249.6
<i>Total females</i>	<i>16.3</i>	<i>18.1</i>	<i>12.4</i>	<i>14.8</i>
Persons				
0–14	3.9	3.2	2.7	1.9
15–24	6.2	5.5	2.5	2.5
25–39	5.5	5.6	3.2	3.6
40–64	8.9	8.3	4.8	4.9
65–79	42.2	46.6	29.7	30.1
80+	244.8	264.4	181.8	213.6
Total persons	13.1	14.3	9.8	11.5

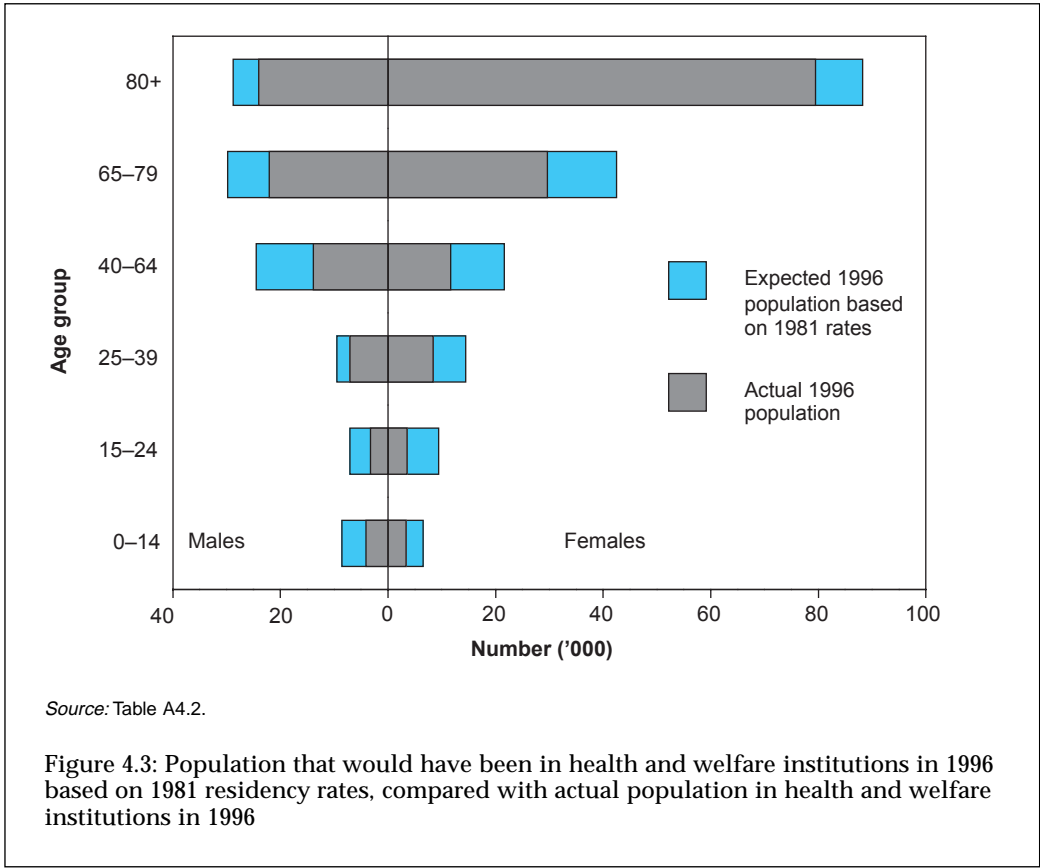
Source: AIHW analysis of ABS census data.

While the actual numbers at older ages have increased over the period, the residency rates show a clear downward trend. There has been a marked reduction in the residency rates at ages 65–79, from 42.2 per 1,000 to 30.1 per 1,000. The reduction is slightly more evident among women, but residency rates for women remain somewhat higher than those for men in this age group (32.1 per 1,000 compared with 27.8 per 1,000). At ages 80 and over, the rates have also declined, from 244.8 per 1,000 to 213.6 per 1,000. The pattern was more pronounced for men. The residency rates for women remain significantly higher than those for men throughout the period. In 1996, they were 249.6 per 1,000 for women and 144.5 per 1,000 for men.

While residency rates at older ages declined between 1986 and 1996, there was an increase in the period between 1981 and 1986. This pattern of an increase followed by a decrease was consistent with the policy directions of the period, as in aged care the

emphasis on expanded home-based care options, and control of the expansion of residential aged care beds, did not come into play until the mid-1980s. Between 1986 and 1996, residency rates declined from 46.6 to 30.1 among those aged 65–79 and from 264.4 to 213.6 among those aged 80 and over.

Figure 4.3 shows the number of people in each age group who would have been in health and welfare institutions in 1996 if the 1981 patterns of use had been maintained until that time. In other words, it shows the situation as it would have been if the rate of institutionalisation in 1981 had continued into the present and if other factors (e.g. technology, pharmaceuticals) had remained unchanged. The differences are significant: there would have been an extra 7,700 under 14; 9,700 aged 15–24; 8,500 aged 25–39; 20,700 aged 40–64; 20,600 aged 65–79; and 13,500 aged 80 and over. Taken together, this totals 80,700 people, or 38% more people than were actually present in health and welfare institutions in 1996.



4.4 Specific policy areas

Aged care

Policy context

By the early 1980s, there was a general recognition in the aged care field that Australia had an overly large and expensive long-term institutional-care sector, and a correspondingly under-developed home-based care sector. A series of government reports emphasised the need for this shift in emphasis towards community-based care (DCS 1986; HRSCE 1982; Senate Select Committee on Private Hospitals and Nursing Homes 1985). Since 1985, the whole system has experienced a lengthy period of substantial reform, aimed at improving the level of efficiency, equity of access, service quality and responsiveness.⁴ These reforms (loosely referred to as the Aged Care Reform Strategy) were initiated under a rubric of social justice combined with fiscal restraint; in 1997, a further round of reforms (the *Aged Care Act 1997*) emphasised the need for cost containment and efficiency, in addition to improved service quality and responsiveness. New directions included the merging of the former nursing home and hostel sectors into a single system, and a greater focus on user charges aimed at improving the sustainability of the aged care system.⁵

A key component of these reforms has been the drive to reduce reliance on institutional care for older people, and to increase the range of services available in the community. In 1986, an official planning ratio of 100 places (40 nursing home places plus 60 hostel places) per 1,000 people aged 70 and over was established to guide the allocation of additional nursing home and hostel places in the institutional care sector. The aim was both to contain growth of the sector overall, and to shift the balance of supply away from the more intensive nursing home care and toward less intensive hostel care. In 1985, the Home and Community Care Program (HACC) was implemented by combining and expanding a number of existing community care services previously delivered under a range of disparate arrangements. Between 1992 and 1995, the official planning ratio for residential care was progressively revised down to 90 places per 1,000 persons aged 70 and over, with 10 equivalent places per 1,000 people aged 70 and over to be supplied through community aged care packages. The latter program had commenced in 1992 to further expand access to home-based care.

4 The Aged Care Reform Strategy emerged from a series of government reviews and inquiries during the 1970s and 1980s. These reviews and inquiries raised concerns as to the over-supply of institutional care, the quality of services provided, the efficiency and equity of the system, and the lack of flexibility and responsiveness to service users. See, for more detailed information, Gibson (1996), Gibson (1998) and DHHCS (1991).

5 See AIHW (1997b:255–8) and AIHW (1999:176–7).

Community-based services

The HACC program provides a range of home-delivered and community-based services to older people and to younger people with disabilities. The target group for the program is described as people with moderate to severe disabilities living at home, and their carers. The program provides assistance in the form of home help, personal care, home nursing, delivered meals, centre-based meals, in-home respite, centre-based respite, home maintenance, transport and paramedical services. It is jointly funded by the Commonwealth, State and Territory Governments, and generally delivered by not-for-profit agencies, although local governments have traditionally played a significant role in Victoria. Some larger agencies (e.g. Home Care in New South Wales and Silver Chain in Western Australia) provide a range of services to clients, while others are service-specific. The HACC program also provides some brokerage services through community options or linkages projects, which coordinate services for clients with more complex care needs.

While the HACC program provides the bulk of community care services to older people, the community aged care package program has been growing rapidly since its inception in 1992, and particularly so in more recent years. From a base of 235 packages in 1992, it grew to 6,124 in 1997, and then quadrupled over the next four years to reach 24,430 packages in 2001. This Commonwealth-funded program provides a similar range of services to the HACC program (excluding home nursing), and is aimed at assisting people who would otherwise require low-level care (formerly hostel care) in an aged care home. The key difference between community aged care packages and HACC is that community aged care packages involve a central agency which organises all services required by the client, either through direct provision or purchase from other agencies.

The broad concept of aged care homes has remained largely unchanged through this period, without the shifts towards cluster housing or group housing which have emerged in mental health and disability services. An alternative style of accommodation for older people has emerged in the private sector with the creation of retirement villages, but these are not aimed at highly dependent older people. While there are no national data on retirement villages, they are recognised as an increasingly popular alternative for some older people.

Although aged care institutions may not have developed in the same way as those in the mental health and disability services fields, it would be wrong to suggest that institutional care for older persons has remained a static phenomenon. Reforms over the period have seen attention paid to de-institutionalising aspects of aged care homes, with an increasing emphasis on the desirability of one resident per room, and a rejection of the old ward style provision of residential services. Values such as privacy, dignity, choice, individuality and a home-like environment were emphasised by the quality control mechanisms put in place in the late 1980s, and there is considerable evidence of shifts in the style of care which is deemed to be acceptable in aged care homes (AIHW 1997b; Braithwaite et al. 1993). These values remain evident in the revised system of accreditation implemented under the *Aged Care Act 1997*.

Trends over time

Services

The national database on aged care homes (formerly nursing homes and hostels) provides the most reliable source of data on the use of institutional care by older people in Australia. Unlike census data or survey data, which can be affected by classification problems, these data provide an exhaustive accounting of those being cared for in aged care homes as they are based on financial information systems. While detailed data are really only available for the 1990s, there are some baseline data for earlier periods. In 1981, the level of residential provision was 111 places per 1,000 people aged 70 and over. This had fallen to 99 places per 1,000 people aged 70 and over by 1985, and to 94 places per 1,000 people aged 70 and over by 1991. In 1995, this fell further to 90 places per 1,000 people aged 70 and over, and then again to 82 places per 1,000 people aged 70 and over in 2001. This change is even more marked if one takes into account the ageing of the aged population which occurred during this period. The use of residential aged care services increases sharply at around age 80, and even more so at age 85. In 1981, 11% of the population aged 70 and over were aged 85 or over; by 2000 this proportion had increased to 15%.

Table 4.5: Aged care institutionalisation rates, age by sex, 30 June 1992 and 2000

Age	Females		Males		Persons	
	1992	2000	1992	2000	1992	2000
65–69	7.8	6.5	8.2	6.8	8.0	6.7
70–74	19.8	16.7	16.1	14.7	18.1	15.7
75–79	54.5	44.0	36.0	31.2	46.8	38.5
80–84	137.3	111.9	80.3	65.2	116.3	93.8
85+	362.3	315.3	202.9	174.7	316.0	271.8
Total 65+	73.3	72.2	33.7	33.2	56.3	55.0

Source: AIHW analysis of DHAC data.

More detailed data on residency rates in aged care institutions are presented in Table 4.5 for the period from 1992 to 2000. These data show a decline in residency rates for all age groups. The decline has been most marked in the 80–84 age group, dropping from 116 persons per 1,000 to 94 persons per 1,000 and in the 85 and over group, dropping from 316 persons per 1,000 to 272 persons per 1,000.

Table 4.6 provides data on the hours of HACC service provision in relation to the numbers of people aged 70 and over. For personal care, in-home respite care, and centre day care there has been a substantial increase in the hours of service delivered. Home maintenance services and paramedical services also increased. For home nursing and home help services, there has been a decrease in the number of hours provided per 1,000 persons aged 70 and over, and there has also been a decrease in the provision of home-delivered and centre-based meals per 1,000 persons aged 70 and over. Given the rapid growth of the population aged 70 and over during this period, these changes in HACC service delivery per 1,000 persons aged 70 and over are underpinned by a substantial absolute growth in the program over the period from 1985 onward, as is

evident in the expenditure data (AIHW 1995; Chapter 6 of this volume). This growth was, however, more rapid in the early to mid-1990s, and has slowed in more recent years.

Table 4.6: HACC^(a) service provision, in a sample month, by main service type, 1993–94 and 1999–00^(b)

Service type	Per 1,000 persons aged 70 and over	
	1993–94	1999–00
Home help (hours)	428	378
Personal care (hours)	109	150
Home nursing (hours) ^(c)	206	129
Paramedical (hours)	20	24
Respite care (hours)	155	192
Centre day care (hours)	421	539
Home maintenance (hours)	42	48
Home meals (meals)	746	683
Centre meals (meals)	101	91

(a) Home and Community Care.

(b) Data on transport, other food services and other unspecified services are not included in this summary table. For more detailed information, see Table A6.2.

(c) Home nursing services are not provided by the Northern Territory.

Source: DHAC unpublished data; AIHW 1999:186.

At the same time, there has been an expansion of community aged care packages since their inception in 1992. The level of provision increased from 1 per 1,000 persons aged 70 and over in 1994 to 4 per 1,000 in 1997, and then more rapidly to 11 per 1,000 in 2001 (see Chapter 6: Table 6.12).

Expenditure

Table 4.7 documents expenditure on home-based and institutional care services in the aged care sector over the 14-year period from 1985–86 to 1999–00. Over this period, total recurrent expenditure on aged care services (including nursing homes and hostels, HACC (including Community Options) and the more recent community aged care packages and National Respite for Carers Program) has increased from \$1,379.4 million to \$4,612.6 million. This represents an increase of 111% in real terms since the mid-1980s and an increase of 49% since 1993–94.

With the inception of HACC in the mid-1980s, followed by community aged care packages and the National Respite for Carers Program in the early to mid-1990s, it is no surprise that the increase in community care funding has been more dramatic than the increase in residential care funding: 263% in real terms since 1985–86, compared with 93% for residential care. However, this difference is not as dramatic for recent years. Since 1993–94, the increases in recurrent expenditure for community and residential care have become more similar, at 57% and 47% respectively.

Table 4.7: Recurrent expenditure on aged care, by sector, 1985–86 to 1999–00 (\$m)

Sector ^(a)	1985–86	1987–88	1989–90	1991–92	1993–94	1995–96	1997–98	1999–00
Current prices								
Community care	151.8	234.1	322.2	413.2	498.5	587.1	714.3	871.3
Residential care	1,227.6	1,553.2	1,827.3	2,145.0	2,283.4	2,695.0	3,381.0	3,741.3
<i>Total</i>	<i>1,379.4</i>	<i>1,787.3</i>	<i>2,149.6</i>	<i>2,558.2</i>	<i>2,782.0</i>	<i>3,282.1</i>	<i>4,095.3</i>	<i>4,612.6</i>
Constant prices^(b)								
Community care	235.1	329.4	399.8	463.2	541.9	620.6	731.1	852.5
Residential care	1,900.8	2,185.4	2,267.2	2,404.7	2,482.0	2,848.8	3,460.6	3,660.8
<i>Total</i>	<i>2,136.0</i>	<i>2,514.8</i>	<i>2,667.0</i>	<i>2,867.9</i>	<i>3,023.9</i>	<i>3,469.5</i>	<i>4,191.7</i>	<i>4,513.3</i>
Proportion (per cent)								
Community care	11.0	13.1	15.0	16.2	17.9	17.9	17.4	18.9
Residential care	89.0	86.9	85.0	83.8	82.1	82.1	82.6	81.1
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>

(a) Community care includes Home and Community Care (HACC), Community Options (COPs), Community Aged Care Packages (CACP) and expenditure on the National Respite for Carers Program (NRCP).

(b) Deflated to constant prices using the 1998–99 GFCE deflator (ABS 2000).

Source: AIHW health expenditure database; DHAC 1998, 2000a, unpublished data; DHFS 1996.

The relative allocation of funds between community and residential care shows a rapid change in favour of community care between 1985–86, when 11% of expenditure was devoted to community care, and 1993–94 when this proportion reached 18%. In the period from 1993–94 to 1999–00, the proportion has remained relatively stable, at around 17–19%.

Disability services

Policy context

As discussed in Section 4.2, the late 1960s and early 1970s saw important changes in attitudes toward disability, driven by normalization theory and the growth of the human rights movement.⁶ These changing attitudes were translated into changes in policies and services in the 1980s, with a greater emphasis on consumer involvement, integration, and an emphasis on moving away from institutional models towards community-based services. These directions were clearly evident in the *Disability Services Act 1986*.

In 1991, the first Commonwealth/State Disability Agreement (CSDA) was signed by the Commonwealth and State and Territory Governments. Under the first CSDA, the Commonwealth assumed responsibility for employment services and agreed to provide transition funding of \$5 million in 1991–92, increasing to \$53 million in 1995–96 to help with the process of transferring accommodation services from the Commonwealth to the States and Territories. Key initiatives implemented with these funds included the closure of institutional-style services, such as special purpose nursing homes and hostels, and the opening of community-based services, including group homes and

6 See AIHW (1993, chs 1 and 6) for a further account of these developments.

community access/recreation services for clients living in the community. The second CSDA (1998) confirmed Commonwealth responsibility for the planning, policy setting and management of employment services, with the States and Territories having these responsibilities for all other specialist disability services (see Box 7.7 for definitions of service types). Advocacy, print disability and information services are considered shared responsibilities under this agreement.

In relation to accommodation services, the deinstitutionalisation of disability services has thus, during the 1990s, been largely a State and Territory government responsibility, with each jurisdiction introducing a range of reforms emphasising community-based care and in-home support. There were developments also in the field of employment support services. As part of the 1986 reforms at Commonwealth level, employment services were separated from other support services, reflecting the move away from whole-of-life service provision by one organisation. Open employment services are now a significant feature of CSDA service funding by the Commonwealth, accompanied by initiatives to move away from the sheltered employment model. Commonwealth income support payments such as the Disability Support Pension and the Carer Allowance provide financial support to people with disabilities and their families living in the community (see Box 7.5 and Tables 7.6—7.8). These payments are (respectively) descendants of the Invalid Pension, first introduced in 1910 as significant outdoor relief, and the Handicapped Child's Allowance introduced in 1974 (AIHW 1993:279).

The shift towards community-based care is continuing in jurisdictions across Australia. Different terms are used to describe the process, and there are some differences in policy approaches. In New South Wales, for example, devolution describes a staged approach aimed at moving all people currently in institutions into community-based accommodation over the next 10 years. In Victoria, the redevelopment of institutions is in process through a combination of closure, infrastructure improvement and the development of new cluster housing. A number of alternative systems of assistance have been put in place in all States and Territories to support community-based living for people with disabilities. A particular landmark in 2000 was the closure of Australia's oldest institution for the care of people with an intellectual disability the Willow Court Centre in Tasmania. The centre closed its doors after 173 years; since 1987, almost 300 residents had been progressively relocated to community-based services (Jackson 2000).

Community-based services

In-home support services and individual support packages

These services provide support and assistance to people with disabilities living independently in the community, most often with the assistance of family and friends. Services provided under the CSDA include attendant care, in-home living support, recreation and holiday programs, social and community support and respite services. During the 1990s, State and Territory Governments committed growth funds to an expansion of services, such as post-school options, service brokerage and early intervention, to help prevent or delay the need for out-of-home accommodation. Services provided under the HACC program are also an important source of assistance to people with disabilities, and to informal carers.

Another recent development is the growth in individual funding packages, which allocate funding to the individual consumer, with the aim of providing a flexible mix of services to meet the individual's needs. There is considerable variation from jurisdiction to jurisdiction in the way in which these packages operate, with some providing funds to the individual directly and some via a brokerage agency, with varying degrees of input from the client in deciding what services are purchased.

Group homes

Group homes provide combined accommodation and support services to people living in the community. Usually no more than six people live in a house, and a single organisation controls the house and provides support services. Group homes appear to remain the dominant accommodation model for people with intellectual disability moving out of institutional settings (Bostock et al. 2001), and are generally accepted as an important community-based accommodation option. However, questions have been raised about the degree of autonomy and choice experienced by the residents of some group homes (AIHW: Maples & Madden 1996; Parmenter et al. 1994), and more individualised in-home support options are also being emphasised. Increasingly, the group home is being seen as a half-way house, in both the physical and policy senses, in the evolving deinstitutionalisation process.

Centre-based care

Despite the general trend to community-based care, there is a recognition that some form of centre-based care is needed as an option within the disability services system (Young et al. 2001). Here, too, however, there are moves away from traditional large-scale institutions, with cluster housing as in the case of Kew Residential Services emerging as a viable alternative (Bracks 2001). Cluster housing models have been implemented or flagged for development in several jurisdictions, including Queensland, Victoria and New South Wales. The redevelopment of existing institutional sites to reduce the scale of facilities is also occurring (Bostock et al. 2001:36; Emmerson et al. 2000).

Trends over time

The main source of data for looking at trends over time in the accommodation of people with disabilities is the Survey of Disability, Ageing and Carers conducted by the Australian Bureau of Statistics in 1981, 1988, 1993 and 1998. Despite some changes in methodology between the surveys, comparisons are possible for the 17-year period from 1981 to 1998. As is evident from Table 4.8, the proportion of people with a severe or profound core activity restriction living in cared accommodation has decreased substantially over this period. Persons with a severe or profound core activity restriction are those who always or sometimes require personal assistance or supervision with activities of daily living (self-care, mobility and verbal communication).

For those aged 5–64 with a severe or profound core activity restriction, the percentage living in cared accommodation fell from 10% in 1981 to 3% in 1998. The reduction is very pronounced in the 15–29 age group, moving from 19% in 1981 to 3% in 1998. The proportion of such persons aged 5–14 living in cared accommodation has all but disappeared, at 0.4% in 1998. Much of this change occurred during the 1980s for the younger age groups, but at middle to older ages the changes were more concentrated in the 1990s.

Table 4.8: People aged 5–64 with a severe or profound core activity restriction, by accommodation type and age, 1981–1998

Year	5–14	15–29	30–44	45–64	5–64
Living in cared accommodation					
1981	3,525	7,340	4,920	11,253	27,038
1988	997	6,866	5,533	10,815	24,211
1993	1,130	3,091	6,165	8,756	19,142
1998	471	2,541	5,608	10,803	19,423
Per cent					
1981	8.5	18.9	8.4	8.5	10.0
1988	1.8	13.1	7.0	7.8	7.4
1993	1.6	4.5	6.3	5.6	4.9
1998	0.4	2.8	3.8	3.5	2.9
Living in households					
1981	38,023	31,470	53,420	121,236	244,149
1988	54,286	45,492	74,063	128,652	302,493
1993	69,581	64,846	92,360	146,528	373,315
1998	117,758	88,519	143,898	294,522	644,697
Per cent					
1981	91.5	81.1	91.6	91.5	90.0
1988	98.2	86.9	93.0	92.2	92.6
1993	98.4	95.5	93.7	94.4	95.1
1998	99.6	97.2	96.2	96.5	97.1

Source: AIHW analysis of the ABS Survey of Disability, Ageing and Carers; ABS population data.

Another source of data is the annual CSDA minimum data set collection, which provides information about the disability support services provided or funded under the CSDA. The collection is an annual census of services provided on a single snapshot day. For accommodation services, the number of consumers on the snapshot day provides a good indication of the number of clients who receive services (it provides a less good indication for services which are accessed with low frequency, such as in-home respite care).⁷ Table 4.9 presents data on the period between 1996 and 2000.

Over the 5-year period, the proportion of services received from institutions and large residentials has decreased steadily from 32% in 1996 to 24% in 2000. Likewise, there has been a trend of decline for hostels: from 5.7% to 3.6%. While there has not been a clear trend of increase or decrease for group homes, they accounted for 43.5% of all

7 These data are counts of the number of times people received services on the snapshot day, rather than counts of individual consumers. A person may have received services from more than one provider on the snapshot day and would therefore be counted more than once. It is necessary to use counts of services received to look at trends over time, because the statistical record linkage key, which allows estimation of the number of individual consumers, was not available before 1999. This is not considered to be a significant issue with regard to accommodation, however, as clients are unlikely to be using more than one accommodation service at a single point in time. It is of more relevance for other service types covered by the collection (see Chapter 7).

accommodation support services received in 2000, which was higher than in the four previous years. Outreach, in-home and drop-in support services have increased steadily between 1996 and 2000, from 14.6% to 20.4% of all accommodation support services received. These are community-based services, such as in-home living support, that are supplied independently of the person's accommodation.

Table 4.9: CSDA-funded accommodation support services received on a snapshot day, 1996–2000 (per cent)

Service type	1996	1997	1998	1999	2000
Institutions/large residentials	32.1	29.6	26.4	25.8	24.3
Hostels	5.7	6.0	5.6	4.5	3.6
Group homes	39.4	42.3	40.1	41.1	43.5
Attendant care	3.5	2.9	4.8	6.2	5.1
Outreach/other 'in-home'/drop-in support	14.6	16.5	16.5	19.8	20.4
Alternative family placement	0.5	0.3	1.3	0.6	0.5
Accommodation support: other/not stated	4.3	2.3	5.3	2.2	2.5
<i>Total number of accommodation support services received</i>	<i>19,093</i>	<i>20,149</i>	<i>21,124</i>	<i>21,453</i>	<i>21,870</i>
<i>Accommodation support services as a percentage of all services received</i>	<i>27.9</i>	<i>31.3</i>	<i>30.5</i>	<i>28.9</i>	<i>29.2</i>

Source: AIHW analysis of CSDA minimum data set collection, 1996–2000.

Some younger people with disabilities have also traditionally been accommodated in residential aged care homes. These numbers have increased slightly over the 1990s, from 5,890 in 1993 to 6,151 in 2000 (see Table 7.17). The reasons for this rise can only be speculative. The residential aged care collection has no information about the types of disabilities of residents, nor indeed about the appropriateness of these placements.

A national research project investigating the placement of younger people in nursing homes collected data from 811 nursing homes across the country (NSW Department of Community Services 1995). There were 1,515 current or very recent younger nursing home residents aged under 60 years participating in the study, equivalent to approximately 4% of the total nursing home population. People were spread across all age groups, with 51 (3% of the sample) aged under 25 years; however, 832 (over 50%) were aged 50 years and over. The majority of younger nursing home residents had an acquired brain injury as their primary disability type. It appeared that the relative support needs of those remaining in nursing home care do not appear significantly greater than those former younger nursing home residents who have been relocated to other residential options (page 24).

Mental health services

Policy context

Historically, Australians have relied on stand-alone psychiatric hospitals as the focal point for the provision of specialised mental health care. The advent of effective anti-psychotic medication, changes in clinical practice and the emergence of the human rights movement provided the impetus for major structural reform of mental health care. Reforms undertaken have encompassed both a shift in the treatment and

accommodation of people with a mental health disorder from institutional to community-based settings and the integration of specialised mental health care into mainstream health services.

Deinstitutionalisation of services for people with mental health disorders became an international issue in the 1960s, with the development of humanitarian and medical arguments against institutional health care. In Australia, there was growing pressure for the reform of mental health services, evidenced by the formation of the Australian National Association for Mental Health in 1968 (Dax 1992), and the emergence of consumer-based associations such as the Schizophrenia Association in the 1970s. These shifts began to take more tangible policy forms in Australian mental health service delivery systems in the 1980s.

In 1983, the Richmond Inquiry documented the conditions of institutional care and limited community services available for people with a mental health disorder in New South Wales. The inquiry recommended a process of deinstitutionalisation, with the development of community-based care and rehabilitation services as high-order priorities. Later, the Human Rights Commissioner undertook a National Inquiry into the Human Rights of People with Mental Illness (Burdekin 1993) which continued the themes of the Richmond report at the national level, and drew attention to the need for expansion of community-based mental health services.

In recent years, the policy framework for enhancing mental health care nationwide has been the National Mental Health Strategy (NMHS). The strategy was endorsed by Australian health ministers in 1992 and commenced in 1993. The strategy included the *Mental Health Statement of Rights and Responsibilities*, the *National Mental Health Policy*, and the *National Mental Health Plan* (AHMC 1991, 1992a, 1992b). Medicare agreements were drawn up detailing the transfer of federal funding to support the reform process.

The *Mental Health Statement of Rights and Responsibilities* (AHMC 1991) outlined the directional changes to be undertaken across the mental health care sector. The statement promoted equity, access, social justice and a compassionate society, with mental health as its primary goal, and aimed to promote consistency with the United Nations Resolution for the Protection of the Rights of the Mentally Ill. The *National Mental Health Policy* (AHMC 1992a) codified the acceptance of community-based mental health treatment in Australia and acknowledged the impact of the transition on both community services and specialist carers. The objectives of the policy included improving and expanding access to care, support for non-government organisations, establishment of service standards and practices, research and service delivery monitoring. Reiterating the need for reform of the mental health services, the policy defined mainstreaming and identified community-based care as a basic human right.

The Mental Health Strategy identified nationally agreed priorities and outlined agreed approaches to reform in five-year National Mental Health Plans for 1993—1998 and 1998—2003. The first plan strengthened the reforms in the provision of mental health services of the past two decades, leading to substantial change in the way people with a mental health disorder are treated. The service reform objectives included reducing or closing existing psychiatric hospitals and providing sufficient acute hospital, accommodation and community-based services. The first plan also aimed to integrate

the management and delivery of psychiatric services within general health care services and to establish effective links between mental health, general health and non-health services.

The second and current phase of the strategy (1998—2003) has focused on improving quality of care, increasing consumer participation and developing models of best practice. Throughout the strategy there has been a strong focus on promotion, prevention and early intervention and a recognition that the care of people with a mental health disorder in the community was not the sole responsibility of the mental health sector, with accommodation and social support services critical for community-based care (AHMC 1992b, 1993; AHM 1998).

Service types

In the Australian health care system, mental health care is provided by both hospital-based and community-based services. Mental health care for admitted patients is provided by stand-alone public psychiatric hospitals and specialised psychiatric units and wards in public acute care hospitals. Patients of public psychiatric hospitals tend to remain in hospital for longer than those in public acute care hospital psychiatric units. Private psychiatric hospitals and private hospitals with psychiatric units also provide a substantial amount of admitted patient mental health care, which tends to be of shorter duration (AIHW 2001b).

Public hospitals increasingly provide mental health care for non-admitted patients through psychiatric outpatient services and community outreach programs. The involvement of private hospitals in non-admitted patient mental health care is limited, reflecting the way in which health insurance funds pay benefits for mental health care.

In the past two decades, there has been substantial development in public community mental health services. Community-based mental health care services provide a range of residential and non-residential services. Residential mental health care services include those which are staffed 24 hours a day and those with less frequent staff support. Special psychiatric units for the elderly are often included in this category of care, including psychogeriatric units, also referred to as units for the confused and disturbed elderly (CADE units) in New South Wales. Non-government organisations also play a role in the delivery of community-based mental health care, including the provision of psychiatric disability support services.

The available data indicate that, in comparison to community-based services, hospital-based services tend to have better-developed systems for capturing and reporting service activity data. Significant systems development has been undertaken by community-based services nationally to rectify this imbalance.

Care in acute care hospitals

Deinstitutionalisation has been primarily concerned with moving service delivery away from institutions and towards community-based services, such as community support services, home services, rehabilitation programs, training programs and residential care services. Within mental health care, shifting psychiatric care from stand-alone psychiatric hospitals to specialised units in acute care hospitals has been seen as an important contemporary trend, which has run in parallel with deinstitutionalisation in

Table 4.10: Establishments providing mental health services and available beds, 1989-90 to 1999-00

Institution type	1989-90	1991-92	1992-93	1993-94	1994-95	1995-96	1996-97	1997-98	1998-99	1999-00
Institutions										
Units in public acute hospitals ^(a)	n.a.	n.a.	n.a.	94	105	108	129	104	115	112
Public psychiatric hospitals ^(b)	59	45	36	37	35	34	32	24	21	22
Residential care ^(c)	n.a.	n.a.	n.a.	40	48	56	65	n.a.	32	n.a.
Available beds^(d)										
Public acute hospitals ^(a)	n.a.	n.a.	2,189	2,258	2,406	2,551	2,645	2,876	n.a.	n.a.
Public psychiatric hospitals ^(b)	8,513	7,266	5,802	5,348	4,673	4,000	3,723	3,112	2,943	2,759
Residential care ^(c)	n.a.	n.a.	824	792	975	1,157	1,313	1,363	1,301	n.a.

(a) These data come from two separate sources: National Survey of Mental Health Services data for 1993-94 to 1996-97 (1997-98 for available beds) and National Public Hospital Establishments Database data for 1997-98 to 1999-00. Psychiatric unit data from acute care hospitals not available prior to 1992-93.

(b) These data come from three separate sources: Hospital Utilisation and Costs Study data for 1989-90 and 1990-91; National Survey of Mental Health Services data from 1992-93 to 1996-97 and National Public Hospital Establishments Database data for 1997-98 to 1999-00.

(c) These data come from three separate sources: National Survey of Mental Health Services data from 1992-93 to 1997-98 and National Community Mental Health Establishments Database data for 1998-99. Residential services unit record data not available prior to 1993-94.

(d) Average available beds where possible, otherwise available beds at 30 June.

Source: AIHW National Public Hospital Establishments Database; AIHW/DHAC National Survey of Mental Health Services; AIHW National Community Mental Health Establishments Database.

recent years. Although this shift is more accurately seen as desegregation or mainstreaming than deinstitutionalisation, it is viewed by many in the mental health care field as a significant component of deinstitutionalisation, which has allowed for the downsizing or closure of stand-alone psychiatric hospitals.

In this context, the term *mainstreaming* refers to a reduction in the amount of care that is delivered in settings isolated from mainstream services or from the general community. The intention is to allow people with severe mental disorders to receive treatment when required in the specialised psychiatric units of acute care hospitals rather than spending extended periods in stand-alone psychiatric hospitals.

Trends over time

The National Survey of Mental Health Services (NSMHS) is the main source of historical data on mental health services (DHAC 2000b). The survey is an annual collection of establishment-level data from publicly funded hospital and community mental health care services. The NSMHS has been used for annual performance monitoring for the Mental Health Strategy since 1993. Some earlier data on psychiatric hospitals is available through the Hospital Utilisation and Costs Study data.

The development of mainstream health care data collections, such as the National Public Hospital Establishments Database and the National Hospital Morbidity Database (NHMD), has progressively replaced data from the NSMHS, the future of which is currently under review. In recent years, activity data from NHMD have provided detailed information on hospital separations from specialised psychiatric care, including the number of days spent in specialised psychiatric care. In 1998–99, separations with specialised psychiatric care accounted for 2.9% of total hospital separations (168,579 separations) and involved 2,174,551 days in specialised psychiatric care (AIHW 2001b). In years to come, these data will enable accurate tracking of service provision trends in hospital-based mental health services.

There was a substantial reduction in the number of public psychiatric hospitals between 1989–90 and 1992–93, from 59 to 36 facilities, reducing to 22 establishments in 1999–00. The number of available beds in these institutions has declined from 8,513 in 1989–90 to 2,759 in 1999–00, while those in specialised psychiatric units in public acute hospitals have increased from 2,189 in 1992–93 to 2,876 in 1997–98 (Table 4.10).

There has been a corresponding increase in the number of beds provided in community-based residential care services with 24-hour staffing, from 824 beds in 1992–93 to 1,301 beds in 1998–99. These community-based residential care services represent a growing segment of the overall service delivery in specialised mental health services. They provided 9% of the available beds in 1992–93 in all admitted or residential care settings (that is, psychiatric and acute hospitals, and community-based residential units with 24-hour staffing); the proportion increased to 19% in 1997–98. Data are not yet available to adequately describe the volume of care in non-residential community settings (e.g. outpatient clinics, day programs in community mental health services), either in terms of patient numbers or occasions of service, nor are there reliable data to monitor changes over time.

Census data also provide an indication of the number of persons accommodated in mental institutions. These data show a distinct decrease in the number of patients over the period, from 21,248 residents in 1981 to 7,135 in 1996.

Monitoring shifts in expenditure

Total expenditure on public mental health service delivery⁸ (not including expenditure for central health authority or regional administration, nor other items such as teaching, research or health promotion activities) increased from \$1,082 million in 1992–93 to \$1,433 million in 1997–98 (Table 4.11), representing an increase in expenditure of 34% (or 19% in real terms) over the 6-year period (DHAC 2000b).

As a proportion of total expenditure on public mental health services, expenditure for psychiatric hospitals decreased from 48% in 1992–93 to 28% in 1997–98. In the same period, expenditure for designated psychiatric units in acute hospitals increased from 21% to 24%, as did expenditure in the community residential care sector (24-hour staffed only) (from 4% to 6%) and on ambulatory patient services (from 22% to 33%). Ambulatory patient services include same-day services for admitted patients, outpatient services for non-admitted patients and community-based non-residential care services.

Table 4.11: Recurrent expenditure in specialised public mental health services, 1992–93 to 1997–98 (\$'000)

Year	Stand alone public psychiatric hospitals	Co-located services, acute hospitals	Residential services	Ambulatory services	NGOs ^(a)	Indirect expenditure	Total expenditure
1992–93	515,599.0	229,958.8	46,425.7	242,659.7	20,931.6	26,855.2	1,082,429.9
1993–94	492,265.1	226,392.8	41,658.1	273,598.9	24,518.2	27,904.5	1,086,337.5
1994–95	480,129.8	243,333.3	52,373.2	317,849.4	30,546.9	32,317.3	1,156,549.8
1995–96	421,636.3	281,464.7	71,530.8	389,969.4	38,383.0	35,654.0	1,238,638.2
1996–97	416,028.8	303,341.2	84,036.3	441,293.3	54,530.0	47,535.2	1,346,764.8
1997–98	395,310.4	345,972.1	84,948.9	476,793.6	68,217.8	61,331.7	1,432,574.5

(a) Non-government organisations.

Notes

1. Recurrent expenditure includes all services managed by State and Territory agencies, from all funding sources. Agreed indirect costs have been distributed across service settings.
2. Depreciation excluded for all years.
3. For all years, NSW and SA expenditure includes expenditure on psychiatric service delivery in repatriation hospitals transferred from the Commonwealth on 1 July 1994.

Source: DHAC 2000b.

8 Public mental health services exclude private psychiatric hospitals and private psychiatric services.

Substitute care for children

Policy context

In the area of substitute care for children,⁹ the move away from institutional care began somewhat earlier than it did for other fields of care described in this chapter. Developments in psychology from the early 1950s drew attention to the adverse effects of institutional care on child development (Bowlby 1951). While patterns varied across jurisdictions, the late 1950s and early 1960s saw the beginning of a trend away from large-scale institutional care in most States and Territories.

Apart from these changing ideologies of care, there were also concerns about the quality of care provided in institutions and growing financial considerations. Many institutions were under-funded, with low staff numbers and children themselves required to undertake many of the domestic functions (Commission of Inquiry into Abuse of Children in Queensland Institutions 1999:99). As moves were made to improve the conditions in these institutions, the costs associated with providing institutional care increased (Markiewicz 1996:35). By the mid-1970s, the cost of institutional care had increased considerably, providing an economic incentive for governments to develop alternative forms of care for children. It has been estimated, for example, that in 1974–75 the weekly cost of care per child in Victoria was \$100 in children's homes, \$75 in family group homes and \$15 in foster care (Boss cited in Mellor 1990:14).

Another important element in the area of assistance for families with children was the substantial expansion of cash assistance provided to low-income families by the Commonwealth Government over the last quarter of a century. The introduction of the Supporting Mothers Benefit in 1973 (renamed in 1977 the Supporting Parents Benefit) extended government assistance to unmarried mothers, deserted de facto wives and other separated wives not previously eligible for a government pension. During the 1980s and 1990s, there was a significant expansion in government assistance to all low-income families with children, beginning with the implementation of the Family Income Supplement in 1983. The result has been a reduction in the number of children living in poverty between 1982 and 1997–98, despite increases in the number of low-income families over the period (Harding & Szukalska 2000:26). These government benefits have made it much less likely that parents will relinquish the care of their children to the state for financial reasons.

Today, intervention by the statutory welfare services is most likely to be due to allegations of child abuse and neglect or harm to a child, rather than solely because of family poverty as in earlier years. The research indicates, however, that the majority of

9 Substitute care refers to care provided to children and young people whose parents are unwilling, unable or otherwise deemed unsuitable to care for them. There are four main types of substitute care: adoption, residential care (including institutional care where care is provided in large establishments), foster care, and relative/kinship care. For further details, see Chapter 5.

children in the child protection system are from families with low socio-economic status (AIHW 1999:282; Hood 1998:29).

During the 1990s, child protection responses have become less punitive and interventionist, and more focused on collaboration and providing assistance to families to prevent children being removed from home. Where it is necessary to remove a child, placement in the wider family and community is preferred. Foster care and placements with relatives or kin account for the large majority of placements in out-of-home care.¹⁰ Residential care is now, almost entirely, cottage-sized family-type care, rather than institutional care.

State and Territory governments continue to fund a diverse range of services that provide support to families. Child protection services are increasingly being complemented by these family support services which build on strengths which exist in families rather than focusing on dysfunctional aspects of family life. There is also a focus in many jurisdictions on preventative services and early intervention (AIHW 2001a). The Commonwealth Government also funds a range of initiatives aimed at strengthening family relationships (see Chapter 5).

Trends over time

National data on children in substitute care are fairly patchy, with annual data on children in out-of-home care available only from 1996 onwards. There are, however, data available from various other sources that provide a broad indication of the trends in the number of children and young people in substitute care.

Between 1972 and 1993, the estimated number of children in substitute care fell by 68%, from 39,600 to 12,800 (Figure 4.4). From 1993 onwards, however, the number of these children increased, rising by 34% to reach 17,200 in 2000.

There were also major changes in the types of care in which children were placed over the last 40 years. In the 1960s and 1970s, adoption was a significant form of substitute care for babies, but this is not the case today. The number of children in residential care, including institutional care, also fell from the 1960s onwards. This trend can be illustrated using data on children on guardianship orders (who constitute the majority of children in out-of-home care) that were collected for various years from 1980 onwards. Between 1980 and 2000, the proportion of children on guardianship orders who were living in residential care fell from 29% to 8% (Table 4.12).

In relation to institutional care, between 1968 and 1982, the average number of children in institutions decreased from 57 to 17 (Senate Standing Committee on Social Welfare 1985:44). Today there are very few larger institutions left and most residential care for children is provided in family group homes or in smaller residential establishments. The decline in the institution as a form of residential care is evident in the trends in Victoria between 1970 and 1990, when the number of children in institutional care fell by 90%, from 2,487 to 258 (Markiewicz 1996).

10 Out-of-home care refers to that sub-set of substitute care that is reimbursed. For further details, see Chapter 5.

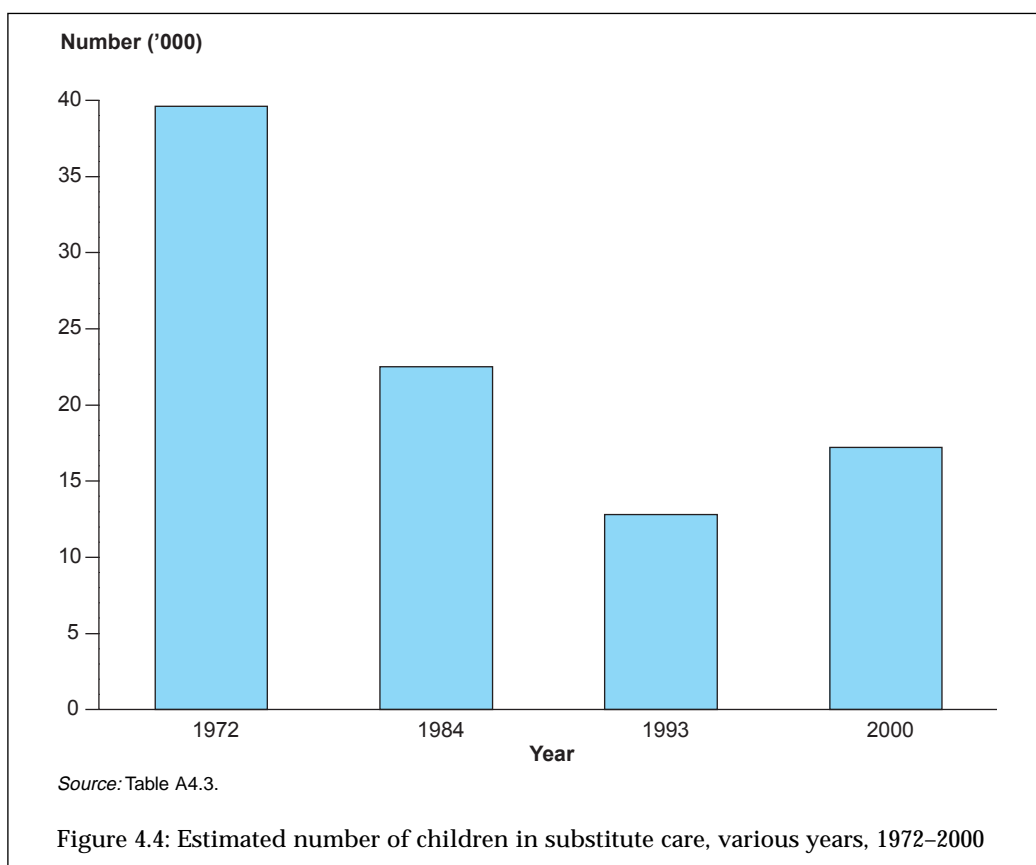


Figure 4.4: Estimated number of children in substitute care, various years, 1972–2000

Table 4.12: Children on guardianship orders, by living arrangements, selected years from 30 June 1980 to 30 June 2000^(a)

Type of living arrangement	1980	1982	1991	1993	1995	1997	2000 ^(b)
	Number						
Residential care	5,218	4,548	1,657	1,260	1,144	1,296	1,106
Foster care	5,936	5,346	4,273	4,596	5,088	5,520	6,097
Living with parents/other relatives	4,407	4,361	1,778	1,319	1,024	3,048	6,118
Other ^(c)	2,148	1,313	606	640	744	900	1,375
Total	17,709	15,568	8,314	7,815	8,000	10,764	14,696
	Per cent						
Residential care	29	29	20	16	14	12	8
Foster care	34	34	51	59	64	51	41
Living with parents/other relatives	25	28	21	17	13	28	42
Other ^(c)	12	8	7	8	9	8	9
Total	100	100	100	100	100	100	100

(a) Table excludes South Australia.

(b) In 2000, the guardianship orders category was expanded to include administrative arrangements that had the effect of transferring custody or guardianship.

(c) Includes children living independently, other adult placement and unknown.

Source: AIHW: Johnstone 2001.

Between 1980 and 1995, there were increases in the proportion of children on guardianship orders in foster care: from 34% to 64%; followed by decreases between 1995 and 2000, with the proportion falling to 41% (Table 4.12). These later decreases coincided with the emergence of a growing proportion of children on guardianship orders living with parents or other relatives in the late 1990s. These relatives or kin may or may not be reimbursed by the state, but the trend is evidence of the increasing value placed on maintaining children within their own family environment. While this trend is not part of deinstitutionalisation per se, it is consistent with the increased emphasis in the shift towards community care on maintaining individuals in their home environment to the maximum extent possible. Recent data from the Institute indicate that, between 1997 and 2000, there was an increasing proportion of children on guardianship orders living both with relatives/kin who were not reimbursed (from 12% to 22%), and with relatives/kin who were reimbursed (from 7% to 12%) (AIHW: Johnstone 2001).

The shifting trends in substitute care are nowhere more evident than in the history of the removal of Aboriginal and Torres Strait Islander children from their families by state welfare authorities. There were large numbers of Indigenous children in institutional care in the 1960s, while in the 1970s and 1980s increasing numbers were placed with non-Indigenous foster families (HREOC 1997:34). Current policies seek to place Indigenous children with their extended families or with other Indigenous caregivers.

Hospitals

Policy context

Hospitals are the key institutions of the health sector, hence their inclusion in this discussion of deinstitutionalisation in a report which is predominantly concerned with welfare services may seem unusual. However, the focus of this chapter is on the move from institutional to community-based care, and this is a trend which has spanned both the health and community services sectors. While deinstitutionalisation as a term is not usually applied to the hospital sector, there is no doubt that this area of service delivery has been subject to the same trend towards community-based care:

...the nature of acute health care services is changing. Patients are increasingly being cared for in the community with support from a hospital, and quite sophisticated surgical procedures can now be done without an overnight stay. (Duckett 2000:107)

Government policy has encouraged the reduction of bed provision ratios, with an emphasis on reduced length of stay and expanded day hospital procedures. These trends are driven partly by pressures for increasing productivity, but also by changing patterns of medical practice and improved medical technology. Procedures such as endoscopy and renal dialysis, for example, now almost always involve day-only admissions (AIHW 1996:153; Duckett 2000:110–14). Private free-standing day hospital facilities have expanded substantially, from 39 facilities in 1989–90 to 207 in 1999–00. The recent introduction of hospital in the home care in both public and private sectors

may well extend this broad trend even further in the future.¹¹ Developments in pharmaceutical treatment and changes in related service areas (such as mental health services, palliative care and residential aged care) have also contributed to shifts in the nature of hospital services.

Data trends

Since 1986, there has been a substantial decline in the hospital bed provision ratio in the public sector, with the private bed provision ratio being relatively stable. In 1985–86, there were 4.1 public and 1.3 private acute hospital beds per 1,000 population, dropping to 3.3 and 1.2 respectively by 1991–92, and then to 2.6 and 1.2 in 1999–00 (Table 4.13). In numerical terms, public hospital beds have fallen from 64,692 in 1985–86, to 57,053 in 1991–92, to 50,172 in 1999–00. Private hospital beds fell from 21,101 in 1985–86 to 20,745 in 1991–92, then increased to 23,665 in 1999–00. The overall ratio of hospital bed provision has thus fallen by 15.5% between 1991–92 and 1999–00, while the absolute number of beds has fallen by 5.1% in this period.

Table 4.13: Available beds, by hospital type, 1991–92 to 1999–00

Hospital type	1991–92	1992–93	1993–94	1994–95	1995–96	1996–97	1997–98	1998–99	1999–00
Available beds									
Public acute	57,053	54,116	56,140	54,211	54,709	53,411	52,597	51,310	50,172
Private	20,745	20,860	21,241	22,370	22,757	22,966	23,091	23,746	23,665
Available beds per 1,000 population									
Public acute	3.3	3.1	3.2	3.0	3.0	2.9	2.8	2.7	2.6
Private	1.2	1.2	1.2	1.2	1.3	1.2	1.2	1.3	1.2

Source: AIHW National Public Hospital Establishments Database; unpublished data from the ABS Private Health Establishments Collection.

Despite this decline in bed provision ratios, there has been an increase in separations per capita over the period (Table 4.14). In 1991–92, there were 236.8 separations per 1,000 population, rising to 297.9 separations per 1,000 population in 1999–00. This apparent contradiction between reduced bed provision ratios and increased rates of use is mainly a consequence of the increased use of day surgery; there has been little by way of reduction in length of stay for non-same-day admissions. In 1991–92, 30.6% of separations were same-day separations; by 1999–00, this had reached 49.2%. Length of stay in 1985–86 was 6.9 days for public hospitals and 5.5 days for private hospitals; by 1999–00, it was 3.9 days and 3.1 days respectively (Table 4.15). Patient days per 1,000 people dropped overall; this was a result of the drop in the public sector.

11 Hospital in the home care is defined as the provision of care to hospital-admitted patients in their place of residence, as a substitute for hospital accommodation.

Table 4.14: Separations from public acute and private hospitals, 1991–92 to 1999–00

Separation type	1991–92	1992–93	1993–94	1994–95	1995–96	1996–97	1997–98	1998–99	1999–00
Separations per 1,000 population^(a)									
Public acute	167.7	176.9	186.0	192.0	193.2	193.1	197.0	198.7	196.5
Private	69.1	70.5	74.7	82.2	85.1	89.2	93.2	95.5	101.4
Same-day separations as per cent of total									
Public acute	29.3	n.a.	34.2	37.7	39.8	42.0	43.3	44.7	45.8
Private	33.9	n.a.	43.3	46.1	48.9	51.0	53.1	54.8	56.2
Patient days per 1,000 population^(a)									
Public acute	868.2	912.5	895.6	826.7	827.1	789.4	774.1	751.3	740.2
Private	276.6	282.0	291.0	293.2	311.6	302.0	303.8	299.4	307.7

(a) Crude rate for years 1991–92 to 1994–95; age standard rate for years 1995–96 to 1999–00.

Source: AIHW National Hospital Morbidity Database.

Table 4.15: Average length of stay in public and private hospitals, 1991–92 to 1999–00

Hospital type	1991–92	1992–93	1993–94	1994–95	1995–96	1996–97	1997–98	1998–99	1999–00
Average length of stay (days)									
Public acute	5.1	n.a.	4.8	4.6	4.4	4.2	4.0	3.9	3.9
Private	4.0	4.0	3.9	3.7	3.7	3.5	3.3	3.2	3.1
Average length of stay excluding same-day separations (days)									
Public acute	6.9	n.a.	6.8	6.7	6.6	6.5	6.4	6.3	6.4
Private	5.5	n.a.	6.1	6.0	6.4	6.0	6.0	5.9	5.9

Source: AIHW National Hospital Morbidity Database.

Deinstitutionalisation, imprisonment and mental health

Prisons are not within the scope of this chapter, yet there is a widespread belief that one consequence of deinstitutionalisation has been an increase in rates of imprisonment among those with intellectual or psychiatric disability. Unfortunately, national data on this issue are not available. A recent AIHW report has emphasised the need for such data, describing information on the health status of prisoners as sporadic, inconsistent and incomplete (AIHW: Grau 2001:1). The report documents the need and likely future direction for the development of an information system on prisoner health. The New South Wales Law Reform Commission (1996), in a report on people with an intellectual disability and the criminal justice system, also drew attention to the inadequacy of information on this topic. Some indicative data addressing this issue are presented below.

In New South Wales, it is estimated that 12–13% of inmates have an intellectual disability, compared with 2–3% of the general population. Research undertaken for the New South Wales Law Reform Commission (1996, ch. 2) suggests that more than one-third of persons appearing before New South Wales local courts have an intellectual disability. The Law Reform Commission suggests that deinstitutionalisation is a likely factor in the increasing contact between people with an intellectual disability and the judicial system.

Similar concerns have been raised with regard to people with a psychiatric disability, although the evidence is scanty. In 1995, the New South Wales Mental Health Review Tribunal reported that an increasing number of prisoners are being transferred from prisons to hospitals because of chronic mental illness which is often believed to have existed prior to, and at the time of, their defence (Hayes et al. 1995 cited in Freeman 1998:7). According to the annual report of the New South Wales Corrections Health Service (1999:42), a significant proportion of inmates have mental health problems: More than 50% of male inmates and 30% of female inmates warrant referral to a mental health professional for major depression, 18% of males and 30% of females for schizophrenia and 11% and 20% of males and females respectively for bipolar illness .

4.5 Conclusion

Although the data are somewhat variable in quality and coverage, the material drawn together in this chapter serves to illustrate that deinstitutionalisation is indeed occurring, and it is occurring across a number of service fields. These trends are most evident in the latter part of the 1980s and the first half of the 1990s, although in some fields they have continued unabated. While the census data have some limitations with regard to the accuracy and consistency of the classification of health and welfare institutions, there is broad evidence of a reduction in residency rates over the 15-year period surveyed. If the use patterns which were in place in 1981 had been continued in 1996 (i.e. in the absence of deinstitutionalisation policies), there would have been an additional 80,700 people in health and welfare institutions at the time of the 1996 Census. This means that, in 1996, the actual population in health and welfare institutions was three-quarters that which it would have been in the absence of such changes in policy and practice.

The data in this chapter provide some detailed information on the process of deinstitutionalisation in different fields. In some areas, this has involved the actual movement of people from institutional facilities out into the community; in all areas, the process also involved reducing the numbers of people who actually entered institutional care. In the fields of aged care, disability services, mental health and out-of-home care services for children, there is evidence of a concomitant growth in home-based and community services, but the question as to whether that expansion has provided an adequate substitute for institutional care across all sectors remains to be addressed.

Studies of deinstitutionalisation have been limited in their scope. They tend to focus on a particular geographic area, a particular jurisdiction, or even a particular institution, and they almost always focus on one particular service area. One of the important points to emerge from this chapter is that services and individuals who are providing care in the community context may be providing assistance to people from a variety of service areas. Their clients may include people who would previously have been cared for in a psychiatric institution, an institution for people with intellectual disabilities, an institution for those with physical disabilities, or an aged care home, or those who are moving out of acute care hospitals more quickly than they would previously have done. Some programs, such as hospital in the home, are set up to deal with a very specific client group. Other programs, such as HACC, provide assistance to a much more

broadly based clientele; HACC does not, as is sometimes assumed, simply draw its clientele from a population which would formerly have been cared for in aged care homes.

The question of the adequacy of current levels of community-based provision is constantly on the agenda of policy makers, service providers, clients and informal carers, and will undoubtedly continue to be so. There is very little by way of national information on this topic, and the political, practical and methodological difficulties inherent in the task make it an area which is probably destined to remain poorly documented at the national level for some time to come.¹² The current chapter does not bear directly on the question of adequacy, but it does serve as a reminder of the importance of the question. Home-based assistance is not the only alternative to residential care imprisonment, neglect, abuse and homelessness also remain possibilities.

Of course, many of those who may need or desire assistance from community-based services would never have entered an institution these are the majority of people with a disability, a mental health problem or frail older people who have always been and continue to be cared for at home by family members and friends. This group of people also draws on and has need of community-based services. Thus, planning for the development of community-based services must take into account not only those who would previously have been cared for in an institution, but also those who always have been and continue to be cared for in the community.

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12 See AIHW (1997a) for one exception to this statement: an investigation of the adequacy of service provision in the disability services field at the national level.

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